

Adherence as therapeutic citizenship: impact of the history of access to antiretroviral drugs on adherence to treatment

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A dramatic increase in the use of antiretroviral drugs in Africa has increased focus on adherence to treatment, which has so far been equivalent if not superior to that in northern contexts. The reasons for this exceptional adherence are poorly understood. In this paper, we examine adherence in the historical and ethnographic context of access to treatment in Burkina Faso, Côte d'Ivoire and Mali. Living where there is no social security and minimal, if any, medical care, individuals diagnosed with HIV are faced with the threat of illness, death, ostracism and destitution, and were obliged to negotiate conflicting networks of obligation, reciprocity, and value. HIV and AIDS programmes value efforts to address social, and indeed biological, vulnerability. In contrast, kinship-based social relationships may value individuals in other ways. These conflicting moral economies often intersect in the worlds of people living with HIV. HIV status can be used to claim resources from the public or non-governmental organization programmes. This may interfere with social networks that are the most stable source of material and emotional support. Self-help and empowerment techniques provided effective tools for people living with HIV to fashion themselves into effective advocates. In the early years of the use of antiretroviral therapy (ART), access to treatment was thus mediated by confessional practices and forms of social triage. We introduce the term 'therapeutic citizenship' to describe the way in which people living with HIV appropriate ART as a set of rights and responsibilities to negotiate these at times conflicting moral economies. Exemplary adherence should be viewed through the lens of therapeutic citizenship. © 2007 Wolters Kluwer Health | Lippincott Williams & Wilkins

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Introduction

The dramatic increase in the use of antiretroviral drugs in Africa, the continent hardest hit by the epidemic, has been a welcome development. Africa is the continent most affected by the AIDS epidemic, with over 25 million people living with HIV and AIDS. Across Africa, access to HAART is being scaled up dramatically. International recognition of the catastrophic scope of the HIV epidemic in Africa and the desirability and feasibility of mitigating its scope through treatment programmes has mobilized

significant political will and resources. Whereas the goal of treating up to 3 million by the end of 2005 was not met, the number of people living with HIV and AIDS receiving treatment continues to increase and is estimated at roughly one quarter of 4.6 million who need treatment in sub-Saharan Africa [1].

Early fears that expanding the use of antiretroviral therapy (ART) could lead to 'antiretroviral anarchy' [2] have yet to be realized, probably because disorganised and inappropriate ART use was more likely in the absence

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of structured treatment access programmes. Early studies from pilot programmes in Senegal and South Africa showed extraordinarily high rates of adherence to treatment [3,4], belying earlier concerns that adherence would be an issue. A recent systematic review confirms equivalent to superior adherence throughout sub-Saharan Africa [5]. Whereas most of the literature has been concerned with the problem of inadequate adherence, this research suggests that the relevant research question is not why a small minority of patients are non-adherent, but rather, why are patients so exceptionally adherent to treatment? Understanding why these individuals are so adherent to their antiretroviral regimens will give us insights into the social impact of ART. This complex result of adherence indexes a significant social impact of ART.

This paper explores the issue of adherence to treatment in the historical and anthropological context, drawing on our work in community-based organizations in the west African nations of Burkina Faso, Côte d'Ivoire, and Mali in providing care to people living with HIV including ART since 1994, as well as more recent collaborative research on adherence with community-based organizations and hospitals providing ART [6].

The simplest explanation for high levels of adherence reported so far from African sites is that potentially non-adherent patients were in effect excluded from treatment, in other words, that treatment programmes operate a strong selection bias, either actively in terms of how patients are enrolled into treatment [7] or passively in terms of barriers that must be overcome to get into treatment. An alternative explanation is that pilot programmes that have been reported in the literature were unusual, benefiting from exceptional financial, human and technical resources including highly motivated expatriate medical manpower [8]. Although both these explanations are plausible, another explanation is explored here. In this paper, we examine the historical context of access to antiretroviral drugs in Francophone west Africa using ethnographic methods, in order to contextualize epidemiological notions of selection and provider bias.

