

Living with HIV and ARVs: Three-letter lives

Section I

Living with HIV and ARVs in the treatment possibility era

1: Why the three letters matter

This book is about living with the Human Immunodeficiency Virus, or HIV, and with antiretroviral, or ARV, therapy, the combination of medications that helps HIV positive people to live long and healthy lives. Today, when ARV treatment is more and more available to those who need it, and is in prospect for those who do not yet have access, the two three-letter acronyms, HIV and ARV together, increasingly index people's experiences of the pandemic. The book examines lives lived with HIV and ARVs in different national contexts, primarily the United Kingdom and South Africa, where I have conducted interviews about HIV support with people living with HIV, since 1993 in the United Kingdom (most recently in 2011), and since 2001 in South Africa (most recently in 2012).

There have been dramatic improvements in people's access to treatment, and in their health and life expectancies, across the pandemic. In the United Kingdom, ARVs arrived in 1996. In South Africa, they began to be available in the early 2000's, though rollout has been fastest since 2009. The World Health Organisation has made strong moves to encourage earlier treatment, to preserve HIV positive people's health so that illness does not compromise it before they start ARVs. South Africa is likely to join the United Kingdom in following these guidelines (World Health Organisation 2013). Annual HIV counselling and testing (HTC) became a universal expectation in South Africa in 2010, and it is an increasingly general part of primary health practice in the UK. Both countries are working to reduce HIV stigma and discrimination, with some success (UNAIDS 2012a). These hopeful characteristics of the two epidemics are reflected more broadly in suggestions within international HIV policy that the end of the HIV pandemic may be in sight, and in assumptions within some social research that, whatever the practical problems, the pandemic no longer poses important theoretical issues.

The major impetus for the book came from hearing my HIV positive research participants in both the United Kingdom and South Africa talk about the continuing difficulties of living three-letter lives. The interviews indicated that in many ways, despite positive indicators, the pandemic was very far from its end. HIV's naturalisation, that is, its incorporation into the natural order of people's lives, through processes of medicalisation,

social normalisation and marketisation, seemed to be stalling, undoing itself, and leaving things out (Squire 2010). The interviews intimated that these difficulties derived partly from the global recession's impact on three-letter lives, and the problems of living with HIV alongside many other illnesses, and with socio-economic constraints. Other common difficulties were narrated around what it was like to be diagnosed, still a problematic moment although no longer a death sentence; telling and not telling people about being HIV positive, and their good and sometimes bad reactions; and the impact of HIV on children and relationships.

Some of the commonalities across the interviews were less obviously about problems, more about the complex shape of HIV experiences. This complexity was emblematised in the clouds of other acronyms suffusing the interview. 'HIV' itself, for instance, was a term sometimes used interchangeably with 'AIDS' (as happened frequently, earlier in the epidemic). 'ARVs' were described variously, across different national and socio-historical circumstances, as 'ART' (anti-retroviral therapy) or 'HAART' (Highly Active Anti-Retroviral Therapy), or 'combination therapy'. I have used the term 'ARVs' throughout this book because it was deployed by the majority of interviewees across both South African and UK studies. Another three-letter (or more accurately, two-letters-and-a-number) acronym, the CD4+ T cell count, signalling immune activity, was used by interviewees to indicate levels of health before and while taking treatment, together with 'viral load' numbers. The many three-figure acronyms that hide behind or substitute for ARV brand or generic names, such as AZT (generic name, Zidovudine), D4T (generic name, Stavudine) and 3TC (generic name, Lamivudine), were regular currency within the interviews. Three-letter lives now also encompass newer, still-uncertain uses and outcomes of ARVs, similarly acronymised. TasP (treatment as Prevention), PrEP (pre-exposure prophylaxis) and PEP (post-exposure prophylaxis) emblematised the acronymic optimism about treating away the pandemic expressed by many medical and policy organisations, though these acronyms, especially the first two, were used less often by interviewees themselves. The acronyms 'MTCT' or 'PMTCT', for mother to child transmission, or prevention of mother to child transmission, indicate programmes to prevent vertical transmission that involve giving ARVs to both mother and baby, and that interviewees, women interviewees particularly, often mentioned.

