New forms of citizenship and socio-political inclusion: accessing antiretroviral therapy in a Rio de Janeiro favela

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Abstract
Brazil has received praise internationally for its national health policy against HIV. Whilst the ethical stance of the Brazilian programme has been widely applauded, there is a lack of empirical data on how the commitment to equitable and universal HIV prevention and treatment works in practice among the poorest population groups. The aim of this paper is to explore the broad ethics of the Brazilian AIDS programme by investigating how universal access to HIV treatment is being implemented within a favela (shanty town). Data collected through anthropological research show that in settings such as the favelas, the universal character of this public health programme is challenged by a number of issues such as local definitions of illness, problems related to the understanding of and adherence to treatment, structural violence, political alienation, and lack of perspectives about the future. It is also argued that such health intervention has contributed to the promotion of novel attitudes towards individual notions of socio-political participation. These are explored with reference to the notion of therapeutic citizenship, which in the context of a favela neighbourhood translates into a new set of concerns around free access to and availability of treatment, the right to health care and the sustainability of public health policies.

Keywords: antiretrovirals, antiretroviral treatment, socio-economic marginality, biopolitics, therapeutic citizenship, HIV/AIDS

Introduction

Brazil was the first ‘developing’ or ‘middle-income’ country to implement free and universal distribution of antiretroviral therapy (ART), which successfully resulted in lowering AIDS morbidity and mortality rates throughout the country, and particularly in large urban centres (Ministério da Saúde 2004). In the early 1990s the World Bank predicted that by 2000, 1.2 million of Brazil’s 186 million people would be infected with HIV; surveillance data suggest that ‘only’ about 600,000 Brazilians are infected (Okie 2006). Four main trends characterise the profile of the HIV epidemic in Brazil: the increase of infection in women, the increase of heterosexual transmission, the spread of the epidemic to regions outside large cities, and the increase in poor population groups (Galvão 2002, Ministério da Saúde 2008). Available epidemiological data on AIDS in Brazil show a clear breaking point in the evolution of the epidemic: 1996–1997 is a watershed period, before which there was a constant growth in the cumulative number of reported AIDS cases, and after which there is a distinctive decline (Ministério da Saúde 2003). These turning-point years
correspond to the time when Brazil began to distribute ART on a ‘universal’ basis, free of charge at the point of access through its national health system, which continues to be one of the best-known parts of the Brazilian National AIDS Programme (NAP). The persistent negotiations between the Brazilian Ministry of Health and the pharmaceutical industry, together with the increase of the local production of generic drugs, contributed to a dramatic reduction in the price of antiretrovirals since 1996 (Okie 2006). These measures have been the focus of important press coverage and, in stark contrast with the South African example (Fassin 2006, Robins 2005), the Brazilian government is commonly portrayed as a ‘pioneer’ and ‘leader’ in the fight against HIV in low- and middle-income countries (Biehl 2006). The Brazilian NAP is now considered a model for other countries that need to put in place effective infrastructures to produce locally and provide access to antiretroviral drugs.

Given the international significance of the Brazilian approach, it is crucial to explore its effectiveness through a range of perspectives, and not simply through the national statistics currently available on overall mortality, morbidity and sexual behaviour. Whilst the ethical stance of the Brazilian programme has been widely applauded, there is a lack of empirical data on how the commitment to equitable and universal HIV prevention and treatment works in practice among the poorest population groups. Through an anthropological and observational research design, I proposed to explore the public health rhetoric of universalism, and assess the Brazilian programme primarily from the perspective of life in a favela (shanty town) in Rio de Janeiro.

Drawing on Rabinow’s concept of ‘biosociality’, defined as the forging of a collective identity under the emergent categories of biomedicine and allied sciences (Rabinow 1992, 1996), I refer to the idea of ‘biosocial changes’ to describe modifications in the life of an individual that relate to the interaction of biological and social forces, as illustrated in the work of Petryna (2002) and Nguyen (2005). I examine shifts in individual notions of social participation, and discuss how the ‘medicalised body-self’ may be linked to new citizenship claims for individuals treated for HIV and AIDS in the favelas.

