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# Producing and Reproducing Inequality: Biopolitical Exclusion, Marginalized Bodies and AIDS Care in Central Mozambique

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## Abstract

Studies of African countries' response to HIV/AIDS and more recently to Ebola helped call into question not only individual and behavioural factors related to those conditions, but the centrality of the healthcare delivery systems themselves, particularly in the face of challenges of such magnitude. Weak, insufficient, underfunded and understaffed national health systems, compounded by international financial agencies' discouragement, if not prevention, of increasing state budgets for social sectors, are usually considered the main challenges in assuring the population's access to healthcare. In addition, and based on two years ethnographic fieldwork in central Mozambique (where in a neoliberal context, AIDS treatment is being provided through institutional arrangements comprising the state, aid agencies and international NGOs), this article suggests that access to healthcare and AIDS treatment, particularly by the poorest, can also be hindered by three factors. First, the adoption of a 'one size fits all' international AIDS treatment delivery model independent of context. Through the research of biomedical AIDS treatment services, this study brings to the fore the interplay of global health policies with the specificities of healthcare delivery at the local level, showing the importance of biomedical services' organizational culture and history. Second, the production of institutionally stigmatizing categories to label non-adherent patients. As Ian Hacking pointed out categories have consequences for the ways we conceive of others, and those categorizations influenced the ways in which those patients were thought of, talked about and were dealt with within public health units. Third, the valorization of socio-economic markers of differentiation such as the tidiness and educational level of patients. Biomedical care is a complex social process performed within particular cultural matrices and laden with values. This study seeks to make visible the role played by the valorization, if not of a single and hegemonic conception of modernity, then at least of a 'modern way of life' (associated with the urban, hygiene and education) in access to AIDS treatment in central Mozambique.

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## Résumé

Les études de la réponse des pays africains au VIH/sida et plus récemment, à l'épidémie d'Ebola, ont permis de remettre en question non seulement des facteurs individuels et comportementaux liés à ces situations, mais aussi la centralité des systèmes de prestations de soins eux-mêmes, notamment face à des défis d'une telle ampleur. Des systèmes de santé nationaux faibles, insuffisants, sous-financés et en sous-effectif, avec comme facteur aggravant le fait que les organismes internationaux de financement dissuadent, ou sinon empêchent, l'augmentation des budgets des États alloués aux secteurs sociaux, sont généralement considérés comme les principaux défis pour assurer l'accès des populations aux soins de santé. De surcroît, sur la base de travaux de terrain ethnographiques couvrant une période de deux ans dans la région centrale du Mozambique (où, dans un contexte néolibéral, le traitement du sida est assuré par le biais de mécanismes institutionnels comprenant l'État, les organismes d'aide et les ONG internationales), cet article indique que l'accès aux soins de santé et au traitement du sida, en particulier par les personnes les plus pauvres, peut aussi être entravé par trois facteurs. Premièrement, l'adoption d'un modèle international uniforme de traitement du sida, indépendamment du contexte. À travers la recherche de services biomédicaux de traitement du sida, cette étude met en relief les interactions complexes des politiques mondiales de santé avec les spécificités des prestations de soins de santé au niveau local, montrant l'importance de la culture et l'histoire organisationnelles des services biomédicaux. Deuxièmement, la production de catégories institutionnellement stigmatisantes pour étiqueter les patients qui n'adhèrent pas au traitement. Comme l'a souligné Ian Hacking, les catégories ont une incidence sur notre façon de concevoir les autres, et ces catégorisations influençaient la manière de penser à ces patients, de parler d'eux et de les traiter dans les centres de santé publics. Troisièmement, la valorisation des marqueurs socioéconomiques de différentiation, tels que la propreté et le niveau d'instruction des patients. Les soins biomédicaux sont un processus social complexe, qui se déroule dans des matrices culturelles particulières et qui est chargé de valeurs. La présente étude cherche à rendre visible le rôle joué par la valorisation, si ce n'est d'une conception unique et hégémonique de la modernité, à tout le moins d'un 'style de vie moderne' (associé à l'urbain, l'hygiène et l'éducation) dans l'accès au traitement du sida dans la région centrale du Mozambique.

## Introduction

This article explores HIV/AIDS care in central Mozambique and is framed to examine the role played by the national healthcare delivery system during epidemics of such magnitude. I suggest that access to healthcare and the probability of patients' adherence to treatment can be hindered by, first the adoption of a 'one size fits all' AIDS treatment model independent of context; second, by the valorization, if not of a single and hegemonic conception of modernity, then at least of a 'modern way of life' (associated with the urban, hygiene and education); and third, by the institutional production of stigmatizing categories to label non-adherent patients. I bring to the fore the lived experiences and narratives of people living with HIV/AIDS in an attempt to show the effect of policies and political decisions on their daily lives and on their bodies, as well as to give names to otherwise faceless information and numbers.

After independence from Portugal, Mozambique adopted universal access to primary health combining basic curative care with prevention at the primary level (Pereira 2010:150; Walt and Melamed 1984). In the present neoliberal context, Mozambican healthcare is provided mostly by the government through the National Health Service (NHS), but also by NGOs and some private clinics. The NHS is characterized by one of the lowest health worker to population ratios in the world (Pfeiffer 2013:168)<sup>1</sup> as well as by a dearth of infrastructure dating back to colonial times and further weakened by structural adjustment and a sixteen-year long war (Cliff and Noormahomed 1988a; 1988b; Kanji, Kanji and Manji 1991; Pfeiffer and Chapman 2010; Pfeiffer 2013).