History of access to treatment in Francophone west Africa

In the early years of the international response to the epidemic, the focus shifted to 'empowerment', understood largely in terms of improving the social conditions of those most vulnerable to HIV by emphasizing their human rights [9]. This led to the deployment of confessional technologies that were used to train Africans to give testimonials about being HIV positive [10]. These were a cornerstone of AIDS prevention efforts that

stressed 'giving a face to the epidemic', drawing on lessons from the epidemic in the west to argue that knowing or seeing someone with HIV could reinforce prevention [11]. From the mid-1990s onwards, training workshops proliferated and participants learned to build up community groups and to set up discussion groups to encourage other individuals with HIV to talk about their condition [12]. Community groups, testimonials and discussion groups, anchored in western notions of self-help through disclosure, often offered the best opportunity to gain resources that could help feed the family and maintain one's position in kinship networks (Bayer and Oppenheimer, this issue). In a context of poverty in which the state provides only minimal services, these kinship networks are often the only available forms of social solidarity.

We have observed hundreds of these narratives over the past 13 years, remarking that they were frequently couched in an evangelical idiom, describing the process of being diagnosed with HIV as the beginning of a conversion-like process, the first step on a road that led to greater enlightenment and the adoption of a more responsible, moral life, followed by exhortations to the audience to get tested. In the early years of the response to the epidemic, these evangelical themes often disturbed many of those who worked for the agencies that funded these efforts, many of whom came to international AIDS work through activism in the north and were sympathetic to the culture of sexual openness that characterized the response to the epidemic in the gay community there. Whereas it is possible to view these evangelical forms as either historical residues of the colonial period or a reflection of the growing popularity of Pentecostal churches, an alternative explanation emerges from working with these people living with HIV.

Rather than expressing a rigid moral position, these testimonials of being HIV positive were a working-through of the radically altered domains of possibility in which individuals living with HIV found themselves. The testimonials crystallized an ethical project, as individuals diagnosed with HIV sought to re-make themselves as bearers of both rights and responsibilities. Living where there is no social security and minimal, if any, medical care, individuals diagnosed with HIV were faced with the threat of illness, death, ostracism and destitution. In response, they enacted a way to move forward with their lives. A major challenge was to negotiate conflicting networks of obligation, reciprocity, and value. Much of the response to the epidemic has, at times unwittingly, constituted a moral economy, understood as the cultural basis for evaluating value. This particular moral economy values efforts to address social, and indeed biological, vulnerability. In contrast, kinship-based social relationships may value individuals in other ways than their vulnerability. Perhaps the most obvious example of this is the way in which men are often valued more than

women, but even within the same sex one's value may be determined more by one's position in the kinship hierarchy than by one's vulnerability. These conflicting moral economies thus intersected in the worlds of individuals living with HIV, who were obliged to use their biological status to claim resources from public sector or non-governmental organization (NGO) programmes while simultaneously maintaining social networks. These are, after all, the most stable source of material and emotional support; NGO and donor programmes work on short programme cycles whereas families do not.

Anthropological studies of evangelical movements in Africa suggest that they shared with self-help techniques and workshops the way in which they made available instruments and strategies for self-fashioning [13–15]. These could then be taken up in order better to navigate the overlapping moral economies in which individuals living with HIV found themselves enmeshed. The market for testimonials, anchored in western notions of self-help through confession, offered the best opportunity to gain resources that could help feed the family and maintain one's position in the kinship networks that, in the absence of a viable state, are the only available forms of social solidarity.

Until very recently, in the absence of any real political or economic engagement to address the structural issues driving the epidemic, many local observers viewed these testimonials as only so much 'theatre', performances devoid of authentic meaning, used only instrumentally. This proved not to be the case, however, as these confessional technologies did more than produce testimonials. We have seen over the years how the use of these techniques helped some of those in the first cohort of individuals living with HIV to gain a range of interpersonal skills that were not only self-transformative, but also transformative of relationships. In short, these techniques also transformed social relationships around those who grew fluent in their use. In addition, they produced a vanguard of activists.