I also refer to other new types of ‘biopolitics’ such as ‘biological citizenship’ (Petryna 2002, 2006, Rose and Novas 2005), and ‘therapeutic citizenship’ defined by Nguyen (2005, 2007) and Biehl (2004, 2006, 2007). In the wake of the Chernobyl disaster in post-Soviet Ukraine, Petryna (2002) examined the moral and political consequences of remedies available to locals and sufferers. Petryna tracked the emergence of what she calls a ‘biological citizenship’ through which sufferers stake claims for biomedical resources, social equity, and human rights. She defines ‘biological citizenship’ as both a collective and an individual survival strategy: a complex intersection of social institutions and the intense vulnerabilities of populations exposed to the determinations of the international political economy, also part of a larger story of democratisation and new structures of governance in post-socialist states (2002: 219). Rose and Novas (2005) also attest to the emergence of ‘biological citizenship’. In common with Petryna, Rose and Novas characterise ‘biological citizenship’ as individualising to the extent that people shape their relations with themselves in terms of knowledge of their somatic individuality, and collectivising through biosocial groupings – a collectivism formed around a biological concept of shared identity (2005: 443). Nguyen (2005, 2007) and Biehl (2005, 2007) have also produced meaningful illustrations of the concept of ‘biological citizenship’ and have used the idea of ‘therapeutic citizenship’ to describe the way in which people living with HIV (PLHIV) appropriate ART as a set of rights and responsibilities to negotiate these at times of conflicting moral economies (Nguyen 2007), resulting in a system of claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies (Nguyen 2005).
My intention in this paper is to illustrate how emerging claims to citizenship and bio-political inclusion are associated with accessing ART in a low-income population group, and how they may be understood as a series of claims made on a global social order on the basis of a therapeutic predicament (Nguyen 2005). I describe how a series of biosocial changes are formed and articulated within a specific socio-political setting and in relation to prevailing forms of structural violence. Bio-political debates were largely developed in European and North American contexts, or in relation to observations made within NGOs and institutional settings. I aim to show how these notions might be equally relevant in a low-income ‘marginalised’ population in a non-Western and non-institutional setting, namely in the context of accessing HIV treatment in Brazil’s favelas.

Methods

The methodology used needs to be contextualised within the specific nature of fieldwork in the favelas of Rio de Janeiro; observations were limited by the perilous conditions of the chosen location, and by the sensitive nature of topics such as HIV and related therapeutic issues. The research is based on 13 months of anthropological fieldwork in Brazil. The bulk of the fieldwork took place in a favela close to the Centro of Rio de Janeiro, in the neighbourhood of Santa Teresa. This favela was selected because of its relative accessibility, although violence and the presence of armed gangs were great impediments to the progress and completion of fieldwork. An estimated 10,000 individuals live in this favela. Through participant observation of daily life and informal conversation with inhabitants, it was possible to place issues around health, treatment and equity, in local context. Over a period of five months, I followed a team at the local health centre (Centro Municipal de Saúde) composed of paediatricians, psychologists, counsellors, and social workers, as they organised a series of activities on health and disease prevention for teenagers living in the favela. Additional observation in NGOs was conducted through participation in the activities of two local organisations working in the field of HIV, whose work is directly linked to low-income population groups in Rio: CEDAPS (Centre for Health Promotion) and Grupo Pela Vidda Rio (GPV – Group for the value, integration, and dignity of people living with AIDS). Three focus groups were conducted at CEDAPS with a group of 15 women living in different favelas in Rio. These meetings were organised with the aim of collecting a range of spontaneous definitions of structural problems, and to provide data on a wide spectrum of experiences related to health, illness, health care, and HIV in other favelas throughout the city. Over a period of seven months with CEDAPS, I worked closely with a group of women who ran the Núcleos Comunitários de Prevenção das DST/AIDS (STD/AIDS Community Prevention Centres) and local health-promotion teams in 15 different favelas of Rio. I also participated in the activities of Grupo Pela Vidda (GPV) where I regularly took part in meetings for a support group of around 30 participants living with HIV.