In Mozambique, even though the number of persons on anti-retrovirals (ARVs) increased dramatically and nearly half a million people were receiving anti-retroviral treatment (ART) in 2013, data show that only 31.7 per cent of adult and children (25.9 per cent of males and 36 percent of females) with HIV receive ART (GARPR 2014: 40–3).

The increase in the number of health facilities providing ART – from 316 health facilities in 2012 to 563 in 2013 – occurred in the context of the Acceleration Plan and the new definition of AIDS mobile clinics previously named 'satellite' ART facilities. However, it is important to stress that presently, at country level, 82 per cent of ART is provided through only 140 health facilities (GARPR 2014: 41). The Global AIDS Response Progress Report (*ibid.*) mentions that in Mozambique 'weak financing, human resources and institutional capacity are envisaged as the main concerns hindering to meet several challenges, including introducing viral load measurements in the country'.

#### Methods

My data derives from twenty-two months ethnographic research from 2007 to 2009, followed by short visits in 2012 and 2013. Fieldwork was carried out mostly in Manica province in central Mozambique but I also did research in the capital city, Maputo. The core of this research was an ethnography of health facilities. I studied a total of eight health facilities<sup>2</sup> in Manica: the

AIDS Clinic at Chimoio Provincial Hospital (CPH) as well as 1° de Maio and Nhamaonha Health centres also in Chimoio; Catandica Rural Hospital; Honde and Cruzamento de Macossa Health Posts in Barué District; Vila Manica Hospital and the Machipanda Health Center. Participant observation in health units of waiting locales, registration of HIV/AIDS patients, taking of blood whether at a laboratory or not, pills pick-up, anti-retroviral counselling sessions, clinical appointments, social services, Directly Observed Therapy (DOT) and the Emergency Rooms took much of my research time. I was present in most Anti-retroviral Treatment Committee weekly meetings in CPH for over a year. I kept field notes of what I saw, heard and experienced.

I interviewed sixty-five key-informants as well as 150 persons living with HIV/AIDS (ninety-two women and fifty-eight men) some of whom were in the process of accessing ARVs, some of whom were already using ARVs, and still others who had interrupted their treatment. The selection of people living with HIV/AIDS in health units was random and occurred at different times (e.g. before and after the appointments). I resorted to snowball sampling for the other interviews and tried to have a balance of snowball sampling and random selection. In-depth interviews were conducted in a mixture of Portuguese and local Shona variants, recorded and later transcribed. Most participants were in their twenties and thirties and had two to three years of schooling. Only very few had six to eight years of schooling and some females in the rural areas did not go to school at all. The great majority did not have formal jobs. They usually combined agricultural work with a myriad of activities in the informal sector and 'voluntary work' at associations as their sources of cash.

I followed eight persons living with HIV/AIDS (five women and three men) as they went about their lives and interacted with the health services, for an average period of twelve months. I accompanied them in their quest for therapy, I visited them in their homes, and I was introduced to their families as well as to some friends and neighbours. This strategy proved to be quite useful, as it is one thing to observe patients being asked to return on another day because their lab results could not be found, and another to know what that meant for the particular patient, to be aware of the effort that patient made to be present that day, and how many other unsuccessful attempts preceded this one.

I also researched the scholarly literature and archival resources in Portuguese at the Mozambique Historical Archives and collected the life histories of the eight persons I followed, building towards a historically informed ethnography.

## 'Suffering from Walking': Decontextualized ART Delivery Model as Biopolitical Exclusion

This section explores patients' experience of the HIV/AIDS care process, particularly the ART delivery model. I am interested in how the implementation of a decontextualized model can act as an inclusion/exclusion mechanism that ends up marginalizing the sickest and poorest. I look at who is initiated in treatment in a timely manner and who is not? Who shall live? And who is left to die?

#### Shifting HIV Policies and Services in Mozambique

Until 2001 the Mozambican government's official position was against including ART within AIDS programmes. Laboratory and human resources shortcomings as well as the incapacity of people living with HIV/AIDS to fulfil treatment requirements due to poverty were listed, among other factors, which made the introduction of ART problematic. However, private clinics and transnational NGOs were already providing ART in Mozambique (Matsinhe 2005:104-20). The introduction of ART was approved and regulated by the government only in 2001 and the NHS began providing AIDS care and treatment services in 2003 (CNCS 2010:73). The expansion of ART through the public sector began in July 2004 when the country adopted the WHO public health approach to ART (Sherr, Micek, Gimbel et al. 2010:S60; Gilks, Crowley, Ekpini et al. 2006:505).

Several transnational NGOs operated in different provinces and interacted with the NHS in different ways, that is, provision of ARVs occurred through a variety of institutional arrangements throughout the country. In Manica province the HIV/AIDS therapeutic apparatus was an assemblage where Mozambican national health services, HAI (an American NGO) and later FHI 360, home-based care networks, associations of people living with HIV/ AIDS and other civil society organizations (some of them church-based) and funded mainly through PEPFAR (the American President's Emergency Plan for AIDS Relief) interacted to provide HIV/AIDS care and treatment. HIV/ AIDS care was provided initially though a 'HIV care networks model' that linked HIV testing centres, AIDS outpatient clinics locally designated 'Day-Hospitals' and several types of civil society and community-based groups.

