

Being naturalised, being left behind: The HIV citizen in the era of treatment possibility

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Abstract

With around five million people accessing anti-retroviral treatment, which significantly reduces mortality and extends life, the HIV pandemic now exists in a context of treatment possibility, if not access. This paper discusses ways in which the pandemic is becoming naturalised through medicalisation, normalisation and marketisation, and how these processes undermine themselves internally. The paper goes on to examine some further denaturalising discontinuities in how the contemporary HIV era is lived, which derive from HIV's specific biological, socioeconomic and psychological characteristics, and which leave many at some distance from the relatively hopeful HIV present. The paper argues that naturalisation, and aspects of 'being left behind,' are important elements of HIV experience which require continued attention. Throughout, it examines the significance of naturalising and denaturalising processes for HIV citizenship. The paper draws on narrative data from studies of HIV support in the UK, 1993-present, and in South Africa, 2001-4, to make these arguments.

Introduction

33.4 million people are living with HIV; there are 2.7 million new infections yearly. But over five million people worldwide now receive antiretroviral therapy (ART), the medication regime which significantly reduces mortality and extends life for people living with HIV (UNAIDS, 2009a; WHO, 2010). Even HIV positive people who require ART but cannot access it - notably, in sub-Saharan Africa - are living in an era which we can call that of HIV treatment possibility (Davis and Squire, 2010).

This paper begins by addressing HIV's contemporary naturalisation within the treatment possibility era. In this era, across different epidemic circumstances, HIV is increasingly constructed as a natural, that is, a general and comprehensible, though still difficult to deal with, part of our biological, social and economic worlds. The paper argues that naturalisation operates through a number of processes. These include HIV's medicalisation - its comprehensive medical management, care, and self-care; HIV's normalisation, that is, its constitution as a regular part of health and social relations; and HIV's marketisation - its ordering within and through relations of consumption. The paper examines what these naturalised - medicalised, normalised, marketised - HIV citizens are like, and what internal contradictions they display.

The paper then focuses on some of the broader uncertainties within the pandemic that put naturalised HIV citizens in question, or denaturalise them. These uncertainties derive

from many people's physical, economic, political and psychological distance from the apparently hopeful HIV present. Such distancing means that many within the pandemic are being 'left behind.' (fn 1 This expression is taken from the title of a song in Roger Bourland's (1992) *Hidden Legacies* cycle, but it has been used in many other contexts within the pandemic) The paper examines how this situation relates to the uncertainties of HIV as a biological condition, HIV-related socioeconomic resources, and HIV's psychosocial characteristics.

In this paper, HIV appears as a focus of governmentality, that is, of a nexus of discourses and practices through which local, national and international organisations generate and manage their subjects as HIV citizens (Foucault, 1991). Many contemporary discussions of HIV citizenship treat it along these lines, rather than as, more conventionally, a matter of individual rights and responsibilities - though the latter may be seen as a strategic way of formulating the former (Mbali, 2005; Robins, 2009). This structural orientation towards HIV citizenship seems to derive from the highly socialised and politicised nature of the pandemic: the socially embedded nature of HIV's transmission, its social stigmatisation, the socioeconomic differentiations within its epidemiology and the strongly politicised histories of national and international approaches to HIV. However, HIV citizenship is, the paper argues, a complex condition that admits of further theoretical elaboration; some of these elaborations may be relevant to other health conditions. Through the paper's analysis of naturalising and denaturalising processes, a fuller account of the characteristics of HIV citizenship is built up.

The paper develops its arguments in relation to citizens of all HIV statuses. Being both naturalised and left behind by the pandemic are conditions that all of us living within the temporal and social contexts of the pandemic encounter. Nevertheless, these conditions are particularly intense for people who are HIV-affected, living or working with HIV positive people, and they are especially salient and powerful for HIV positive people.

The paper draws on the author's longitudinal interview research with people living with HIV in the UK, predominantly London, between 1993 and 2010, and in South Africa, largely around Cape Town, between 2001 and 2004. In so doing, it aims to avoid simplistic divisions between the pandemic's global-north 'haves' and global-south 'have-nots.' South Africa, like the UK, is a significant international power; both countries have high GINI indices - a measure of internal inequalities - and high levels of migration. These common factors impact their HIV epidemics. However, South Africa is a medium-income and the UK a high-income country; unemployment in the former is around 50%, around 8% in the latter. People living with HIV in high-prevalence, low- and medium-income countries such as South Africa are half as likely to have ART as HIV positive people in high-income nations (WHO, 2009a) and experience severe resource constraints. In South Africa, they live with the aftermath of AIDS denialism, as well as successful mass political struggle (Mbali, 2005). Such particularities, though not an analytic focus here, must be recognised (Davis and Squire, 2010a). While the pandemic's naturalisation, and its denaturalising uncertainties, occur in many contexts, it is important to acknowledge unevenness across those contexts, particularly since ART access and the naturalisation processes associated with it happened later and with less generality in the global south.

The paper deploys its two datasets in order to explore processes of naturalisation and denaturalisation occurring, in different pandemic contexts, at the beginning and, in the UK case, after over a decade of living with treatment possibility. ART became generally available in the UK in 1996; South Africa's national ART rollout began in 2004. However, some South African interviewees had ART access via trials and pilots in 2001. From 2003, all who needed it had access via NGOs or the Western Cape Health Department. By the late 1990s in the UK, and by 2003 in South Africa, many interviewees were dealing with lifelong ART use, HIV's consequent naturalization, and the uncertainties that undermine that naturalisation. Of course, interviewees were still speaking and living in drastically different epidemic contexts, with distinct HIV and national histories and sharply divergent resource availability. Nevertheless, some common narrative patterns around naturalisation and resistance to it emerged in UK and South African studies, as life with HIV on ART became possible.

The appearance of such patterns in data from a developing-world or a developed-world epidemic might indicate more about the resource contexts of the epidemic, than about HIV citizenship. The patterns' appearance in both epidemic contexts, in the global north and the global south, could mean that processes of naturalisation and denaturalisation characterise contemporary HIV citizenship more widely. However, nationally specific epidemic patterns have important modulating effects, and data from these two countries can be taken only as suggestive evidence for more general narrative patterns.

The studies involved semi-structured interviews about HIV support from medicine, social services, the voluntary sector, family and friends, faith communities and popular media. Interviews were conducted in collaboration with local HIV organisations under ethical approval from the University of East London. The UK research involved 55 people living with HIV, about 50% women, two-thirds in London, with up to five interviews. The South African study involved 37 interviewees, 29 of them women, living around Cape Town, with one or two interviews. Analysis addressed the content of the interviews, but also their narrative forms, because participants frequently used the interviews to tell their HIV life story, or structured significant amounts of the interview in narrative ways (Squire, 1999; 2003; 2006; 2007). The resultant complex narrative material demonstrates both the subtle yet persistent elements of 'being left behind,' and the powerful but compromised processes of naturalisation. These processes may also be discernable in other forms of pandemic representation - in policy documents, media accounts and artistic representations, for instance. Personal narratives, however, often display emergent aspects of HIV citizenship earlier than do other representational forms. They also exhibit naturalisation and denaturalisation processes at their most interlinked and codetermining.

The paper uses interview citations that exemplify general patterns. For instance, a quotation from a UK interviewee living with HIV and on ART in 2001, will exemplify interviews from that participant grouping. At the same time, the paper restricts the number of interviews cited, in order to maintain a sense of individual participants' narratives and the complexities within them.

Naturalisation

This section of the paper describes HIV's naturalisation, a process involving three interlinked processes of medicalisation, normalisation and marketisation. These processes have, overall, the effect of turning the virus into something universal, permanent, and incorporated into biological, social and political relations - although still with the trace of otherness that any 'naturalised' citizen carries, and that I want to unpack in each case.

Naturalisation can have progressive effects. Its constitution of HIV as a condition of general relevance and acceptance can reduce stigma-producing divisions and establish associations between and rights for citizens of all HIV statuses. However, some sociological theories use the term 'naturalisation' to describe processes that turn social and political hierarchies into 'natural', unchallengeable and unchangeable states, assimilated to the biological rather than the sociopolitical field (Bourdieu, 2001; Foucault, 1995 [1975]). Such theories suggest that HIV's 'naturalisation' might obscure its politics - the polarities and contests between HIV citizens, and between HIV citizenship and other kinds of citizenships. They indicate the importance of understanding HIV citizenship, like other citizenships, within the frame of multipolar, changeable, agonistic politics (Mouffe, 2006), rather than as an achieved state.