A number of research participants were identified throughout that period and later interviewed. Snowball and opportunistic sampling methods were used to identify 25 research participants. Their life histories, narratives of illness, and in-depth semi-structured interviews were collected during the second phase of the fieldwork. In addition, key informant interviews were conducted with 16 NGO workers and 12 health practitioners from local health centres and hospitals. The interviews addressed different issues according to the research participants’ circumstances, but each was broadly organised around a set of topics referring to experience of HIV therapies, health and illness, socio-economic situation, family and household composition, education and local politics. It was not possible, for the
purpose of this paper, to provide as many facts and details about each of the informants and their specific circumstances as I would have wished. Instead, I have deliberately selected a number of topics from my fieldwork observation, and retained only those issues directly connected to my overall argument. Individual names and locations have been modified in this script to comply with the relevant ethical guidelines on confidentiality and protection of informants against potential harm as a consequence of the research.

Political alienation and renewed marginalisation

The experiences of accessing ART that I describe through my observation within the *favelas* of Rio de Janeiro are only intelligible in the light of experiences of stigmatisation and structural violence. One of the key social problems in Rio de Janeiro is the lack of progress in improving the distribution of income. Regional income inequalities have pushed thousands of migrants from rural to urban areas over the last few decades throughout Brazil, which led to the expansion and development of new *favelas*, mainly in large cities. In Rio de Janeiro, wealth disparities are particularly prominent and the city is composed of a patchwork of poor and wealthy neighbourhoods living side by side. Today, there are more than 750 *favelas* in Rio de Janeiro, with approximately 1.65 million inhabitants (Perlman 2005).

Although significant variations in income levels exist both within the *favelas* and in other neighbourhoods, the great majority of *favela* residents have few financial resources and live in poor housing conditions. The *favelas* have changed over the past 100 years; most houses are now made of bricks, connected to electricity since the end of the 1970s, and have had water as well as sewerage systems since the 1980s (Zaluar and Alvito 2003). Whilst the *favelas* have gradually increased the quality of their urban amenities and expanded in size, progress is slow, however, and today’s *favelas* face a novel set of difficulties, such as the recurring conflicts resulting from the presence of the drug traffic. Throughout most of the 20th century, the *favelas* were singled out as places propitious to the development of disease and bad hygiene (Valladares 2005). More recently, numerous *favelas* have become ‘extra-territorial zones’ controlled by drug traffickers, where the absence of public authorities (federal, state, or municipal) is almost complete (Inciardi *et al.* 2000). To that extent, the ‘narcotization’ (the increase of the influence of narcotic drugs) of Rio’s *favelas*, in conjunction with the militarisation of the drug traffic since the progressive introduction of cocaine over the last 25 years (Dowdney 2003), has significantly reinforced the isolation of these neighbourhoods, now commonly labelled as dangerous and unsafe. The presence of the drug trafficking has not only renewed, but also intensified, a process of marginalisation of the *favelas* and their inhabitants. The simple fact of living in a *favela*, say many of the local inhabitants, is enough to be seen as a marginal. A *favelado*, literally ‘the inhabitant of a *favela*’, has become a pejorative term, which some *favela* inhabitants themselves find offensive, as it is commonly linked to negative perceptions of the *favelas*. Nevertheless, through employment, education, consumption, social life and leisure activities, *favela* residents are far from confined to the territory of their own neighbourhood, and are fully involved in the daily life of the rest of the city (Perlman 1976, Zaluar 2002, Valladares 2005). This constant flow of people between the interior and exterior of the *favelas* constitutes one of the most striking aspects of the social, political, cultural, and economic life of Rio de Janeiro.