Chimoio, the Manica provincial capital with approximately 240,000 inhabitants, had an adult HIV prevalence rate of 25 per cent<sup>3</sup> and Chimoio Day-Hospital was a space within a government medical facility that provided HIV/ AIDS care and treatment, including ARVs. It was managed by a Mozambican medical doctor and its staff was a mix of Mozambican civil servants (nurses, MDs, non-physician clinicians and support staff) and lay personnel hired by the transnational NGO through associations of people living with HIV/AIDS. Patients were attended to by the NHS's MDs and non-physician clinicians but 'clinical advisors'<sup>4</sup> provided mostly management and technical support. AIDS clinics were later integrated into primary healthcare raising lively debates and widespread discontent from people living with HIV/AIDS, a process which falls outside the purview of this chapter and which I address elsewhere (Braga forthcoming). In neighbouring Tanzania government medical facilities were also 'housing externally funded facilities' such as AIDS clinics which were considered examples of NGOs providing services from within the state and constituting 'biomedical and bureaucratic enclaves' (Sullivan 2011:203).

In Manica the 'HIV care networks model' comprised five key steps:i) test for HIV, ii) register for care at the AIDS clinic, iii) undergo CD4 testing, iv) start ART if eligible, and v) adhere to ART. Even if it ran smoothly, which it didn't, as we will see later, this was a cumbersome and lengthy process which could sometimes take several months. Within Manica, access to ARVs also became available through AIDS mobile clinics functioning regularly in some distant health posts. Health workers came periodically (generally once a week) to provide HIV care, including initiation into ART for the patients living far from district headquarters. However, they resorted to the same ART delivery protocol used in urban settings within the province.

As for step 3 of the ART delivery model, CD4 testing, it is crucial to emphasise that at the time CD4 lab equipment existed only in Chimoio, the provincial capital and in the rural hospital in Catandica in a province with a high level of HIV prevalence (INSIDA 2009).

Patients' complaints about giving multiple blood samples and making multiple visits to health centres each time there was need of a CD4 count result were sometimes voiced during clinical appointments. When updated CD4 count information was not found in a patient's record, as the clinician was requesting another lab exam, she was harshly interrupted by a male patient: 'They already took my blood, I already did it [showing a form he took from his pocket] look here... on April four. We are just tired of walking!' This patient seemed to be well aware of the process. He spoke in the name of AIDS patients in general who not only had to make multiple visits to health units in order to access AIDS care but were tired of the inadequacies and inefficiencies of a weak and fragile National Health Service.

The relationship between adequate follow-up of patients and their CD4 count was once voiced by a home-based care activist who was frustrated with deaths among her patients. She angrily said to the AIDS outpatient clinic chief nurse: 'This has to stop! We cannot go on giving you a patient with an initial

600 CD4 who ends up dying with 8 CD4 or something like that, such as Roberto without having been in ART, there are no excuses for this!'

Lara (2009:12) also refers to patients being repeatedly asked to come back another day because lab results were not ready, thus imposing even more financial and time constraints on them. Patients' frustration with frequent visits to health units to get their CD4 examinations is exemplified by Adélia, a middle age widow who relentlessly tried to begin ARVs. She was filled with anger with the delay and kept repeating: 'each time they gave me a new date, a new date!' meaning each time she came for the results they would tell her to come back on another date. 'My card is full, it is written all over with different dates!'She died soon after she finally began ART and I still recall her frail and wasted figure sitting on her home-based care volunteer's bicycle.

Problems with lab exams, particularly CD4 count, was even worse in AIDS mobile clinics. Patients' blood samples had to be collected, stored and transported appropriately to the few health facilities equipped with a CD4 machine in the entire province. Health workers complained that samples get lost, and the ones that get to the lab were often not in a condition to be analysed. Sometimes patients had to come to the health centre and give blood samples two or three times to get a single lab result. From the patients' perspective, the main complaint was that the multiple trips depleted their cash.

This research showed that a diversity of issues prevented an adequate followup of patients: i) lab equipment, particularly the CD4 machine breaks often;<sup>5</sup> ii) blood samples get lost and did not reach the lab; iii) blood samples got to the lab but were of such compromised quality they could not be used; iv) difficulty in getting clinical appointments; v) lack of capacity to file and make CD4 lab results available to clinicians in updated patients' records; vi) some clinicians not used to dealing with chronic care focused on acute sickness episodes on the appointment day rather than following up on treatment. Overworked and demotivated clinicians might not pay attention to CD4 cells count monitoring as part of the clinical management of a 'chronic disease' and sometimes would not even consult patients' medical records.

Implementing eligibility criteria to access ART emphasising a CD4 threshold implies close monitoring, medical management of patients and medical recordkeeping, hence it implies the availability of a large and knowledgeable health workforce, equipment, and institutional cultural change towards chronic care, all of which are problematic in Mozambique. In these circumstances, the probability that follow-up does not really take place as such, or that it occurs with many deficiencies is quite high, and chances are that patients do not begin ART when prescribed, or die before they begin treatment, or begin it so late they die anyway. Several studies show transportation challenges as a barrier to AIDS care in sub-Saharan Africa (Hardon, Davey, Gerrits et al. 2006; Kalofonos 2010; Peters ,Kambewa and Walker2007:92). Micek, Gimbel-Sherr, Baptista et al. (2009) loss to follow-up study in central Mozambique shows that at the same time the 'HIV care networks model' was implemented it was also established that patients should get cash for transportation under the item of 'adherence subsidies'. That is, somehow there was knowledge from the onset that transportation could become a barrier. What intrigues me is that quite paradoxically the programme design itself was not reconsidered and was left untouched, the option was instead to have patients following all those steps and receive 'adherence subsidies', an approach that proved to be neither enough nor efficient. I suggest that patients became invisible and were thought of as a homogeneous and malleable entity which was supposed to adjust to and fit the ART delivery model under the notion of 'patient flow'.