In philosophy, naturalisation refers to something different: to an emphasis, within theories of knowledge, on empirical investigations, by ordinary people as well as scientists, of human capacities of for instance language and cognition as the route to understanding knowledge, rather than reliance on prior ideas about what knowledge is (Quine, 1969). Of course, prior ideas cannot be erased from knowledge-making, and contemporary naturalist epistemologies acknowledge this; nor do they suggest science is the higher truth. Their naturalism is a pragmatic and heuristic matter (Stich, 1993). Such epistemological naturalisation can be applied analogically to HIV knowledge. It suggests that a 'naturalised' knowledge of this new, complex and changeable field would be the outcome, not of assumptions translated from existing personal, religious or even scientific but rather, of negotiated, limited knowledges, constituted via ongoing academic, professional and everyday investigations - by investigations, that is, by HIV citizens of all statuses, in every field.

Finally, naturalisation's meaning within everyday citizenship discourse provides a guide to the limits of HIV's naturalisation, by indicating both HIV's social incorporation and its continuing particularity. A 'naturalised' citizen retains this status, always marked out from citizens who did not undergo naturalisation. Similarly, HIV's naturalisation is accompanied by the continuing specificity of the pandemic, that limits naturalised understanding of it and leaves the status of the HIV citizen open to question.

The following subsections of the paper explore how HIV's naturalisation is played out through the three processes of medicalisation, normalisation and marketisation, which all operate in inclusive and progressive, but also at times simplifying and limited ways.

The medicalised HIV citizen

The UN's Millenium Development Goal 6, 'Combat HIV/AIDS, malaria and other

diseases' includes halting and beginning to reverse the spread of HIV/AIDS by 2015 and achieving universal HIV/AIDS treatment access for those needing it by 2010. The latter goal is more or less met in high-income countries. ART now reaches an estimated 5.2 million in mid- and low-income countries (WHO, 2010). International HIV organisations are committed to expanding treatment to those without access, treating people earlier, and using simpler, cheaper, better-tolerated drugs.

Meeting the HIV part of MDG6 relies on a raft of resource-intensive strategies, for instance, social prevention programmes, economic development, and women's empowerment, as well as scaled-up ART, treatment for opportunistic infections, and testing. Medical strategies are particularly costly, requiring continuing, ever-increasing provision - by governments, international NGOs and other donors - of standard medications, cheaper generic versions, and second- and third-line treatments (MSF, 2009). Moreover, HIV's medicalisation is intensifying. International HIV organisations support earlier treatment, which research suggests improves survival as well as reducing transmission. Some researchers and policymakers argue that HIV's continuing high incidence should be addressed by regular, universal - though voluntary - testing, and lifelong ART for all HIV positive people to reduce their infectiousness, alongside continuing education and prevention campaigns (Granich *et al.*, 2009). HIV policymakers and activists advocate ART as effective post-exposure prophylaxis, or PEP, after possible exposure at work or through rape or abuse, (ILO/WHO, 2005). Some researchers and activists also advocate selective use of ART as pre-exposure prophylaxis, PrEP, where high transmission risk and risky behaviours coexist (Rosengarten and Michael, 2010).

Most international organisations, policymakers and activists emphasise multifactorial approaches, and caution against relying on medical technologies (Piot *et al.*, 2009) .

However, the HIV pandemic is now characterised by the possibility of effective medical treatment, expanded treatment access, and diversifying ART uses. These medical technologies allow clearly defined goals, implementation strategies and evaluations, and are supported by powerful commercial and professional stakeholders. As a result, the contemporary medicalised field can work like an implicit override button on other fields, especially those of social HIV policy and practice. (Kippax, 2010)

Institutional practices around HIV operate with medical treatment, prevention, education and care as their goals, but tend to neglect the last three (Van Damme *et al.*, 2006). These latter, though featuring in policy discourse, are largely left to individual HIV citizens, NGOs and markets to sort out, a tendency likely to increase (Hecht *et al.*, 2009. (Of course, this medicalised skewing is not unique to HIV; see Wills *et al.*, 2008; Sanders *et al.*, 2008.) HIV positive people are educated primarily about medical treatment and safer sex, with occasional appended advice on lifestyle and nutrition. They receive

psychosocial support predominantly around diagnosis, adherence and having children. Unknown-status people are offered HIV testing antenatally; in public clinics in high-prevalence epidemics; in low-prevalence epidemics by health services if they are perceived as at risk and via self-test kits. Testing in non-medical contexts - malls, schools, taxi-ranks - remains rare (UNAIDS, 2009b). People of all statuses access medicalised forms of prevention - condoms, PEP and in some countries, male circumcision – but markedly less resources are devoted to social technologies around sexualities, relationships and gender inequities.

How does medicalisation play out around HIV treatment? At one end of the ART access continuum, those who need ART but do not have it are aware of and campaigning for it. In these circumstances, social approaches to the pandemic take second place. However, they are less integral to many contemporary ART programmes than they were in early ART scale-ups which emphasised treatment literacy, psychosocial factors and community decisionmaking (Abdullah and Squire, 2010). (Recent international treatment policies reemphasise these elements (UNAIDS, 2010).

In the middle of the ART access continuum are HIV positive people, in developing and developed worlds, who take ART and are dealing with sideeffects and their treatment, resistance and the need for alternative medications, the implications of lifetime ART use, and longterm HIV-related illnesses. Interviews with John, (all names are pseudonyms), a research participant in his 50s who has participated in my UK HIV study since the 1990s, provide useful perspective on the epidemic's ongoing medicalisation. In 2009, John began not with HIV, but with the story of an HIV-related precancerous condition:

John:...(the cancer specialist) looks, he says there hasn't been any change. It hasn't progressed to cancer/Right/ but it, but that will be the next stage if, if, that's the only way it will go if/Right/ if it gets worse, um, so that's quite worrying but I realise because I'm quite well read on HIV treatments and all the complications of it all, that the, um, you can have {precancerous signs} for many, many years and it never progresses/mhm/and you can end up dying of old age or of something completely unrelated but it is something that's got to be monitored fairly closely and, um, so I'm now going to go for six months without any treatment, because the treatment that they give you although it works at the time hopefully, if it hasn't worked it carries on working even when you stop which is quite interesting so hopefully over the next six months, there might be, you know maybe the {precancerous signs} will get smaller or go down a grade. So, um, I've just got to get on with my life really and try not to think about it too much/mhm/...so, um, so that's that, so in some ways that is a far bigger issue than the HIV which is, um, very well controlled/mhm/by the medications, I've been on my current regime now for certainly six years and I just had my CD4 results from three months ago, um, that was 1300 which is excellent, my doctor said 'could I have some please / (laughs) / because you've probably got a higher CD4 count than I have'. A viral load undetectable again, apart from two viral blips over the last six years it's, um, it's been undetectable most of the time /mhm/so, and even when we had the blips it went back to being undetectable without having to change treatment which is handy because I'm very heavily pre-treated, so my options are somewhat

limited/mhm/for future treatment so, um, that's, you know, going, quite, quite well.

John tells the story of his new HIV-related illness at length, saying that he has discovered the precancerous cells early, there is a likelihood they will not progress, he has gotten appropriate treatment, and noting that his CD4 counts and viral load are good. This is a medicalised, naturalising narrative: John knows a lot about HIV-related illnesses, their risks, monitoring and treatment; he says successful ART means HIV itself is not a concern; he talks about himself and his doctor as 'we' - they are associates, even friends. At the same time, John's story denaturalises itself by putting HIV's medicalisation in question. Potentially fatal new medical problems arise around HIV, cannot be completely solved, and this is worrying; sometimes the only solution is not to think about it; even John's successful ART is potentially in jeopardy because of his pretreatment earlier in the epidemic.