In the *favela* Morro dos Reis, on the hillsides of Santa Teresa in Rio, local people often express feelings of impotence towards the ubiquitous violence that they experience. The
ongoing struggle for control between the police and drug traffickers has profound consequences for both local inhabitants and for the organisation of the *favela* in general. Locals perceive the control held by drug factions over their neighbourhood to be in conflict with their individual civil rights. On the other side of the ‘battlefield’, as they label their own neighbourhood, the frequent and brusque invasions by police forces such as the BOPE leave inhabitants stressed, traumatised, and feeling vulnerable (Dowdney 2003). Unable to rely on either side, the same individuals feel largely ignored and ‘abandoned’ by the local authorities and by their government for their lack of intervention in improving the situation. Harris (1994) shows how, in a different Latin-American setting, violence is explicitly treated as a necessary alternative state rather than a breakdown of normality. In the Brazilian context, seemingly, violence is a ‘plural subject’ (Kleinman 2000). Its definition varies according to various situational circumstances but also, and perhaps more importantly, in relation to a watershed between *favelas* and middle class experiences. Widely spread definitions of violence among *Cariocas* (inhabitants of Rio de Janeiro) encompass criminal behaviour, the use of physical force, aggression, domestic violence, and the actions of drug traffic (Penglase 2005). *Favela* inhabitants, in addition to the latter, very often use the term ‘violence’ as a substitute for ‘the drug trade’ at large. Feldman (1991) described how the body is used, commodified and injured to serve nationalist discourse in the process of civil war in Northern Ireland. In the same way, the violence resulting from the presence of the drug trade within *favela* neighbourhoods induces a particular form of political violence. This violence is constantly re-enacted through the concatenation of forced dependency on the traffic, menace and threat, and it is also inflicted by the drug commandos’ ubiquitous presence as they constantly watch and control the *favela’s* entrances.

This political form of violence and the feelings of impotence that it creates among locals have taken root quickly in the *favelas* because the state (national and regional) has been unsuccessful in asserting and sustaining its authority, both in political and economic terms, among these neighbourhoods. Penglase (2005) shows how local drug gangs have repeatedly used tactics such as the ‘shutdown of Rio de Janeiro’ as a way of demonstrating that the city’s drug traffickers possess a power that the local authorities do not have: new forms of power are being constructed, and a new type of war conducted, at the very moment when there is a deep, region-wide disenchantment with democracy, and when the role of the state as the central economic and political actor is increasingly being called into question (Penglase 2005). Thus, today *favela* inhabitants find themselves involved in a political form of marginalisation which, unlike any previous forms of marginality (Perlman 1976), is deeply embedded in a political form of violence that results from the absence of sustained intervention from the state to tackle the growth of the drug trade.

**Taking ART in the favelas**

The specificities of the local context described above proved to be central to *favela* inhabitants’ experience of taking ART. The *favela* Morro dos Reis has been Valedio’s family home for the last 20 years. Now aged 48, he was born near Recife, in one of Brazil’s North East poorest neighbourhoods. After his parents’ separation when he was 12, his mother moved to Rio de Janeiro to find a job. Valedio moved to Rio a few months later with his three brothers and sisters. There he had to give up school, and worked in a succession of manual jobs, first as a cleaner and then in retail. At 12, he already felt like a grown man, he says, as he needed to work for himself and ‘fight for his own life’. When he was 13 he met his future wife, a young woman also from the North East called Paula. She
is a couple of years older than he is, and they had their first child a year after they met. Valedio’s life changed dramatically at 18 when he was convicted for robbery and was sent to jail for nine years. In 2002, he discovered after an operation to remove a cyst that he was infected with HIV and hepatitis C. His wife Paula tested HIV positive a few weeks after he received his diagnosis. Both of them have been taking antiretrovirals for four years. They are followed-up regularly – once every three months – by the lung specialist at the local health centre, from where they also collect their antiretrovirals and test results.