As the supply of donated antiretroviral drugs increased from 1998, groups were increasingly faced with the gut-wrenching prospect of deciding who should get the medications. No matter how many donations they received, demand always outstripped supply. In a setting in which poverty is endemic, and where the state provides few, if any, services, any organization offering even the most minimal services was quickly overrun. This was certainly the case of the HIV/AIDS groups in which fear of stigma did not appear to be much of a barrier to a steadily increasing stream of would-be beneficiaries. Many of these individuals were already ill, or suspected themselves to be HIV positive because they had lost a spouse.

The concept of triage was initially developed in wartime, as a way to use scarce treatment resources most rationally;

those most likely to live are prioritized to receive care, whereas those whose prognosis is poor are left to die. HIV/AIDS groups were faced with a similar situation. They made the difficult decision of who should benefit from the limited source of drugs by adopting a form of social triage. Those whose continued health was most likely to translate into increased resources for the group were the first beneficiaries, but how did the groups choose? They reasoned that those who were most charismatic and most able to deliver effective testimonials would be the best advocates for getting more drug donations. These individuals were being identified mainly on the basis of their performance in the discussion and self-help groups, which were ideally suited to cultivating their testimonial skills. It was a subtle, implicit process, but it highlighted how the discussion groups, conjugated with the confessional technologies, were veritable social laboratories, safe zones where new forms of disclosure could be experimented and made effective.

Sometimes the decision as to who should get the drugs was more directly pragmatic. Prioritizing access to drugs for beneficiaries who could be counted on to facilitate the group's work in virtue of their professional position was an example of how groups used drugs to increase access. In one group we worked with, for example, a conscious decision was made to offer a rare treatment to a customs officer because he would be able to facilitate further entry of medications; his wife, who was also positive, was initially not offered the treatment. These strategic forms of social triage contrasted with the rhetoric that framed international donors' aid, which was meant to target the most vulnerable members of society, not the most valuable. It also differs from patient selection mechanisms made through NGO protocols and medical practitioners (Bayer and Oppenheimer, this issue) [16].

Over time, those who were gifted communicators also became those with the most direct experience with the drugs as they benefited first from the trickle of antiretroviral drugs. Echoing the experience of AIDS activism in the north, these patients were often the most knowledgeable about antiretroviral drugs. Now, as treatment programmes expand, they are ideal candidates for assuming leadership roles in treatment literacy and expanded access programmes.

This narrative account of how ART initially became available reflects the experiences of many whose early experiences with the AIDS industry, its discourses of empowerment, and its confessional technologies trained them to become effective advocates. South Africa's Treatment Action Campaign (several media profiles of its founder, Zackie Achmat, have made him the best known African AIDS activist in the north) is an example of an organization that explicitly harnessed this process to identify and train future activists from the ranks of patients [17]. In our discussions with colleagues and fellow

activists over the years, however, it seems that throughout Africa the inchoate strategies of other groups and activists amounted to a kind of implicit process of producing activists through access to treatment. Whereas some individuals, particularly well versed in the social arts or endowed with charisma, were naturally well suited to draw on the repertoire of confessional techniques to mobilize others, even those less-skilled were able to benefit from the drills, exercises, and training that proliferating workshops disseminated throughout the continent. This 'production of activists' was not, however, exclusively driven by social forces. The issue of access to ART in effect simultaneously provided both a therapeutic goal and the means of sustaining the therapeutic quest. Bluntly put, skill at telling the right stories got activists drugs, and kept them alive. The confessional technologies drawn upon in this therapeutic quest were conjugated with the growing availability of antiretroviral drugs to fashion, biologically and socially, therapeutic citizens. The activist slogan of 'drugs into bodies' tellingly illustrates how social forms are incorporated into local biology [18].