Paul Farmer (201:227) insightfully points out that a focus on patient non-adherence can be a mechanism to set aside unexamined programme failure. Non-adherence should only be considered after examining programme design and lack of access.

The steps prior to the initiation into ARVs were particularly labour intensive, and cost demanding. A woman in her late thirties whose husband died of HIV/AIDS put it as follows:

It is too much work to go there, they ask for lots of things and it is difficult to do everything. ... My husband ... walked and walked, he did analysis and more analysis, again and again. He went there two, three, four times and sometimes more, and you know.... he died without beginning treatment. My husband really suffered from walking. My husband was... how can I put it? He was civilized, he used to go to the hospital and not to healers, but at the end he did not get better anyway, he did not even begin taking those pills.

There is an implicit criticism of the prevailing discourse that blames patients and their cultural beliefs for looking first to healers, thus delaying HIV testing and treatment. This woman stresses that her husband was 'civilized', meaning that when his health deteriorated he looked for relief to the modern health system, but died without getting alleviation anyway.

The need for multiple visits to the health units increased due to heavy bureaucratic procedures too. There were three different patient ID cards (one for medical appointments, another for dispensation of cotrimoxazol, and another still for dispensation of anti-retrovirals). Each of these cards indicated different dates for patients to come to the health unit, thus considerably increasing the health unit visit load for people with HIV/AIDS. These challenges, including the need for multiple visits to health units and their association with depleting family funds, are even worse in distant rural areas. The large urban/rural gap in health provisioning constitutes another dimension of inequality expressed in the differential access to health care (O'Laughlin 2010:22-7). The national AIDS commission acknowledges impressive inequities in ART coverage among the different regions of the country (CNCS 2010:77-80), but its data nonetheless conceals other dimensions of inequality, namely the disparities in access to ART between urban and rural areas within each region.

There is growing evidence that deficiencies in healthcare delivery in Africa, namely in terms of human resources, infrastructure and equipment, constitute major challenges to ART adherence and treatment continuity. Interruptions in treatment might also be related to patients' dissatisfaction and 'negative experience with the healthcare facilities' (Boyer, Clerc, Bonono et al. 2011:1384).

Most HIV/AIDS patients and their families complained incessantly of 'suffering from walking'. Others in a rather biblical tone would mention 'sacrifice from walking' to allude to the effort and pain caused by lengthy walks on their multiple and frequent visits to health units in search of care and relief.

The cumbersome ART delivery model, combined with a weak, bureaucratic and understaffed NHS, as well as the institutional incapacity to adequately follow-up with patients, put an extra burden on patients who tried to fulfil the demands of a decontextualized ART delivery model.

In suggesting that AIDS care was decontextualized, I base my argument on three issues. First, the same ART delivery model was used in both urban and rural areas which are different in terms of human settlement patterns and health unit coverage. Second, even in urban areas the problem with transport and the need for countless visits to health units was dealt with in terms of 'subsidies' and the lengthy ART delivery model was left untouched. Third, the emphasis on the CD4 threshold as an eligibility criterium ignores the need for a well functioning, better equipped national health service, as well as the need for a bigger and more knowledgeable health workforce.

#### Socio-economic Status and Triage

Nguyen (2009:208-9) argues that the need to rationalize scarce resources like ART is associated with the enrolment of some patients and the exclusion of others from treatment based on medical criteria and information that predicts the likelihood of good adherence. This implies triage, 'a complex process where objective assessments of value are carried out'. Value may be defined in terms of both medical and social criteria which are part of AIDS programmes and which aim, for instance, at selecting the most adherent or the most likely to be adherent patients.

During my regular observation of the weekly ART Eligibility Committee at Chimoio Day-Hospital's meetings, no patient was ever dismissed based on the likelihood of poor adherence, for instance on the grounds of living at a distance from a health unit. However, patients living far away and unable to come repeatedly to the health unit ended up being excluded. In effect this is 'de facto' triage. But through which mechanisms did triage, and hence inclusion/exclusion take place?

#### Clean, Educated Portuguese-speaking Bodies

In Manica people often take great care in how they present themselves to the health services. They would use limited cash to buy a bit of soap to take a bath, wash clothes and show up in a presentable way at health units. I noticed patients being reprimanded for not presenting themselves cleanly and for not keeping their prescriptions, lab requests or other documents crisp and clean as well. In neighbouring Malawi patients with ragged clothes 'or poorly washed bodies' are also treated unkindly by clinicians (Peters, Kambewa and Walker 2010:284).

A political economic reading of the emphasis on hygiene shows how ironic it is to blame the destitute and sick, particularly AIDS patients, for untidiness in a context of widespread poverty and material scarcity. In shanty towns, water costs 15 meticais/month (US 60 cents per month). Handicapped female AIDS patients had to pay four extra meticais for each water container in order to bring them to the house. Besides, most women with AIDS complained they had difficulties carrying out their gendered domestic tasks. Depending on their health condition, some of these women could no longer carry 20 litre water containers, and were able to wash only three or four *'capulanas*'<sup>6</sup> at a time.

Though it seems 'unreasonable' and apparently contradictory to make hygienic demands where water is not easily accessible, the discourse on hygiene is nonetheless intelligible in terms of bio-power, which has become a broader grid through which to appreciate modernity (Foucault 1990:89-141).