Similarly to other research participants on ART, although Valedio and Paula said they took ART as prescribed by their physician, it became apparent with time that they did not adhere, either occasionally or regularly, to their treatment. The most frequent reason given for the temporary cessation of treatment seems to be the recurrence of various side effects. In some cases, because side effects can affect one’s capacity to go to work, the treatment itself is seen as the source of illness, and non-adherence to the therapy was seen as one of few options available when work is a means of survival in the short term; for many PLHIV in the favelas, adhering to ART is a ‘luxury’ that poor people simply cannot afford because however strongly the side effects may affect their body, they need to carry on and work to make a living. In-depth interviews and participant observation showed that favela inhabitants involved in the research, regardless of their age, gender, family, and racial background, see a strong connection between the concept of ‘illness’ and that of ‘immobility’ or ‘paralysis’ of the body. An individual suffering from an illness is broadly defined as someone whose physical ability to move or walk is seriously impaired. Importantly, given that illness is seen as an impairment affecting mobility, it is also identified in connection with one’s ability to work, or more precisely to go to work. In the Morro dos Reis favela, because local definitions of illness are closely linked to work and mobility, they also become a significant factor in the success of treatment for HIV. The asymptomatic nature of HIV infection and its relatively slow development in the body means that, in the context of the favelas, any illness or complications related to HIV are generally not taken care of, unless they interfere with a PLHIV’s mobility and daily activities.

Another reason PLHIV gave for missing some of the daily doses of treatment is related to alcohol consumption. They say some of the pills are not compatible with beer, and explained to me why they deliberately omit to take them during weekends, since this is the time of the week when they tend to drink more alcohol. Respondents also often described the treatment they are receiving, the appearance of the drugs and their functions in a number of ways. These descriptions were associated with the physical attributes of the drugs, such as their colour, shape, and boxes, and often pills were associated with a physiological need and were linked to the time of the day when they were taken. Some of the drugs that must be taken in the evening were described as helping them sleep, while the daytime pills helped one to feel hungry or maintain a certain level of physical activity.

An important observation is that even when research participants missed doses of ART, some on a regular basis, they continued to pick up the drugs from the local health centre at regular intervals, as required by their prescription, but either kept the extra pills at home, or gave away the surplus to one of the local Evangelical churches. A few of those I met had also started to share or exchange antiretroviral drugs between themselves. Valedio and Paula, for instance, said that they were being given too much medicine to treat themselves and their bodies could not possibly cope with such a large quantity of drugs. At some point, Paula decided to stop collecting her own treatment from the local health centre and she started to use her husband’s drugs to ‘help him get through them’.

A local definition of ‘illness’ strongly linked to the ability to work is not exclusive to favela neighbourhoods but has serious consequences in the context of HIV treatment. One
of the immediate consequences of illness being so closely defined by the capacity/incapacity to work, is that favela residents tend to seek medical advice in the later stages of ‘disease’ development. Herbal and home remedies are preferred until worrying symptoms appear; that is when mobility is significantly affected, or when one is unable to go to work. Seeking medical help at the later stages of disease development, as well as late diagnosis, has some consequences on HIV prevalence and increases the risks of individuals unaware of their seropositivity infecting others through unprotected sex. In terms of mortality, late diagnoses as a consequence of symptomatic manifestations of AIDS and opportunistic illnesses, means that HIV has already significantly weakened the immune system. Lower rates for HIV testing which were reported within favelas (Ministério da Saúde 2002) might be explained by this phenomenon, at least partially.

New biosocialities

Elza is a good-looking, tall, 22-year-old woman, who lives in the favela with her six-year-old son, Pedro. Four years ago, she was diagnosed HIV positive when she was treated for meningitis. Elza does not want the rest of her neighbourhood to know about her serostatus, and she is frightened that she could face discrimination or rejection if it becomes known she is HIV positive. She said that, within her favela, access to health care is extremely poor. In contrast, she thinks that the level of health care she receives for HIV is very good, as for other poor people. She considers the service that deals with HIV to be better organised, more efficient, and more reliable than the rest of the public health-care system. She stressed that she was lucky to be living in Brazil because they have the NAP. Importantly, her experience of being treated and receiving antiretrovirals via a public health policy seems to be linked to positive opinions about the government: ‘I think the government is good, very good, it continues to make medicine available for us, I think it has to continue to do so’.