While the precise medical history delineated here belongs to the UK epidemic, the narrated pattern of medicalised management increasing across an epidemic and across chronological time, yet continuously undercut by uncertainties, failures and new problems, appears in the South African interview data too, and may be of more general occurrence. It is often argued that the pandemic's medicalisation, particularly via treatment, has depoliticised it, narrowing and marginalising the field of HIV citizenship, especially in high income countries (Mykhalovskiy and Rosengarten, 2009). More specifically, Davis (2009) has pointed out HIV positive people's contemporary difficulties in addressing their HIV-related problems in other than medical treatment terms. John's concerns are indeed framed almost entirely medically here. Davis discusses how difficult it can be to approach even clearly social issues, such as unprotected sex in relationships, outside the medical parameters of different HIV strains, viral load, and infectivity. Yet it is clear that such issues are of major, ongoing significance, **not just in well-resourced epidemic contexts**. Studies of longterm ART patients in the global south report side-effects, transport, food and wage costs, and psychological difficulties with lifetime medication, as unaddressed issues that reduce treatment retention if non-medical, social support is not available (Roura *et al.*, 2009).

What about medicalisation's impact on prevention? It has been argued that 'treatment optimism' might disinhibit safer sex, particularly if expanded treatment steals prevention resources. However, there is evidence from a number of epidemic contexts that ART reduces transmission rates (Fang *et al.*, 2004), that knowledge of ART and openness about HIV promote condom use and HIV testing (Bouille *et al.*, 2009) and that longterm ART affects sexual practices in complex ways not reducible to disinhibition (Davis, 2009). Nevertheless, efforts to negotiate condom use may be undercut by early treatment availability if it medicalises away the salience of prevention discourse and practice. There are other circumstances, too, where medical HIV technologies may supplant, not complement, social technologies. Some HIV negative people who have access to ART through friends, family, health system leakage or private commercial sources, are using it, pre-exposure and unprescribed, to reduce risk in situations of potential transmission, for instance if they choose to have unprotected sex with people of HIV positive or unknown status. Here, questions about dosage, sideeffects and resistance replace questions about

the negotiation of condom use.

Treatment possibility, expanded treatment access, earlier treatment and diversified ART use constitute a medicalised field which allows HIV to be lived with longer, with better health, as a condition that is part of life. At the same time, these medicalised discourses and practices can overdetermine HIV strategies, marginalising non-medical aspects of the pandemic and underplaying the limits of medical knowledge. The medicalised HIV citizenship thus seems an emblematic example of the biological citizenship described by Foucault (1991), Rose (2007) and others. Citizens today are, Rose suggests, defined and called into active existence by their biological as well as their conventionally political characteristics, and this 'politics of life itself' offers both possibilities and limitations. In the case of HIV, people are always citizens in relation to this viral condition, obliged to live within the pandemic but also enabled by this definition to take action as biological HIV citizens. Similar benefits and limits appear in the case of the second naturalisation process, normalisation.

The normalised HIV citizen

The treatment possibility era, and the growing emphasis on treatment-led prevention, means the HIV pandemic is not just medicalised, but normalised (Green, 2009). If HIV positive people, HIV-affected people, and people at risk of becoming HIV positive can be treated and protected by western medicine, they turn into regular, unremarkable citizens, just like anyone else. HIV itself becomes part of a broad group of medically treatable and preventable 'chronic' illnesses. It is thus doubly normalised, as itself a manageable, familiar health condition, and as a condition with features comparable to for instance diabetes, heart disease, tuberculosis, and some cancers.

HIV's normalisation also operates through its constitution of people living with HIV as self-regulating, healthy citizens. As with other chronic but potentially fatal conditions, discourses and practices operating around HIV constitute its citizens as biomedicine's partners in a normalised enterprise of survival and, as far as possible, healthy living. These discourses and practices give their citizens normalising self-care responsibilities in realms where medical and lay expertise overlap. People living with HIV are induced, and induce themselves, to pursue good nutrition, exercise, stress management, and to deploy 'complementary' or 'traditional' treatments where these do not compromise western medical approaches. They are expected, and expect themselves, to be citizens like any others, able and obligated to live healthily, work and love.

Within my South African interview study, Mhiki, a woman who in 2001 had ART access through a hospital trial, began her interview with a tale of entwined medical and self-management, and healthy 'living with HIV,' that exemplifies UK and South African interviewees' articulations of normalised HIV citizenship. Of course there are important specificities in Mhiki's account, related to the resources available to her, to gender, and to the epidemic's South African history. Nevertheless, many of the common requirements of self-regulating HIV citizens mentioned above, make themselves heard:

Mhiki: With regard to things that are helpful to one living with HIV firstly, you must

accept it. When you are told that you have HIV, accept that because that is what will make you live a long life. Secondly, it's good behaviour. If you were drinking and or smoking, you must stop all that. Thirdly, if you are taking medication, you must take your medication as prescribed. Finally, if you have a boyfriend, you must condomise... Since I told my family, I'm feeling very well... If you've got a problem, you can share with the other people in the support group... if I have a problem (with side effects) I can phone Sister {name} and go to {hospital}. If I don't have money I can borrow it from my neighbour and when I come back the sister give 20 rand to pay the neighbour back... I try to eat good food and even exercise because, every Saturday I go to play a netball. We've got a netball club. So, I'm doing exercise.

At the levels of personal, interpersonal and social relations, Mhiki thus articulates HIV as a normalised phenomenon, allowing HIV positive citizens to accept their condition, take their medicines, live healthily and talk openly.

People who view themselves as potentially HIV positive are also positioned in a normalised way, required to self-govern via social and educational technologies around for instance abstinence, partner reduction, and partner testing, and health technologies such as male and female condoms, male circumcision, PEP and potentially, PrEP. These prevention efforts are, at the same time, situated in the normalising medical context of the ART era. More broadly, HIV has become a normalised, manageable part of political, economic and social worlds, in high- and low-prevalence epidemics, partly through treatment availability, also via health system testing and monitoring, education, popular culture, and international aid.

Perhaps, then, the normalised HIV citizen is a specific form of the contemporary biological citizen (Rose, 2007). Her/his citizenship is biological but concurrently and necessarily social and political - and, as Butler (2005) points out, ethical. To be called into being as a normalised HIV citizen is to take on certain responsibilities towards truth and life. Who we are in relation to HIV, is also who we ought to be.

The normalisation of HIV encourages some extremely important moves - towards, for instance, destigmatisation, universal voluntary testing, early treatment, prevention technologies and rights and justice for citizens of all HIV statuses. The normalised HIV citizen is enabled to act socially and politically in association or alliance with other health citizens, other biological citizens, and to claim rights and justice (Epstein, 2006; Rose, 2007; Robins, 2009; Mbali, 2005). S/he may in some ways not be an 'HIV' citizen at all. In South Africa in 2004, most of the female research participants diagnosed during pregnancy were not easily contactable for second interview. Still well, they no longer used the HIV NGOs through which they were recruited, though they attended clinic checkups. Similarly, in later rounds of the UK interviews, some participants doing well on ART declined further participation, saying they did not want to focus on HIV in their lives.

HIV's normalisation can also challenge the pandemic's medicalisation. Normalising educational and social HIV technologies often depart in important respects from medical technologies. The South African edutainment charity *Soul City* (2008), for example,

which has a widespread, normalised television and radio presence, is running a 'OneLove' campaign foregrounding discussions about multiple versus single partners, sexuality and relationships, encouraging high levels of questioning and uncertainty that are unlikely to be part of mainstream health education campaigns. The inscription of HIV within normalised biological citizenship also allows activist groups to challenge medical expertise, campaigning against accepted medical HIV technologies and for alternatives (Epstein, 1996; Robins, 2009; Rose, 2007). And 'health' itself is framed differently by the popular discourses within which the normalised HIV citizen lives, which present it not medically, but as a personally felt and judged entity.

Despite its beneficial effects and its challenges to medicalisation, the normalisation of HIV citizens raises problems because of the many resistant aspects of HIV that cannot be rendered normal. First, HIV is not wholly analogous to other chronic illnesses, because of its associations with pathologised social states - sex work, intravenous drug use, and gay, female and 'promiscuous' sexualities - and its potentially fatal, difficult-to-treat nature. These characteristics, alongside the physical and social visibility of HIV illness, treatment sideeffects, and prophylactic actions like taking vitamins, eating healthily, having caesarians or formula feeding, generate continuing stigmatisation even in situations of accessible treatment and care (Flowers *et al.*, 2006). A number of the South African women interviewees suggested that, however treatable HIV becomes, however strongly discrimination is resisted, the condition's association with transgressive sexuality, particularly for women, will always render it socially pathological - unlike, for instance, TB.