Bio-power is exercised through two poles: i) the anatomo-politics of the human body concerned with the disciplining of the individual body and its activities in a mechanical sense; and ii) biopolitics concerned with the regulation of the species taking the form of population management through the control of biological processes, health and longevity.<sup>7</sup> These two poles are not mutually exclusive. The disciplinary and the regulatory poles can be articulated with each

other and medicine can become 'a political intervention-technique with specific power-effects that affect both the body through discipline and the population through regulatory effects' (Foucault 1997).

Hygienic demands by health workers can be understood as the exercise of disciplinary power. Making patients perform particular activities and conform to norms and values of hygiene associated with modernity is in some form a taming and docilization of those bodies. Furthermore, the combination of medicine and hygiene establishes a connection between both poles of biopower, the body and the population.

On another note, as for the valorization and meaning of 'education', during an ART committee meeting, a medical doctor presented the case of a male patient who did not feel well when his medication was changed and was requesting to revert to his initial ARV line. In a manner quite unusual in these meetings, the medical doctor gave details of the patient's weight loss and weakness, explaining that with the use of Efavirenz the patient's CD4 count began rising, but that it began to fall with Triomune 30. Some MDs voiced doubt about the patient's adherence and his doctor answered: 'Well, he is the only one who knows that for sure, but he is an *educated person*,<sup>8</sup> concerned with his health, he knows by heart how many CD4 he had and how it has been decreasing, he took the initiative and asked for a medical appointment because he is worried....'

To label someone an 'educated person' usually means the individual has at least several years of formal education, which is different from what is implied by saying that someone 'went to school', the latter usually means the person has just a few years of schooling. Education is a key distinction marker and Peter Fry (2000a:70) mentions socio-economic differentiation of the population in Chimoio between those whom he designates as 'more educated and economically successful persons' and 'poorer and less schooled persons'. Sumich (2008a:320) also notes that Mozambican elites perceive themselves as 'fundamentally different' from the majority of the population because they are 'educated' and 'modern'.

Besides, the label 'educated person' is not restricted to formal schooling but also means that the person knows how to conduct her or himself in a socially accepted way, has 'good manners', knows etiquette rules, and so forth. That is, there is also a statement about social status that is conventionally associated with the expression 'educated person'.

In the above case the patient is praised for being concerned, for taking the initiative in asking for a medical appointment. But other patients who do not read or write,<sup>9</sup> may also be concerned but may only blindly wander through different buildings showing papers they do not recognize and asking for procedures they do not understand. Adélia, a middle-aged widow and petty business informal trader who could not read or write, and Xavier a young small-scale farmer who had recently migrated from a rural area to the provincial capital city, were worried and concerned and each came to Chimoio Provincial Hospital asking for help. They did not know how and to whom to express their concerns, and ended up coming and going endlessly without result.

There is a tacit expectation that patients should master the performative aspects of the interactions within health units. Gupta's (2006:217) analysis of the requirement of cultural capital, including a great degree of performative competence in engagement with the state, can be extended to the domain of health services provision. Health facilities can be spaces of disciplining and socialization on how to perform in public spaces such as government institutions. Educated urbanites know how to conduct themselves in such spaces, but this is not the case, for instance, with people from rural areas who have less interaction with this type of institution. If patients do not have that cultural competence, their actions might have unexpected consequences, such as what happened to Helena who was reprimanded for not phrasing a request in an acceptable way, probably for not being familiar with what Mamdani (1996:29) called 'the ways of the city'.

Helena was a young woman who came to her sister's house in the cityin search of alleviation from her suffering. When Helena got pregnant with her second child and later could hardly work her sister expelled her from home. Helena was extremely poor, could not read or write and made me realize the magnitude of the issues one can take for granted as I heard her referring to 'that place where there are medicines' or observed that she did not know what to do in a pharmacy and waited for instructions

In this way, some of the persons I interviewed and followed for some months would fit the description of being 'worried' and of taking the initiative in approaching health services, but would not be considered 'educated persons' who could attract the attention they sought and needed. So, exclusion from timely access to ART occurs along 'social fault lines' (Farmer 2001:98) of socioeconomic status, and perhaps gender. In Cameroon a study of HIV care and access to ART (Loubiere, Boyer, Protopopescu et al. 2009:169) concluded that patients not initiated into ART tended to be of lower socio-economic status, had more difficulties getting clinical appointments and 'seemed to face more difficulties in their relationships with the healthcare delivery system'.

A form of what Joao Biehl (2007:203) calls medical sovereignty and ethics which establishes who is considered worthy of treatment applies here too, when health practitioners made decisions about which patients deserved attention and which did not, and which patient's statements were given credibility and whose were not. These sovereign medical decisions seem also to be based on patients' social and cultural standing. The association of 'uncivilized' African population with dirtiness and lack of 'education' transpires in several accounts throughout colonial Africa (Butchart 1998:135; Vaughan 1991:80). The Portuguese colonial officer in charge of Health Services in Mozambique in 1946 stated:

Indigenous populations are relatively easy to advise, but difficult, if not impossible, to get the advice put into practice. Hygiene rules, even the simplest ones, can only be followed by individuals living at a certain education level, comfort, economic possibilities, etc. (Aires 1946:143).

I want to emphasise the deep historical roots of the association between tidiness, educational level and economic possibilities, that is, between hygiene and socio-economic status. During my observations at health units I noticed that besides hygiene and education, clothing and language were also important markers of distinction and differentiation that could influence the way AIDS patients were attended.