Originally from Fortaleza, Edilson arrived in Rio aged 16, in search of work and ‘better days’ as he put it. Now aged 47, he still lives in one of the favelas and works for eight to nine hours a day selling drinks and refreshments on the beach. He recently joined an HIV support group shortly after testing HIV positive a few months earlier. As did everyone else I interviewed or met who was on ART, Edilson often brought up issues about the price of antiretrovirals, insisting that the drugs he received were extremely costly, and that he would not be able to afford the drugs if he had to pay for them. Like many others, he often compared his situation with that of people in other Latin American countries where there was no similar public health policy for AIDS, and said he felt ‘privileged’ to be living in Brazil.

It was observed during fieldwork that taking antiretrovirals and being involved in the NAP via local health centres and NGO interventions might encourage new forms of biosociality for PLHIV in the favelas. In spite of the fact that many favela inhabitants feel discriminated against for being poor, less educated, for hailing from other regions, and for being stigmatised by the ongoing violence resulting from the growing narco-trafficking, being treated through the NAP seemed to provide a relative experience of ‘inclusion’ into the larger socio-political order. All the informants on ART were aware that they received their antiretrovirals through a public health policy managed by the national government, and they were also aware that Brazil’s neighbouring countries did not provide free ART to their citizens (as of 2005). PLHIV recognise that the Brazilian Ministry of Health has put in place a complex logistical effort to give people access to treatment through the existing National Health System (SUS), and that it has developed a nationwide strategy to distribute
Antiretroviral therapy in a Rio de Janeiro favela

It was also observed during this study that access to ART for some favela inhabitants living with HIV has influenced individual perceptions about, and personal relations to, the medical system as a whole. PLHIV attend their health centre regularly, once every other month on average, and through regular visits to a local health centre, individuals on ART have developed close relationships with health practitioners (nurses, doctors, pharmacist, social workers, administrative staff). Some also told me that since they had started ART, they had become more disposed to use biomedical drugs as a first recourse instead of using home-made remedies. These individuals said that they had started to consult a doctor more spontaneously, without allowing the early symptoms, however benign, to worsen to the point of being perceived as ‘worrying symptoms’ or being ‘immobilised’.

Similarly, PLHIV in the favelas have developed better skills in identifying where to get further assistance, for instance through the contact they have with local NGOs working in the field of HIV. People on ART appeared to be more disposed to seek help and support from one of the NGOs specialising in HIV. Not only do these groups provide participants with new social networks formed of other participants and NGO staff members, but they also represent the synapses of the AIDS political activism throughout the country. These are places where people can find support and through which many of them become more sensitive to their individual rights. My observations suggest that through these various meetings, workshops, courses, and local support groups, PLHIV involved in these environments are exhorted both implicitly and explicitly to claim further rights to receive treatment, to obtain financial compensation, to be involved in decision-making processes, to achieve greater social inclusion, to reduce stigma in the workplace and within families, to gain further rights (such as access to free public transport) and, importantly, to do so on the basis of their therapeutic needs.

Politicised bodies

As described earlier, a large portion of favela residents expressed experiences of ‘exclusion’, felt ‘excluded’ from public policies and had lost faith in politicians, who had ‘let them down’ along with the rest of the population on many issues, including social exclusion, violence and unemployment. By focusing on favela residents living with HIV and taking ART, I suggest that the NAP has contributed to lessening the existing pervasive negative attitudes towards the national state and its representatives. In-depth interviews and case studies indicate that favela inhabitants taking ART seem to adopt more sympathetic views towards their government and its representatives, as they endorse the work of the Ministry of Health and express sympathy for the politicians who were involved in the implementation of the NAP.