Second, HIV's contemporary treatment does not unproblematically normalise it medically. ART has difficult sideeffects and may not work consistently, or at all, for everyone. One participant in my UK study withdrew at the last interview round, despite ART success, because of a disability related to longterm HIV infection. Many longterm participants, like John, experienced new HIV-related illnesses as time progressed. Such medical uncertainties also trouble HIV negative people's 'treatment optimism' and any potential normalisation of treatment-led prevention, affecting people's understandings both of the health consequences of being positive, and of treated positive people's infectivity.

Thirdly, HIV positive people are not always able to relate 'normally' - that is, like non-HIV positive citizens - to work, parenting and relationships. They may not fully self-govern into healthy, risk-free actions. Nor do can HIV-negative or unknown-status people always conduct themselves in a normalised way in relation to HIV, treating it without stigmatisation, minimising their risk. This is of course true of other health conditions such as other STIs, TB, diabetes, cancer and obesity, but the problems are intensified by HIV's particularly stigmatised character and its relation to discourses of sexual irrationality. In both UK and South African studies, for instance, women interviewees told stories of times when when 'love' or desire meant they decided not to use condoms, a normalised moment of abandonment for people unaffected by HIV that nevertheless violated the normalised self-management required of HIV positive citizens.

Mhiki's interview, which contained the emblematic story of normalised self-governance

at the beginning of this section, went on to unpick this normalisation. Mhiki said, for instance, that one of her sisters could not be told of Mhiki's status because she would gossip; her own boyfriend rejected her when she told him her status, causing her to leave him; her HIV positive child, who did not yet know her own status, hated HIV positive people and was causing her serious problems on this account; and a friend had told her to just abandon this sick child in the hospital. Mhiki herself had been, she said, one of those who thought HIV only affected the promiscuous, the foreign, travellers like truck drivers, or those who had blood transfusions (see also Squire, 2007). If Mhiki's initial account sounds at first like unproblematically normalised life with HIV under treatment, within this wider skein of difficult stories, it reads more as an effortful assertion of normalcy, against many stigmatising factors. Many of those factors are specific to Mhiki's context. The effort to oppose stigmatisation through normalisation, however, has more general significance.

Mhiki's narrative of her life with HIV exemplifies how HIV's normalisation can oppose stigmatisation. But this story is at the same time the tale of how non-normal HIV citizens continue to be. HIV still produces very particular, often socially pathologised kinds of citizens. Its compromised normalisation in fields beyond that of medicine points to the limits of seeing 'biological politics' as an undifferentiated field, and to the difficulties of configuring 'health citizenship' in generalized ways. This is not to endorse 'AIDS exceptionalism' (De Waal, 2006), a perspective that turns HIV into a uniquely tragic, implicitly low-income, African, othered condition, conveniently leaving little possibility of effective - and difficult and expensive - action. Rather, HIV citizens' failures of and resistance to normalisation, based in the ongoing pandemic's particularities, articulates the multipolarity and specificity of HIV citizenship and can be a continuing source of criticism and activism (Crimp, 2002; Epstein, 1996; Robins, 2009; Watney, 2000)

HIV's normalisation naturalises by undoing stigmatisation. It turns HIV into a regularised part of biological and social life. But naturalisation via normalisation tends to underestimate the power relations around the pandemic, and the uncertainties of HIV knowledge. Moreover, through normalisation, individuals become HIV citizens with human rights, but also individualised human responsibilities - including an unfulfillable responsibility to understand fully and act rationally about HIV.

The marketised HIV citizen

If HIV citizens cannot be completely medicalised into health or comprehensively normalised, perhaps they are more fully naturalised via their incorporation into contemporary relations of consumption, as consumers of goods within markets. By substituting economic technologies for medicalisation's knowledge-based and normalisation's ideologically-based technologies, marketisation seems to operationalise HIV citizens more thoroughly, turning them into manageable packages of buyable, sellable elements.

It is clear that even with a condition as difficult to 'buy out' of as HIV, health markets exist at every level in the pandemic. Cities, regions and nations purchase branded or generic drugs from national or international companies. They enter into contracts with

developed-world governments and international nongovernmental organisations, who give them ART, other drugs, and other HIV services, on the basis of their agreement to meet health and political governance standards, and sometimes on the basis of agreements which guarantee pharmaceutical markets within donor countries. Treatment and prevention initiatives are also researched, developed and implemented within a market frame, often weighed against the putative costs of other actions (Granich *et al.*, 2009).

These are notable, often-criticised aspects of HIV's marketisation. In addition, the citizens of the HIV pandemic are themselves committed to researching, cultivating, finding, buying and using whatever will improve their own HIV-related health, whether or not they are positive or have access to ART. The very general finding that HIV positive people conduct their own self-care by buying traditional alternative and complementary medical remedies, or the ingredients to make such remedies, alongside conventional western treatment, indexes this commitment (Babb *et al.*, 2007; Joseph *et al.*, 2007; Langlois-Klassen *et al.*, 2007; Milan *et al.*, 2006). So does the consumption of prevention 'goods' such as condoms, male circumcision and HIV testing.

In my South African and UK research, many participants reported always being on the lookout for substances and products that they could use in health-promoting ways. This concern was at its strongest in the pre-ART 1990s in the UK, and for South African interviewees who in 2001 needed but did not yet have access to ARTs, for whom alternative products, which might help them maintain their health till effective treatment came along, were often prohibitively expensive. In the later epidemic contexts of free ART, a concern with health promotion through parallel complementary product consumption, remained common, though less intense, in both countries. Benjamin, for example, who was on a South African pilot ART programme in 2001, told at the same time of continually seeking out and buying products said to enhance immune function:

Benjamin: Like if, like I saw a catalogue of medicines and then I find that I do have money to buy that, (I do), because I was told that my immune system is low.

Often such purchasing commitments were broader, tied to normalising discourses of nutrition and lifestyle, also involving popular media consumption, as Zukiswa described:

Zukiswa: When I (used to) buy veggies, carrots for instance I never cooked them, I don't like cooking them not unless I'm cooking for my baby. I usually clean them and eat them raw with er cayenne pepper I mix it with hot water. I heard that from the radio, but before I did that I was losing weight, it was going down, I even saw that my complexion was changing and then my tongue there was that white substance. That thing, like a baby who eats milk/Okay/I ate that, I used those carrots, I used cayenne pepper putting it in warm water. Alcohol, I used to drink alcohol and then I paused I was told that I must er, and then I realised that I am someone that has got the virus so I had to drop the pace. Even if I drink, I should drink less, but I gave up, I quit...I do my own investigations...I listen to the radio and take notes. If they say what helped someone, I write that down.

Another example of the ubiquity of HIV consumption economies are informal

pharmacological markets. Many migrants in developed and developing worlds send remittances to relations living with HIV who cannot access free or cheap ART. Some with excess HIV medications or access to alleged HIV medications online, send pharmaceutical remittances. Within southern Africa, Zimbabwe's political instability and economic problems has led to ART supply problems with attendant profiteering, sales of fake ARTs, and crossborder importations from Mozambique and South Africa (Veenstra *et al.*, 2010). Given the resource restrictions of sub-Saharan Africa in particular in relation to ART, such pharmacological economies are not surprising. Despite the dangers that attend unprescribed and unmonitored ART, some ART access is always preferable to none.

These markets are related to the more general remittance economy; but their shifts are determined by histories of migration and HIV epidemics, as much as by economic gradients between host and countries of origin. In 2010, Nicholas, an African migrant living in the UK since the 1990s, traced his shift from supporting family members back home with HIV and other issues, to supporting his own family, partly to increasing ART availability in his home country, partly to his family's increasing embeddedness in their new home country:

Nicholas: What is happening, access to (ART) in Africa is becoming more and more available there is no doubt about that...you don't have to be in the big city...the country (of my birth) is saturated with so many organisations...And because of the cost of living you can't really afford to live your life here (UK) and then have so many (dependents), it's not working anymore, yeah it's not working anymore... personally when I came in the first two years I was able to live a basic life and able to support the people back at home but as time went on I have got my life here, my lifestyle here has established itself, I have responsibilities here by the time my (family), I don't have any money to spare to anybody, so for most people that comes have families here so you can't keep on looking after somebody who is not here when you have issues here, that won't be that way.