Discussion

This historical context shows how contemporary adherence to treatment, the result of a shifting institutional ecology and a complex human behaviour, indexes a form of therapeutic citizenship. The term describes the way in which individuals living with HIV appropriate ART as a set of rights and responsibilities [18]. This approach suggests that exemplary adherence is a consequence of this therapeutic citizenship produced through practices of self-fashioning and social triage that shaped the early years of access to treatment. A similar phenomenon has been described in the patterns of resort of Indian women organ donors, whose 'therapeutic' trajectory began with the encounter with a skeletal state reduced to the function of family planning [19]. Over the course of our work, we have found therapeutic citizenship to be both a political claim to belonging to a global community that offers access to treatment for the ill, as well as a personal engagement that requires self-transformation. This view is supported by anthropological approaches that view citizenship as enacted through a web of institutional and political cultures, rather than the more classic understanding of the political relationship between citizen and state. It allows us to examine how being on ART embodies the historical process by which local ideas and practices relating to health and the body are articulated with the global political economy of pharmaceuticals and AIDS relief. This contrasts with approaches that examine adherence as the behavioural outcome of individual-level determinants. It also differs with some public health perspectives that view 'culture' as a barrier to adherence to biomedical interventions.

Whereas confessional technologies and discourses of empowerment provide the tools for shaping therapeutic activism, being diagnosed with HIV crystallizes what is at stake in this therapeutic citizenship. The growing availability of antiretroviral drugs, which dramatically restore health in those who are ill and keeps them healthy, in effect sustains activism not only by keeping activists alive and healthy, but also by putting flesh on the biomedical discourse that preaches the very real biological efficacy of these drugs. Living through a diagnosis, with all the uncertainties and challenges this raises, is one thing; living through the 'resurrection' one experiences after one has been ill and has recovered because of the drugs is a whole other magnitude of experience. No wonder that the medicines have only confirmed the evangelical aura that surrounds HIV and its treatments.

Until now treatment activism has largely focussed on the availability of the treatments for a number of reasons. Certainly the life-saving drugs, whose initially prohibitively high cost was rooted in a complex web of intellectual property and the pharmaceutical industry, were powerful symbols of global capitalism and a tangible rallying point for activism. The conjugation of this activism with competition from generic drug manufacturers in India, Thailand and Brazil triggered a collapse in drug prices, suddenly making the drugs far more accessible. The mechanisms for procuring and supplying the drugs have, however, not been able to keep up. The lack of public health infrastructure in Africa means that, currently, drugs can only be delivered through programmes patched together from complex donor programmes (such as the Global Fund and the US President's Emergency Program for AIDS Relief; PEPFAR), NGO, community groups, public and mission hospitals, and workplace health centres. In some cases, other programmes are cannibalized in order to piece together antiretroviral drug distribution mechanisms.

This account shows that adherence must be placed in both social and historical context. Policies, ranging from trade regulations to healthcare funding, the architecture of treatment programmes, and the idiosyncrasies of local funding create a social and indeed cultural landscape that individuals living with HIV must negotiate to gain access to treatment. This landscape comprises both the working relationships among staff and communities and the culture of human rights that animates much of the response (see Gruskin *et al.*, this issue). Whereas this landscape varies from place to place, even between the neighbouring countries in which we work, nonetheless general contours of the social processes by which individuals enter into treatment can be made visible. We have introduced the concepts of confessional technologies, therapeutic citizenship and social triage as analytical constructs to allow scrutiny of these processes in other contexts. In resource-poor settings, poverty and

the state's inability to deliver services and security create conditions of exceptional uncertainty and adversity, at times difficult to imagine for those of us who live in the north, including at times those responsible for the policies and programmes that aim to treat individuals living with HIV. It is our opinion that in order to engage with the ongoing challenges of adherence to treatment, serious attention must be paid to how individuals negotiate the challenges that they face in everyday life in a local context, and to the impact of policies and programmes on these. ART roll-out programmes must be continually mindful, and learn from, how they impact social relationships. More broadly, the conditions that create adversity, poverty and structural de-funding of health systems, will also need to be addressed.

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