ART works as a constant reminder of how much one’s survival relies on the availability of the drugs and, consequently, on the sustainability of the very public health programme that provides the population with free access to them. Research participants expressed their fears that their government would not be able to sustain its policy of free and widespread distribution of ART. ‘I am afraid that we could be in a situation where treatment is not...
available any more, and if there is a lack of treatment it would be fatal, death would be the only outcome [. . .] I’m scared, because I have seen many weaknesses in the government, and I’m scared that it could be another failure’ said Edilson during an interview. Each of the research participants living with HIV and taking antiretrovirals expressed the feeling of dependence on the government because of their medical treatment. On the one hand, they feel grateful that they can access free-of-charge treatment through the public system and, on the other, they are afraid of having to pay for treatment in the future. They often said that their individual health and perspectives about the future depended on the performance of the country. Importantly, they also felt that they were more vulnerable than other individuals with HIV who did not live in *favelas*, because if ART stopped being available for free, they could not afford to pay for it, nor could they move to another country to receive treatment.

Thus, in the local context of *favela* neighbourhoods, receiving antiretrovirals via the public health system is translated by *favela* residents themselves into a right to receive treatment like any other citizen, regardless of wealth distribution and socio-economic disparities, but it is also understood as a relation of dependency on a state programme, namely the NAP, and on the stability of the political system as a whole. Among PLHIV living in the *favelas*, a relationship of reliance is established between the ‘sick’ body and the state, and the chances of staying alive are envisaged in relation to the degree of sustainability of the NAP itself. In that sense, antiretroviral drugs are perceived as a direct ‘link’ between the individual body and the state. Because of the strong side effects, *favela* residents consider that antiretrovirals affect and, in some cases, incapacitate their ability to work and live normally. Hence, the drugs also evoke feelings of suspicion about their ‘invasive’ nature, and they are seen as intrusive and alien to people’s lives, because they are often accompanied by important changes in the social and professional lives of those receiving the treatment.

In addition, through the treatment they receive and related services which they have access to (support groups, counselling, legal advice, housing services, workshops), the same *favela* inhabitants become exposed and sometimes affiliated to new social environments (Galvão 2000). For instance, in Morro dos Reis, those who are unable to pick up their treatment from the health centre receive them via a postal service organised by the National Health System (SUS). Carla, a local volunteer, ensures that every parcel is delivered as she regularly goes around the neighbourhood to ‘check in’ on those receiving treatment. The interactions between Carla and other *favela* inhabitants is one of the examples which illustrates how distribution of treatment and the work of local volunteers trained by a local NGO (CEDAPS) creates therapeutic networks within the *favela*, or between the health-care system and *favela* inhabitants. Hence, the ‘social body’ of *favela* residents on ART is also deeply affected by the AIDS policy, and numerous new social networks are progressively formed from the association of people infected and affected by HIV. Local NGOs play a central role in the formation of these new networks, which they continue to influence through their work as political activists and through their role as the leaders of the so-called ‘social control’ in the field of HIV. Since the early 1980s, NGOs have radically influenced Brazil’s response to HIV; today they work together with the NAP in a dynamic characterised by great tensions – protests and unrest – and collaboration (for instance to distribute condoms and prevention leaflets among men who have sex with men, transvestites and transsexuals, sex workers, and in the *favelas*).

In Latin America, ‘access to citizenship’ is often turned into a synonym for ‘access to an ideal world’, and promoted as such by social militants, including NGOs, international and governmental organisations (Sorj 2004). In the absence of durable positive intervention by
the state in the *favelas*, egalitarian movements such as those first described by Marshall (1950, 1964) materialise on the ground through the work of NGOs. Although local NGO projects do not generally aim to be universal, have specific goals, and rely on particular methods and ideologies, they also constitute, for inhabitants in the Morro dos Reis *favela* and others, one of the only palpable and positive interventions to alleviate problems affecting the local population such as the lack of education, illiteracy, lack of professional skills, unemployment, lack of health care, lack of food, discrimination, and lack of political participation. In the ‘absence’ of sustained state interventions in the *favelas*, NGOs have become powerful political actors and manage to provide a few *favela* inhabitants with some of the basic services that the state has failed to deliver. The activities of local NGOs such as CEDAPS and GPV, who both support PLHIV at the local level, illustrate the extent to which PLHIV gain greater awareness of political activism in the domain of HIV treatment and health care. Through regular workshops, support groups, visits to households, and numerous meetings, trainings, or buddy-type programmes, both GPV and CEDAPS contribute actively in informing and influencing local opinions about rights activism, by encouraging its participants to interrogate ideas around access to treatment, citizenship, and human rights.