HIV citizens' self-governance through medicalised consumption is just part of a constellation of similar health consumption practices. In medium- and low-income countries, the first goods tried to address ill health are usually traditional or non-prescription medicines. In developed and developing worlds, western medications are frequently used in parallel with non-prescription, traditional, and in the west, 'complementary' medicines, for health problems other than HIV. Subjects also address general failures of balance in their lives, not just bodily imbalances, by buying traditional or complementary medical expertise and products.

Living with HIV is also part of broader consumption economies, perhaps most obvious within high income countries though not exclusive to them. Within these economies, citizenship is constructed through sets of responsabilising discourses and practices, including particular forms of thinking and feeling as well as action, that can be bought, or bought into. These patterns may be acquired directly, through employing psychotherapists or traditional spiritual practitioners, for example; or indirectly, through for instance consuming psychosocial services and media messages around HIV education, treatment and care programmes - such as the *Soul City* (2008) 'OneLove' campaign, or magazine advice on how to talk to children about sex and HIV (Wilbraham, 2010).

HIV's marketisation is most ubiquitous in high-resourced contexts, where the markets supporting HIV's medicalised normalisation are most developed and least remarked-upon. In low-resourced contexts where HIV treatment is possible but not always accessible, markets are simpler, but more obvious and contentious. Obtaining and affording ART, and prophylaxis and treatment for opportunistic infections, is a primary concern, supplanting the broader, consumption-driven pursuit of healthy HIV life. People without ART may be consumed by the need to buy available medications and immune system enhancers, whatever their price and effectivity. Nosizo for instance, who told of needing but not having access to ART, followed this with an account of the financial resources poured into her healthy food purchases, and a list of healthy foods that were at the same time items on the government's AIDS-denialist menu of nutritional 'treatment' at the time:

Nosizo: Yes, if you got that money you buy ...(African potato and) garlic and is right for your food and then, the chillies is right when you are cold and fruits, drink with the water, and then the lemon and then if you eat the right food.

Even when ART is available, the marketisation of HIV remains in some cases in competition with HIV's medicalisation, when HIV citizens try to sell or buy alternatives to the difficulties of lifelong ART (McGregor, 2007). Interviewees in both the UK and South Africa mentioned such oppositional consumption obliquely and critically, as a concern of others, not themselves. In 2001 in the UK, Nicholas, for example, told the stories of one friend who briefly forsook the clinic for a church that promised cure by fasting, and another who continually put his money into witchcraft antidotes:

Nicholas: I have a friend who has been using it (ART) for so many years, who still thinks that some of the things happening to them are based on witchcraft and it's sad though (inaudible). They spend their hard-earned cash and say they will go to Africa and have a witch-doctor remove it but it is something like an egg within the body, and they are getting too deep, start thinking that everything is done by witchcraft and all, and it is people's beliefs I guess, yeah.

In the mid-2000s, many South African interviewees, too, mentioned people on the radio, in the newspapers and in their neighborhoods touting alternatives to ART -herbal substances, vitamin regimens, faith cures, spiritual cleansing. These products seemed to them to carry a price tag in lieu of any evidence that would contradict the growing evidence before their own eyes, of very sick people's recovery through use of ART.

When alternative products compete with ART in the HIV marketplace, this competition has considerable personal, medical and policy significance. However, it seemed relatively insignificant for our UK and South African interviewees when ART was accessible. It may be that within the naturalising era of HIV treatment possibility, the strongest market pattern is a bifurcation determined by the epidemic's medicalisation, which allocates complementary products a niche bounded by their pharmacological inactivity in relation to the virus.

Marketisation means that HIV citizens are 'free' within markets. Their relation to the virus

is simplified. This can be a liberating frame within which to understand HIV. It need not be thought of as an intractable health problem, an existential condition or a socio-political conjunction. Marketised HIV citizens are constrained, though, to produce their own health and survival within markets they can never subjugate. This ambiguity undercuts HIV discourses and practices of responsabilised consuming citizens from within. Markets do not always work. Alleged renegeing on governance or accountability agreements may lead donors to cut lifesustaining drugs (Bernays *et al.*, 2007). Difficulties in funding ART have been acute since the 2008 financial crisis. Informal remittances and formal funding have fallen; there is a \$4billion Global Fund shortfall in 2010 and US PEPFAR funding was not increased (Global Fund, 2010; World Bank, 2009). The HIV citizen is thus operating in unpredictable markets that often fail.

The marketised naturalisation of HIV simplifies the set of things that must be known, and holds the possibility of some resource-balancing via informal economies, though many limitations attend these. Moreover, marketisation overlooks the differential powers of market stakeholders, as well as markets' own shifting strengths, which render knowledge of them famously incomplete and non-predictive. HIV citizens themselves, defined economically rather than politically, become only partly knowable. This makes marketisation the most obvious case of a naturalising process which denaturalises itself.

Being left behind

The problematic denaturalisations achieved by medicalisation, normalisation and marketisation appear in acute form around HIV, but they are not particular to it. This paper argues that the HIV citizen's formation by the naturalising processes of the pandemic is also disrupted by factors highly specific to HIV, whose specificities are difficult but important to address. In my UK and South African research, it was these factors which created the strongest discontinuities in HIV narratives, positioning the narratives outside of hegemonic HIV citizenship, the narrators as HIV citizens under erasure.

The naturalisation of HIV can seem like a kind of medical, social, political, even economic progress. The HIV-specific denaturalisations of this progress script that I am going to consider, appear as being 'left behind,' left out of the script. They question the completeness of HIV knowledge. They point to macrostructures of power and microstructures of emotion that put brakes on progress. We would all like improvements in HIV treatment, prevention and care of the kind MDG6 proposes. But such progress does not happen by ignoring the forces operating against it. That is why the second part of the paper focuses on these specific and persistent denaturalising issues within the pandemic, rather than on successful addresses to them, though such addresses do exist.

The denaturalising issues I want to consider are first, HIV's biological mutability and the variety of its physical effects, which puts the medicalisation of the pandemic, especially, in question; second, HIV's place in low-resourced contexts where treatment access is not guaranteed and HIV itself is a significant resource, which renders the pandemic's marketisation particularly problematic; and third, resistant personal, emotional elements of living with HIV, which mean that there is often something ideosyncratic and important

left out of normalising framings of the pandemic.

Not knowing about HIV

The naturalising possibility of knowing about HIV is supported by powerful contemporary medical knowledges around it. But as we have seen, the medicalisation of the pandemic is often oversimplifying. More fundamentally, the nature of HIV itself makes knowledge about HIV unavoidably and continually uncertain. When you are HIV positive, the prognosis is not certain, the future effects and nature of treatments are unknown, there is considerable unmapped individual variability. If you are trying to avoid transmitting or contracting HIV, uncertainties also exist, not just at the level of social relations and emotions, but also around different physiological and genetic vulnerabilities, and the questionable effectiveness of PEP and PrEP. The resultant states of not being sure about what will happen to you in relation to HIV, denaturalise HIV knowledge.

Because HIV is unpredictable, it commits people who are infected or affected to ongoing vigilance about things they cannot fully know about, or alternatively, to a decision to abjure such vigilance and accept ignorance (Rabinow, 2004). Both situations qualify the notion of a medicalised, normalised, self-monitoring and aware citizen. John, for instance, the UK interviewee quoted earlier, who was preoccupied with a new HIV-related precancerous condition, was, as we saw, not just persistently vigilant but also consistently worried about this condition. He was in addition explicitly aware of medicine's prognostic limits - 'you can have {precancerous signs} for many, many years and it never progresses' - and the diagnostic limits for an asymptomatic condition:

John:...but if I hadn't been on that screening programme, which I have been for the last 18 months now, they wouldn't have picked it up and I suspect probably the majority of gay men, long term survivors, particularly with HIV, if you're not having any problems you wouldn't think there was anything wrong and there's no screening programme, I don't think.

Reading John's earlier interviews, similar concerns around ambiguous conditions appear, for example around lipodystrophy, a longterm sideeffect of some ART which redistributes subcutaneous fat from limbs and face to abdomen and back, in 2001. Many interviewees in both samples expressed the difficulties of this sideeffect - from 1997 onward in the UK, and 2003 on in South Africa. While ART sideeffects and lipodystrophy treatment have improved, that does not entirely remove the uncertainty. More generally, longterm ART with changing drug regimes always has the potential to produce new uncertainties about sideeffects.