Directly observed therapy (DOT) was mandatory and consisted of patients taking their daily pills early in the morning in front of a health worker for the initial two weeks of anti-retroviral treatment, which implied that they would be late for work during that time. Later, patients took their medication at home, but had to pick up ARVs at the pharmacy monthly, on a previously assigned date. Exemptions from DOT due to the demands of classes, school exams or jobs were usually accepted, though this depended on the counsellor. Male and female long-distance traders, as well as truck drivers who could often be absent for long periods, would be granted their ARVs in advance. However, exemptions from DOT or from monthly ARV pick-up were rarely, if ever, awarded to agricultural workers.

In a quite illuminating event during a joint counselling session just before ART initiation, a young woman dressed in a cosmopolitan way addressed the counsellor in Portuguese and requested exemption from DOT in order to keep her 'job'; this was granted. Then a peasant woman wearing a *capulana* and a head scarf seized the opportunity, spoke to the counsellor in a local variant of Shona and requested to be exempted from DOT because she had to work on her distant agricultural field. Not only was the demand denied but the counsellor requested the other attendees help her reprimand that woman. She was humiliated and scolded by some of the attendees on the grounds that she did not care for her life and wanted instead to go to work on her agricultural plot. Besides the underrating of agricultural work and the privileging of salaried 'jobs', it is pertinent to briefly explore aspects of personal presentation and language use for each of these women. It is not my intention to construct a stereotypical representation; both women were Day Hospital attendees and like most of the other patients were of lower socio-economic status. This is not to suggest that Day Hospital attendees were a homogeneous group. Besides the difference in terms of occupation between these two women, there were also differences in terms of their personal presentation and the language used to address the counsellor, showing that clothing and language could be out of place. Luedke and West (2006:1) noticed a distinction in women healers in southern Mozambique between those who 'dress as cosmopolitan travellers' and women who are described as 'wrapped in "capulanas" and heads carves' who were considered to 'dress as peasants in the city'. In effect, these two different types of clothing are made to correspond to different and opposed spaces –the urban and the rural. There is a growing cultural valorization of *capulanas* that are fashionable and used in cosmopolitan settings, for instance, in dresses and suits, but not just simply tied around the waist.

The African population in colonial Mozambique was legally categorized as '*indigena*' (native), but those who abandoned their 'usages and customs' associated with backwardness and embraced the Portuguese culture, acquired Westernized dress codes, ways of living, social manners and adopted the Portuguese language, that is, those who assumed modern subjectivities, were considered '*assimilados*' and higher on the social ladder (Fry 2000b:85; Sumich 2008a:324).

#### Categories and the Production and Reproduction of Inequality

Adherence to AIDS treatment is crucial in order to prevent the development of resistant viruses, disease progression and death (Mills et al. 2006:679). In Manica, adherence to AIDS care and treatment was 'measured' mostly by the control of pill pick-up. Patients who did not pick up their ARVs within fifteen days were categorized as '*faltosos*' (absentees) and those who did not collect them for three months were considered '*abandonos*' (dropouts) and their medical records set apart in different cabinets. After several health workers tried unsuccessfully to find a patient's record on the basis of an ID card, nurse Salmina proudly explained how she was able to locate the patient's medical record:

I had no doubts! Just by looking at her I could see that woman was a drop-out and thus looked for her medical record in that cabinet. I was right! These are the people who give us problems! These are the ones who make us look bad for having so many drop-outs!

Nurse Salmina could hardly have displayed more distaste towards the woman in question who was barefoot, was wearing a soiled and ragged *capulana*, who kept her things in a supermarket disposable plastic bag and could hardly speak Portuguese. Her shaved head made me suspect she could be a recent widow. She seemed vague, reacting quite mechanically to the health workers' questions.

Nguyen's (2009:208-9) statement that triage 'separates those who must live from those who might die', and that only the former become part of programmes and are counted as a way of assuring good outcomes and success, helps to understand that nurse's primary concern with showing good results; that is, quantified information to make the case for good NHS performance. Hence some patients, particularly the extremely poor, non-Portuguese speakers or those who are non-fluent and also illiterate were likely to be profiled as non-adherent and were envisaged as a source of 'problems to the services' contributing to the negative image of the institution. Some AIDS patients were blamed for interrupting treatment and/or not fulfilling all the ART delivery model requirements though they have little or no control over most of the barriers they face, in what Farmer (2001:226) called as the exaggeration of patients' agency. What interests me most in that event is the circumstances that led an otherwise kind and diligent nurse I observed working for almost two years, who was much liked by patients in general, to publicly display her distaste for and distance from an extremely poor woman whom she classified as a 'drop-out'.

Ian Hacking (1999:16) states that 'a kind of person comes into being at the same time as the kind itself was being invented'. Following Hacking, Oksala (2010:455) puts it this way: 'we may generate kinds of people and kinds of action as we devise new classifications and categories. Categories of people come into existence at the same time as kinds of people come into being to fit those categories'. Moreover, also inspired by Hacking, Biehl (2005b:29) stresses that 'categories and counting define new classes of people and normalize their ways of being in the world'.

The category of 'drop-out' was institutionally established through HIV/ AIDS care and treatment intervention and new groups of people were constituted. The length of patients' absence quantified and their medical records removed to separate specific cabinets somehow materialized the distinction between 'disciplined adherent patients', on the one hand, and absentees and drop-outs, on the other.