**Conclusions**

The singularity of the therapeutic options offered to *favela* inhabitants taking ART, and thus the singularity of their ‘therapeutic economy’ (Nguyen 2005), is defined on the one hand by the availability of free treatment and medical assistance through the Brazilian public health system and, on the other, by access to a range of social services and discourses about citizenship through new social networks linked to accessing ART and local AIDS activism. I illustrated how, in the context of Rio’s *favelas*, PLHIV’s perspectives on socio-political inclusion are influenced by their involvement in this new therapeutic economy, and how a number of PLHIV’s claims to greater socio-political participation is profoundly intertwined with their novel access to HIV treatment and care. I have argued that accessing ART and other HIV-related services, via the public health system and local NGOs, results in biosocial changes and greater involvement in new or existing therapeutic environments, which allow individuals to enjoy the right (with an emphasis on ‘having rights’) to therapies and treatments. This ‘right to health’ and right to accessing ART must be understood within the perspective of the formation of the Brazilian National Health System (SUS) in the 1980s, in which the concept of ‘health’ itself is defined as a basic human right and a basis for citizenship.

The distinctiveness of the local biosocial changes generated by the Brazilian NAP resides in the inclusive attribute of the programme which facilitates access to expensive antiretroviral drugs through the National Health System, whilst access to virtually any other types of public intervention seems to be increasingly difficult and sometimes impossible from the perspective of *favela* inhabitants. Similarly to Farmer’s (1992) findings regarding ‘conspiracy theories’ in Haiti, local reactions to the NAP – and not only to the local health services – reveal sophisticated readings of the ‘nation-state’ and international efforts at health intervention. These include contradictory understandings, which endorse the timely and accessible health interventions set up by the government, but which simultaneously involve feelings of suspicion towards an alien, interfering state, practising discrimination against a poor and expendable population. Hence, the NAP actually exceeds the design of the public health programme itself, as people also rely very much on the existence of a
‘moral economy’, along the lines of Farmer’s (2003) definition of health as a basic human right, and claim further rights on the basis of their medicalised body-self. The notion of ‘therapeutic citizenship’ allows us to conceptualise the medicalised body as a platform for the formation and development of new claims about the right to health jointly with new attitudes towards socio-political inclusion and citizenship. ‘Therapeutic citizenship’ is however only meaningful when considered through a close examination of the complexities of grounded social interactions. As I have illustrated, notions of social participation and citizenship are embedded in a deep and complex history of exclusion towards favela residents, and the therapeutic economy of PLHIV living in the favelas must be understood within this context. The unique nature of therapeutic citizenship in the favelas resides in the history of the struggle to achieve greater inclusion into the rest of society throughout the 20th century, to improve their living conditions and to alleviate some of the structural violence that affects their daily lives. In the context of this specific political economy, and unlike previous forms of socio-political mobilisation attempted by favela inhabitants, ‘therapeutic citizenship’ translates into a more focused, more conspicuous, and more tangible set of claims and concerns organised around the individual body-self and related to the right to health, the availability of free drugs and treatment, and the sustainability of public health policies.

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Notes

1 The term ‘favela’ is used in Brazil to designate ‘shanty towns’. Many local inhabitants would favour the appellation ‘comunidade’ (community) over the term ‘favela’ to refer to their own neighbourhood, whilst others choose to use the appellation ‘favela’ as a means of affirmation of a distinct identity.
3 Batalhão de Operações Especiais, a special branch of the police force trained to deal with armed conflicts and drug factions.
4 Defined here as the body politic constituting a nation.
5 In this context, the use of the term ‘social control’ (controle social) refers to a common use of the term in Brazil as the process through which ‘civil society’ (in its broadest sense) can, and must, exercise a constant and critical examination of the decisions and actions emanating from the executive, legislative and judicial powers, or from other governmental bodies and their representatives.
References


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