Related ambiguities arose around treatment interruption, which was a particularly intense concern for people taking ART in the late 1990s, when regimes were more difficult, sideeffects less manageable and interruption effects little understood. Morag for instance, a woman who had lived with HIV for many years without severe illness, described in 2001 her early history of ART and drug 'holidays':

Morag: Well (in 1997) I had probably just tried one (ART regime), if I can remember...I think my T cells disappeared completely or went down to 40 um and I took three months off and nothing happened. It didn't make the slightest bit of difference...(my doctor) says they've actually done research in America and they've found that it's cheaper to send people on holiday for a week than it is to keep them on combination therapy (ART), and the results are exactly the same...I've been taking drug holidays since I started, yeah. I mean it's not to be recommended, because I think the lower your T cells are the harder it is to come back. And maybe I should have started this (ART) (earlier), but then I didn't have a choice, by the time I found out my T cells were under 200 there were 60, so I kind of missed out on that (manageable ART, through not) taking them (ART medications) at 200 which is maybe I think about the right time to take them.

Interviewer 1: So when you have taken (drug) holidays, has that been related to your T cells or was it just how you've felt?

Morag: No it's been related to the fact that I've felt um that the side effects didn't outweigh the advantages, I couldn't be in it any longer. Um, I don't know how you would cope with it, but diarrhoea is like, I mean I used to be in tears

Morag's ART story continues with a long account of the problems of diarrhoea.

The cost-benefit analyses Morag reports engaging in at different times are multifactorial, their outcomes imprecise for her and her doctors. ART's sideeffects are today less debilitating, and there is more agreement on treatment interruption's disadvantages. However, people for whom ART is not working or is very difficult - a group that increases as ART scales up - remain involved in medically irresolvable dialogues on this issue. Moreover, the 'right' time to start ART remains a heavily-researched and debated issue.

The pattern of repeatedly facing new, possibly insurmountable medical conditions and treatment difficulties was, then, for participants in the UK and South Africa, a consistently denaturalising aspect of living with HIV, across historical and national differences in diagnosis and treatment knowledge and resources. HIV is always leaving its citizens behind in this biological way, something that is less salient with other less threatening, slower-moving health conditions. Perhaps, as Rabinow (2004) argues, we need to recognise these knowledge limitations as part of science, to accept the non-naturalisable aspects of the 'natural' world, in order to address them in life technologies like those around HIV citizenship and to understand such citizenships as predicated on ignorance as well as knowledge.

Knowledge about HIV is further denaturalised by the virus's positioning within broader discourses and practices of 'health.' 'Healthy living' has no agreed limits, and its content varies. WHO's recent (2009b) guidelines for starting ART at 350 T cells/mm³ may avoid the fatalities associated with late treatment and reduce infectiveness among more people at risk of transmitting HIV, but WHO recognises that in many countries, getting much less healthy people onto ART remains problematic. In a better-resourced setting, the city

of San Francisco now advises immediate treatment on diagnosis, regardless of T cell levels, to maintain 'health' - with transmission reduction a secondary, if welcome, possibility (Russell, 2010) .

'Wellbeing' is a similarly slippery concept (Cameron *et al.*, 2008). Encompassing definitions of wellbeing have been said to operate as divisive, consumption-driven, non-sustainable aspects of western modernity (Carlisle and Scanlon, 2008). However, it is also argued that holistic 'healthworlds' are well-established aspects of traditional health formations that need to be recognised by western approaches to health, especially in the HIV case (Germond and Cochrane, 2010). A notion of 'wellbeing' as involving, following Sen, opportunities to pursue it, not just capacities achieved, may be useful for developing the multilevel approach the HIV pandemic requires (Barnett and Whiteside, 2006). At the same time, discourses of 'wellbeing' and 'healthy living' sometimes fail to address important specificities of HIV. For John and Mhiki, for instance, 'health and wellbeing' are maintained by rigorous pharmacological and behavioral regimes that perpetually mark the possibility of losing both. For many citizens not affected by HIV - and for some HIV positive people themselves, like Nicholas's friends - such regimes would themselves significantly detract from health and wellbeing.

Being left behind by the knowledges around HIV is, then, an inevitable if poorly tolerated feature of living with medicalised knowledge, particularly likely in the changeable and relatively new field of HIV. Being left behind by 'health and wellbeing' also happens repeatedly, across social and historical differences in HIV treatment and care, and in discourses and practices of 'health' itself.

I want now to consider a denaturalising unevenness within the pandemic which underpins some of those mentioned above, but which is perhaps easier to address directly: that of resources.

Not having resources

Where the multiple and, in high-prevalence epidemics, extensive resources required for HIV's naturalisation are not available, people may live in the ART possibility era without ART access. Many people living with HIV also lack cash, nutrition and transport, which affect treatment viability and HIV testing. A specifically disadvantaged, often-overlooked group are HIV positive people who are not full citizens, who have reduced access to health and social services and to economic resources via legal employment (Bloch, 2010). Resource shortages thus undermine naturalisation by constraining HIV's medicalisation. But they also limit social normalisation, which is hindered when people living with HIV must compete for resources, often from positions of disempowerment; and marketisation, since the people, communities and countries most affected by HIV often have few resources to participate in, let alone govern markets.

Within the HIV pandemic, naturalisation as social theory understands it - as the erasure of power relations - is continually undone by material evidence of power imbalances and their deleterious effects. The most broad-based and successful recent HIV activism operates around treatment, where resource disparities are glaring, and takes on existing

power relations by campaigning for cutting edge, 'first world' treatment for a pandemic concentrated in the developing world. In these campaigns, 'treatment' is often formulated in a way that takes account of broader power relations. It is formulated democratically, as community-owned and organised; it is integrated with HIV education and prevention; it is allied with other campaigns around for instance 'human rights', poverty, xenophobia and gender-based violence (Farmer, 2001; Mbali, 2005; Robins, 2009). But access to ART is still the founding demand. As Althusser (1998) might say, the economic here determines the determining, medico-pharmacological field.

The fight for treatment is never a one-off campaign. Once ART is obtained, it is still necessary to campaign for frontline drugs, second line treatment, and the next generation of drugs (MSF, 2009) to be made available to resource-constrained communities.

Treatment, alongside prevention, social care - for instance of HIV-affected children - and other pandemic-related expenditures, if met fully, will, estimates suggest, cost up to \$35 billion yearly by 2031, even assuming 50% fewer new infections (Hecht *et al.*, 2009). Difficulties in modeling human capital losses (Lamontagne *et al.*, 2010) mean this too may be an underestimate. Current recession-driven failures to maintain, let alone expand, treatment, exemplify resource precariousness. Even in developed countries with full ART provision, there is unevenness, particularly around less-common illnesses and new modes of diagnosis and treatment, as John's evaluation of medical provision for HIV-related conditions in the small city to which he moved from London, suggests:

John: I mean it just makes me think, 'god help anybody who's being treated in the provinces' because if I had been going to {home town hospital} for my HIV treatments, well you know they are very good at doing the bloods and giving you the medications and all that sort of thing, anything like Kaposi's Sarcoma or, um, anal neoplasia, they are not very knowledgeable, shall we say about...I am sure that a lot of the people that are treated there are in the same position that I am but they don't know because there is no way they are ever going to find out until it's too late.

In the area of psychosocial services, HIV's increasing medicalisation and the financial crisis were viewed by UK participants in recent interviews as exacerbating a longterm reduction. Nicholas for instance, who has run a small HIV support organisation since the 1990s, began his 2010 interview with the tale of this decline, tracing the mainstreaming of HIV within social services and the dispersal of its advocates:

Nicholas: What I feel is that HIV has gone off the agenda and not deliberate, it wasn't a deliberate (thing), it's just that people have grown now and moved on. People who are so keen and fighting the HIV battle have gone and moved into different areas, they...are at different roles within different organisations, not that they don't have the HIV agenda in their heart but because of their roles they kind of moved on and some unfortunately stop to think about it today....And because of the funding, the last couple of (years) ...it has become much harder yeah for example (for) this organisation.