Labelling diseased bodies as absentees and drop-outs produces categories of disciplined/adherent and undisciplined/non-adherent bodies as 'kinds of people'. To be unable to fulfil HIV/AIDS care requirements was constructed as an individual characteristic, as illuminated by the statement that some AIDS sufferers 'are drop-outs', that is, a particular kind of people. Therefore, the naturalization, de-politicization and de-historicization of adherence takes place and the social and historical complexities of AIDS patients' lives such as poverty or transport difficulties are concealed.

Categories have consequences for the ways 'we conceive of others and think of our own potentialities' (Hacking quoted by Biehl 2005a:259), and the categorization 'drop-out' shaped the ways in which those patients were thought of, talked about and dealt with. The association of extreme poverty with 'non-adherence' produced and provided a rationale for exclusion and stigmatization. Once patients were categorized as 'absentees' and 'drop-outs' a different logic began operating which allowed some AIDS patients to be, if not 'socially blamed for their dying' (Biehl 2005a:263), at least socially blamed for interrupting treatment and eventually dying.

To be labelled an absentee or drop-out had dire consequences since nonadherent patients were blamed for it and were supposed to be reprimanded, humiliated and even punished. Some patients struggled to avoid being slotted into the category of drop-out and those who were more vocal stressed the reasons why they did not come to the health facility. Oksala (2010:462) mentions that

In exposing concepts, categories and practices as sedimentations and expressions of power relations he [referring to Foucault] attempted to reveal the exclusion, domination and violent treatment of those at the losing end of the struggle for objectivity and truth: how their views have been branded as false and irrational and their behavior as abnormal and pathological.

In line with this statement, the category of drop-out may be the effect of the sedimentation of power dynamics involved in the fostering of a hegemonic and single conception of modernity, Western modernity, which is related to specific dualisms: culture and nature, civilized and savage, modern and traditional, passion and reason (Appadurai 1996:3; Sousa Santos 2001:24). I suggest that Western modernity, and the valorization of a particular way of life as the gold standard, is associated with the establishment of hierarchies of economic activities, languages and personal presentation.

#### Categories and the Disciplining of Alberto

The story of Alberto, as well as of many others like him, helps to illustrate some inequities and disparities. He was in his early twenties and had only reached 4<sup>th</sup> grade. He was HIV-positive, his face and arms were covered with skin eruptions, he had sores on his chest and complained of weakness and cold. His mother and siblings established themselves in a rural area near Nhassacara, a small settlement in Barué District and their main source of livelihood was small-scale agriculture.

To get to Cruzamento's health post, where a mobile AIDS clinic functioned once a week, Alberto had to walk for two hours from his homestead to the road passing by Nhassacara where he then picked up a makeshift bus with no schedule to get to the health post. It takes forty minutes to drive on a bumpy tarred road from Nhassacara to Cruzamento. Catandica, the district headquarters where the rural hospital is located is even more distant and a bus round trip Nhassacara/Catandica Rural Hospital costs approx. US \$ 4. Since 38 per cent of the population lives on less than US \$ 1.7 a day, this endeavour is of significant economic magnitude.

Alberto's struggle to access treatment was part of a collective family effort. When he ran out of cash and stopped going to Catandica Rural hospital, his mother travelled to another province to borrow money in order to pay for Alberto's travel. When he could return to the hospital, he was told his medical record could not be found and he had to keep struggling to access treatment. Alberto explains his odyssey navigating health services this way:

I understood everything they told me, when I left the building where one goes for testing I went to the place where the nurses are, they also told me to go to the lab, and to the pharmacy, I went to all those places they told me to go. I would go one day and they would tell me: 'come again tomorrow', I would go again...then they would tell me to come the next day, I would go that day.... I went all those days, but then for lack of money I did not show up in Catandicafor some days ... the only thing I want is to get treatment! They [health workers] told me ... they looked for my medical record in Catandica, they looked for it here, they looked who knows where else and still they did not find it! So, now I only have my patient ID.

Alberto perceives himself as following the instructions he was given but he was anguished, desperately trying to get treatment and holding to his patient ID as the only proof he tested and followed the usual requirements. The lay counsellor/social worker who is part of the mobile ART delivery unit at Cruzamento's health post explained to me that Alberto was a 'drop out'. She said he had interrupted care long ago but was rebuked by Alberto who answered he was tested in June, stopped going to the district hospital in December and we were in the month of February. The counsellor then wrote down his name and patient ID number, told me she was going to look for his medical record at the rural hospital in the district headquarters and told him to return next week. She mentioned she would open a provisional medical record in case she did not find the other one. When I asked her if she could not open a provisional medical record that same day she answered: 'No way!, These drop-out patients are just like this.... We can't open a provisional file right away so that they learn the lesson and don't miss appointments again in the future!'

By saying 'these drop-out patients are just like this' she is in fact considering non-adherence as a personal characteristic of the patient, essentializing and naturalizing it, while decontextualizing the conditions of his engagement with AIDS treatment. The counsellor punished Alberto by not issuing a provisional medical record as a way of disciplining him. Patients categorized as 'drop-outs' first had to undergo Directly Observed Therapy (DOT) again for two weeks before they were given pills to take at home. They had to come to the health unit daily for that period, which was an extra burden in terms of expenses and time spent out of income activities for the patient and sometimes for both patient and family members. DOT was administered punitively and was used to threaten patients as a way of disciplining them and supposedly increasing adherence.