In some developed-world contexts, resource constraints are so powerful, they seem to drive epidemics. In the US, for example, HIV among heterosexuals in poor urban areas is related to socioeconomic status, not 'race' or ethnicity, and is double the 1% level which

for WHO characterises a generalised epidemic (Denning and DiNenno, 2010). However, in the global south, resource shortages are of course much more comprehensive and intense. In South Africa, for instance, many interviewees like Zukiswa, Benjamin and Nosizo, describing their efforts to eat well and bolster their immune systems, accompanied these stories with qualifications of their financial ability to maintain such efforts. And Mhiki's narrative of obtaining successful ART in the early 2000s needs to be situated within the longer story of the hard and contingent struggle for treatment which appears elsewhere in her interview. At this time, ART was not freely or widely available. Mhiki was on a hospital trial only because of an insistent clinic nurse, and family members who could lend her money to get minibus taxis to the hospital. Her treatment was compromised because she was now too healthy to have a disability grant but unable to get a job in a 50%-unemployment economy. Mhiki herself summarised the positioning of HIV within scarcity economies, and the ways in which HIV organisations must fight social injustice as well as HIV and poverty:

Mhiki: So, I've seen that the most pressing thing is poverty. When there is nothing for consumption in the house, no paraffin and the like, that is affecting (us) particularly since I'm the only one who looks after children.... I also came across the movement called {Organisation 1}. This movement helped clear my mind because, if you go there you see and hear everything. Yet at first the movement called {Organisation 2} also found me. It took me under its banner and showed me that I was not gonna die of the disease that I had. I had to make things with my own hands. {Organisation 2} showed me that this was not the end of life. It taught me how to do bangles and ribbons. The problem however is that the stuff was never bought. The government also withdrew its grant from me. {Organisation 1} also showed me that I was not gonna die soon. I had to rise, go make up my mind (to live) and then I would be fine.

HIV citizens often make very clear connections with broader form of health citizenship to advocate for resources. HIV's biological citizenship can thus be not just collectivised and effective in the HIV field, but integrated with politics at varying levels. For Mhiki, the analysis she presented led her to work with the activist Treatment Action Campaign, which centres on HIV but also relates to broader concerns around poverty, gender-based violence and xenophobia. Nicholas's organisation had responded to HIV's naturalization in the developed world by establishing projects in his country of origin at a time of severe HIV resource constraints there. John's concerns about unevenness in UK HIV medical services had led to his involvement in educating doctors about the realities of illness experiences.

However, HIV **also** has some specific resource requirements that make its naturalisation within community activism or mainstream politics difficult. First, the scale of resources

demanded by the pandemic is enormous, as Hecht and colleagues (2009) show. Second, in low-resourced contexts, HIV itself offers resources. HIV organisations and HIV positive people gain goods that other organisations and individuals do not- for instance, as Mhiki mentioned, craft skills, and in South Africa, the disability grant. To avoid this skewing, in some countries, all policy areas now 'mainstream' HIV within their action plans. Funding applicants are often of interest to external donors - or think they will be - if they include HIV among their priorities. HIV programmes in low-resourced, high-prevalence contexts often try to address this situation by focusing on health and social needs generally, as well as on people's HIV-specific requirements. Nevertheless, HIV programmes' drugs, food supplements, donated clothes and toiletries, information workshops, employability skills trainings, childcare and education, are commodities that the non-HIV affected as well as the HIV-affected want, and sometimes take, use, or sell. Even the social and cultural capital created by HIV services for their clients can be an object of envy for people with little family or social support. Lana (2006) for example reported resource-constrained young South Africans saying they wanted to be like the HIV positive people they knew who helped each other in support groups and developed direction in their lives - to the extent of wanting to become HIV positive themselves. This skewing does not just happen in the developing world; HIV services create resource gradients in high-income countries, too. In some of my 1990s UK interviews, for instance, HIV positive ex-drug users reported their non-HIV positive friends envying their status for the goods that accompanied it.

As policy imperatives within the pandemic succeed each other, they generate resource conflicts between themselves. The medicalised approaches to prevention now said to be taking resources from socially-oriented prevention initiatives, for instance, may also be undermining the capacity building and skills transfers that such initiatives have promoted. Women's moves towards determining their sexualities and negotiating condom use, documented in popular media like *Soul City*, and men's moves towards sexual decision-making less constrained by hegemonic masculinities (Higgins *et al.*, 2010; Robins, 2009) - these are resources that may now seem of less value in the HIV economy, running the risk of leaving behind people doing this kind of work.

Paying attention, not just to markets' internal failures, but to wider formations of power, shows up resource lacks and lags across the HIV pandemic. These denaturalising discontinuities cause many citizens 'living with' HIV, particularly HIV positive people, to be structurally 'left behind.'. It is important to recognise these multiple, often disempowering dimensions of HIV citizenship. It is also possible to address if not entirely remedy these structural disjunctures, as many HIV treatment, prevention and education and care campaigns have done and continue to do, despite economic limitations and political constraints (Campbell *et al.*, 2009; Epstein, 2006; Farmer, 2001). However, some more personal denaturalising elements within the HIV pandemic are less susceptible to change.

Not understanding HIV

This section of the paper considers HIV as not just biologically and economically, but also psychosocially non-naturalisable in its particularities. This form of

unrecuperability is again something that emerges in John's account of his 'cancer scare'. Interspersed with its qualified account of medicalised HIV citizenship, John's story contains a description of more personal ambiguities: his long period of living healthily with HIV after diagnosis, amid the deaths of friends; his getting screening and treatment for his precancerous condition, amid continuing fears about that condition:

John: Because I'm a long term survivor and I've outlived so many of my friends who died in the 80s and early 90s I think well I've done extremely well to get this far, so if anything happens now, you know, I've had an awful lot of borrowed time compared to a lot of people and so, um, what will be will be...I'm fortunate that it {precancerous condition} was spotted fairly early on /mhm/...but if I hadn't been on that {screening programme}.....(HIV treatment is going well) so really this is why this {} cancer scare, I suppose I call it, is, is far more frightening now than the HIV itself...

Not being able to know exactly what HIV means for you personally, continually undermines HIV's normalisation. Such inevitable denaturalisations of HIV's meanings appear elsewhere in John's interview too, when for instance he described his grief when a longstanding HIV positive acquaintance died, for the loss of the history this person carried as well as the person themselves; the ART side-effects that he no longer minds but that he thinks mark him out, at least to many gay men, as an HIV positive person of a certain treatment generation; his lack of understanding of some recently-diagnosed people who in the ART possibility era feel none of the fear that he remembers. In these and many other ways John describes being historically and socially marked and marked out as an HIV citizen, shadowed by the epidemic's particularity.

Such marks of personal, historical and social particularity qualify broadly formed notions of health and biological citizenship, as well as more specific framings of HIV citizenships. First, they register the interiority and the expressible limits of citizenly understandings - a form of attention and qualification that characterises Mouffe's (2006) understanding of citizenly identities. Second, they infold an inescapable past into the present. For Morag, for instance, who in 2001 had recently lost several people close to her for whom ART did not work, her own longevity and relatively successful ART naturalised her as a healthy, productive citizen, who could often forget about HIV; but it also isolated her in a position which only she could - imperfectly - grasp:

Morag: It doesn't get any easier. In fact it gets a lot more difficult in a lot of ways. Um it was easy earlier on, because the support was there. But the longer I've been around it's um. You know who's going to support me? There is no one who's been diagnosed longer than me really.

Grief and loss are powerful elements in many HIV narratives, resisting normalisation (Long, 2009). In 2001's South African interviews, people talked repeatedly, with difficulty, about their dead partners, siblings and children. These are losses that few HIV

programmes and indeed few people living in the middle of a generalised epidemic are able to address comprehensively. Busisiwe for example, a young, recently-diagnosed South African woman, told of her discovery of her HIV status just before the death of her child, in a story exemplifying disjunctions within the epidemic produced by loss:

Busisiwe: I was pregnant. I went to {hospital} and the baby came out when the child was four months old and s/he was as small as this radio (voice recorder). I discovered that I was HIV positive. I accepted it in that way. I realised that I had to accept it since I had seen both the tummy and the baby and there is nothing I can dispute.

Interviewer: Was the child alive?

Busisiwe: Yes, I was also having dreams at night and when I was dreaming, I saw people showing me (lifts her beads, those of a trainee sangoma, into the shape of an AIDS ribbon) 'it's okay'.

Here, Busisiwe linked her own enlightenment about HIV, which happened when she was tested during pregnancy and then had a stillborn child, to her ancestors, the 'people' who reassured her about the condition in a dream. Dreams are a common way to communicate with ancestors for some South Africans, particularly for those who, like Busisiwe, are training to be traditional healers, or sangomas. This is, therefore, a story about both personal grief and religious faith. In this story and thereafter, Busisiwe presented herself, not just as a moral HIV citizen, but also as someone called on to testify about and try to cure the condition, on behalf of herself and others. However, it was more difficult to understand Busisiwe's ambiguous talk about the child who died. Her comparison of the baby to the mechanical object on the table - the voice recorder – was distinct from the interactive pattern of the rest of the interview (see also Squire, 2007); it took the baby out of the story, into the present. At one moment, as the interviewer's intervention suggests, Busisiwe even seemed to be saying that the child was born alive. These narrative moments kept the child in the world, as did Busisiwe's subsequent invocation of her ancestors, with whom the child was transhistorically linked and who could care for her. (1). A kind of benign haunting took over Busisiwe's HIV story, reconnecting her with the child her story brought into the room. This was a disruption unlikely to be mended by improvements in health or passing time.

The haunting element of living within HIV epidemics is perhaps an inevitable disruptive subtext of any apparently normalised HIV state. For many naturalised HIV citizens, who understand and manage the condition medically and socially, and consume appropriate products, information, attitudes and feelings, are themselves consumed, not only by an illness with strong resonances with an earlier tubercular meaning of 'consumption' (Sontag, 1988), linguistically marked, pre-ART, by names such as 'slim' that described its wasting effects, but also by 'unproductive', unending grief. As Stuart Marshall (1988) noted in the late 1980s when qualifying ACTUP's appropriation of the phrase 'don't mourn, organise', in the context of the deaths of many people to whom you are close, mourning is inevitable and ignoring it can generate paralysis. People who live with HIV

particularly in high-prevalence circumstances live, in Odets's (1995) resonant phrase describing HIV survivors, 'in the shadow of the epidemic.' They cannot avoid it, and they may like Busisiwe choose to face it. The ART possibility era cannot naturalise the disjunctions of grief that it leaves behind.

Being left behind is an inescapable aspect of the HIV pandemic, perhaps of any health condition that distances the subject from the social world, particularly of conditions that are highly stigmatised. Considerable, important work is devoted to remediating the state of HIV citizens by social inclusion, and by negotiating associations between HIV positive people, and across people of different HIV statuses. But it is important at the same time to bear in mind the particularities that resist such inclusions and associations.

Conclusion

I have argued in this paper that the ambiguities of a 'naturalised' HIV pandemic need to be acknowledged. This acknowledgement involves attending to the contradictions within naturalising processes such as medicalisation, normalisation and marketisation, and to the persistent denaturalisations generated by HIV itself in relation to its biological characteristics, its resource implications, and its psychosocial difficulties, all of which repeatedly 'leave behind' HIV citizens.

Naturalisation is, I suggest, a useful concept for analysing the complexities of HIV citizenship and perhaps of other health citizenships, partly because of its **progressive aspects**, partly because of the denaturalising ambivalences it carries within its own meanings. In everyday speech, 'naturalised' citizens still bear the traces of the naturalising process, as do HIV citizens. In social theory, naturalisation references ignored power relations, but also the possibility of understanding those relations - an understanding that is crucial for addressing the HIV pandemic. In epistemological accounts, naturalised routes to knowledge are messy and multiple, and such accounts of incomplete, revisable knowledges are important for addressing HIV.

The naturalising process of medicalisation appears, within the studies considered here, to allow HIV citizens to live, and to be part of a wider citizenship - but also constrains them within often imperfect medical technologies. Normalisation makes HIV into just one aspect of citizenly existence; but the pandemic's complexities cannot all be normalised. Marketisation integrates HIV citizens into transnational consumption economies, with some gains in citizenly power, but this integration is unstable, and reduces citizenship to the economic.

HIV citizenship operates in a very particular context, characterised by the virus's fatality, medical intractability, stigmatisation and social embeddedness. Nevertheless, the ambiguous processes of naturalised citizenship described here may apply to some extent to other less-stigmatised, less dangerous, but still health-threatening and high-prevalence conditions- for instance, in high- and medium-income countries, cancer, diabetes, heart disease, hypertension and obesity; in medium- and low-income countries, malaria and TB.

The paper has also argued that denaturalisations of HIV citizenship derive from the epistemological intractability of HIV as a biological condition, the enormous resource demands of the HIV pandemic and - perhaps least often considered - inevitable failures of understanding grounded in histories and emotions. Again, these processes depend partly on the specificities of the pandemic- HIV's biological characteristics, its immense social, political and economic as well as medical impact in high-prevalence situations, and the psychic effects of its fatality, unpredictability and abjectification. However, these denaturalising processes may still exhibit some parallels with processes operating around other medical conditions, such as those mentioned above.

The paper suggests that naturalisations and denaturalisations appear often, early, and with useful complexity and depth, in people's HIV stories. The narrative data reported here are limited in extent, and in the epidemics from which they are drawn. HIV narratives gathered at other times and places in those epidemics, or within other epidemics in the global south or north, might diverge from the ones analysed in this paper. However, the patterns of naturalisation and denaturalisation these data display are often strongly evident, and are multiply interlinked, to an extent that is less true of other forms of HIV representation. Indeed, naturalisation and its ambiguities, and the denaturalising processes of 'being left behind', are elements of HIV lives that policy and political formulations of HIV citizenship may gloss over, in order to generate useful collectivities and coalitions, and to operate in the present and future rather than the past. It is, however, important to recognise and work with the difficulties of naturalisation and denaturalisation processes, perhaps more than the onrush of contemporary priorities generally allows. For they act as forms of knowledge about what is left out of HIV discourses and practices. They mark the multiplicity and complexity of HIV experiences (Scott, 1991), in particular, those elements that have not been acknowledged or that are just coming into existence.

How do patterns of naturalisation and denaturalisation, working within narratives of HIV citizenship, promote an understanding of such citizenship that goes beyond a Foucauldian analysis of its constitutive discourses and practices? 'Naturalisation' and its limits suggest the importance of understanding HIV citizenship, not as unremarkable and taken-for-granted, but as polarised and politically contested (Mouffe, 2006). The power and constraints of medicalisation processes point to a citizen defined outside of traditional politics, within the biological field (Rose, 2007). The compromised marketisation of the HIV citizen redirects us to the continuing significance of political, not just economic citizenship. Normalised HIV citizenship, and its failures in the face of lives lived with HIV, points up the multipolar, agonistic (Mouffe, 2006) and also highly specific nature of HIV citizenship. The denaturalising processes of 'being left behind' within the pandemic suggest a bracketed-off HIV citizenship that is at some level impossible to assume. HIV citizenship - perhaps like many other biological and health citizenships - is defined partly by scientific uncertainty, even ignorance (Rabinow, 2007). The pandemic's implication in global power imbalances mean that HIV citizenship involves multiple dimensions of power and more often, powerlessness, that undermine or erase it. HIV citizenship must almost always be struggled for rather than assumed (Robins, 2009). Finally, HIV citizens' inevitable failures of understanding, in the face of overwhelming emotions, and social and epidemic progressions that outpace personal histories, mean that HIV citizenship's

interior worlds need to be taken into account (Mouffe, 2006). The internal contours of HIV citizens' lives may at times place them outside citizenly association, but they are also intrinsic to those citizens' engagement in future, hopeful thinking and action.

As the first pandemic of globalisation (Barnett and Whiteside, 2006) and as a condition with some very particular social, political and affective connotations, HIV may seem to generate unique forms of citizenship. The citizenship framework developed in the course of this paper, however, comprising discourses and practices that operate within the realm of conventional politics but also in the fields of biopower, economics, social disadvantage and psychohistory, may have some utility for considerations of other health citizenships. The analytic path that led to this framework, tracing naturalising and denaturalising processes, can work to map out where a particular kind of health citizenship is situated, to the variable locations of such citizenship that activists, policymakers, health professionals and health citizens themselves may need to acknowledge.

Footnotes

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