By not issuing a provisional medical record and making the patient come each week, the counsellor was in fact depleting the little money the patient had and therefore diminishing his possibility of travelling to the health centre and getting treatment. More 'seasoned' patients tend to elude the bureaucracy, go for testing again and initiate the entire process all over again whenever they lose their IDs or their medical records are not found by the clinics.

The attitude of the counsellor towards Alberto may be seen as part of an institutionally acceptable way of interacting with 'absentees' and 'dropouts'. Observations in the health units confirmed these types of practices including the outrageous verbal abuse of a severely ill patient and her mother on the grounds that the clinician was just trying to figure out whether she 'was one of those patients who lied and did not take the medication'. Blame, humiliation and disrespect are considered appropriate and justifiable ways of treating patients suspected of interrupting their treatment.

Poverty, inefficient NHS bureaucracy, and attitudes towards 'absentees' and 'drop-outs' combine to make it harder for the patient to get treatment. The plight of Alberto and of many others like him bring to mind JoãoBiehl's words in relation to zones of social abandonment in Brazil where the marginalized, unhealthy and mentally ill are left to die. Those deaths appear as if they had been 'self-generated' (Biehl 2005a:52). In a similar way, the suffering of AIDS patients trying to access ART, particularly from distant rural areas, appears 'self-generated', as if it was only the result of the patients' actions and decisions. The label 'drop-out' marks AIDS sufferers' bodies and produces a stigmatized identity that, to borrow Biehl's words (2007), is meant 'both to explain their dying and to blame them for it'.

#### Conclusion

This ethnography shows that healthcare delivery models are not neutral and can become exclusion mechanisms that marginalize the poor. The ART delivery procedure was designed in a vacuum and the context of its implementation was ignored. It was somehow assumed and expected that patients would 'fit' the model and the services provided. The implementation of that model raises some challenges to the expectation that these models designed in a decontextualized way can eventually address health needs at a global level.

ART reinforces existing inequalities and creates new ones. Inequality became institutionalized through the adoption of the same cumbersome and lengthy ART delivery model designed and proposed by international institutions, independent of context and of the differentiated possibilities of AIDS patients in distant rural areas. It ignores the specificities of rural settlement and adopts throughout the province same ART delivery model, which at times demands daily visits to health facilities. The fact that in rural areas, scattered settlements and long d istances between homesteads and health units make it more difficult for patients to reach health facilities regularly was not considered. The treatment scheme itself became a triage technique, a way of separating the patients who must live from those who might die.

There was a primacy of the ART delivery model and the healthcare services institutional bureaucracy over the lives and needs of patients whom they are supposed to serve with dreadful consequences for patients' possibility to access and adhere to ART. But patients' particular lives and bodies come back, as in some kind of the return of the repressed, and proved that decontextualized ART delivery models were not in tune with the health service conditions in Mozambique and patients' needs. I suggest that the model designed to provide ART itself became a sophisticated biopolitical exclusion mechanism.

There is no explicit rule about who should be exempted from DOT and who should not, or who can collect medication in advance and who cannot. In practice, the conception of modernity associated with an urban way of life, tidiness, 'education' and the ability to speak Portuguese constitute the grid on the basis of which health workers take decisions. Biomedicine is not free from value (Comaroff 1982:59) and, as Eisenberg (1977:20) reminded us, biomedical care is rather a 'complex social process, embedded in the cultural matrix and laden with values'.

The possibility of accessing ART and fulfilling its requirements as well as the probability of adherence to treatment is hindered by factors such as hunger and lack of transportation as well as by weak and underfunded health systems unable to deliver appropriate care, and the dearth of a health workforce. However, I suggest that the valorization of a single and hegemonic conception of modernity, Western modernity, also influences how patients are attended to at health units affecting access to treatment and adherence. That is, both material and value-related issues are at stake.

The 'non-adherent patient' is constituted with specific characteristics as poor, unclean and uneducated. The material and symbolic production of categories such as 'absentees' and 'drop-outs' and their effects on patients' lives draw attention to the power of naming, labelling and classifying. The category of drop-out produces dropping-out, to label someone 'dropout' diminishes the possibilities of the patient adhering to treatment and therefore produces the effect of non-adherence, that is, the categorization itself becomes yet another biopolitical triage technique which separates out the patients most likely to fulfil ART requirements.

Following Fassin (2007:xv) who reminds us that health is a biosocial phenomenon and social relationships can affect the biological fate of individuals, I suggest that unequal social and economic relationships manifested in the hierarchy of economic activities and occupations which privilege wage-work, or in the valorization of hygiene, presentation of bodies and language use affect the possibility of accessing ART as well and hence affect AIDS patients' biological fate.

## Notes

- 1. Physicians density per 1000 population was 0.04 in 2012, who.int/gho/data.
- There are different types and levels of health facilities: health centres, health posts, rural hospitals, provincial hospitals and central hospitals.
- Though not referring specifically to the city of Chimoio, updated data show that while 13.1 per cent of women and 9.2% per cent of men in Mozambique are HIV positive, in Manica province 15.6 per cent of women and 14.8 per cent of men are HIV positive (INSIDA 2009:11).
- 4. Internationally recruited expatriate medical doctors hired by the NGO.
- At Chimoio Provincial Hospital from September 2008 to May 2009 (approximately 240 days) the CD4 equipment was out of order for a total of 116 days, including not working at all for two consecutive months.
- 6. '*Capulana*' designates a piece of cloth women generally dress in, tied around the waist but it can also designate the cloth itself.
- Biopolitics led to the emergence of fields such as public health and demography (Foucault 1990:139–46).

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