As with 'HIV' and 'ARV,' other acronymic descriptions of the epidemic have changed over time. The acronym PWA, 'person with AIDS,' developed, as Adam Mars-Jones' (1992) character in a story written early in the UK epidemic, 'Slim,' puts it, to remind

people that he was indeed a person, has been modified, as treatment has developed and people live with HIV rather than progressing to AIDS, to 'PLWHA' or 'person living with HIV/AIDS'. The call for VCT (voluntary counselling and testing) is now often superseded by emphasis on universal testing. The prevention mantra 'ABC', 'Abstain, Be faithful, Condomise', has given way to emphasis on condoms, circumcision, and work to reduce risky sexual encounters, and ARV-based prevention, especially TasP. Treatment and prevention initiatives are now frequently related to another acronym, Millenium Development Goal 6, or MDG 6, which aims to provide universal treatment access and to reverse the spread of HIV by 2015 (United Nations 2013). UNAIDS's 'three zeroes', the triad of zero deaths from AIDS, zero new HIV infections and zero HIV-related discrimination, have shaped many prevention and treatment campaigns since 2010 (UNAIDS 2010b). HIV citizenship, which takes in the ways that people living with HIV or affected by HIV define themselves, and act and campaign in their social worlds, is related to an acronym, this time of four letters: GIPA, the principle of Greater Involvement of People Living with HIV and AIDS in all decisions made about them, which has been integral to international HIV policy since 1994 (UNAIDS 2007). Within specific national contexts, local acronyms play large roles in HIV citizenship, particularly those of service and activist organisations such as THT (Terrence Higgins Trust) in the UK, and the TAC (Treatment Action Campaign) in South Africa.

People do not live among all of these letters, all of the time. Moreover, many problematic elements of HIV experience are not acronymised. People who are HIV positive or otherwise affected by HIV and ARVs, however, do now tend to live with crowds of other acronyms as well. They navigate their way through these swirls of letters extremely effectively, and the letters themselves can be useful. They signify medical social science and policy knowledge in condensed, appropriated and owned form, without people having to be HIV clinicians, epidemiologists, virologists, behavioural scientists or policy experts in order to use them.

At the same time, acronyms can set up barriers for people who do not know what they mean. They can also create a sense of uncertainty among those who are HIV positive or HIV-affected themselves, even if they use them, because of doubts about what, *exactly*, they mean, what precisely is the expertise they impart, and what their own relationship is to that expertise. The perpetual recoinings of HIV acronyms testify to the struggles for the power of definition and knowledge conducted by people living with the condition, as well as by doctors, policymakers and activists.

It is medical, social and political shifts in addressing the pandemic that have made these particular sets of letters into powerful determinants of living with HIV. In 2008, the journalist Jonny Steinberg published a book about the difficulties South Africans were facing in getting tested for HIV and in accessing treatment. These difficulties arose not just from resource shortages, but also from competing belief systems, politically as well as culturally produced; concerns around social stigma and discrimination; and psychic conflicts, themselves the results of political and social as well as personal histories (Steinberg 2008). The book drew on interviews and encounters Steinberg had had in times and places where HIV was highly prevalent, mostly untreated, little talked about and usually fatal. In this book, called *Three Letter Plague (Sizwe's Test in the United States)*, 'HIV' were the three letters referred to. In *Living with HIV and ARVs*, the arrays of letters framing the epidemic are multiple, ARVs are as important as HIV, treatment access is greatly improved, people have the potential for a long and healthy lifespan and stigma is reduced in high-prevalence situations (Zuch and Lurie 2012). Difficulties, including some of those described by Steinberg, remain (Abrahams and Jewkes 2012; Flowers et al. 2006; Zungu 2012). Nevertheless, *Living with HIV and ARVs* addresses the contemporary realities of the HIV pandemic as the difficulties of particular lives as citizens, rather than, as in Steinberg's book, which appeared just five years ago, the problems of living in the midst of a plague. And *Living with HIV and ARVs* focuses on two sets of letters, not one, on ARVs as well as HIV, since these two three-letter sets, taken together, have increasing salience.

One of the ways in which three letters can act is as a declaration. Just saying 'HIV', let alone saying 'I am living with HIV', makes an impact. But three letters can also be a kind of shorthand that evades the actualities of the condition, leaving behind its complexities and difficulties, especially when 'ARVs' are added to HIV, as if, by themselves, they constitute a solution. On the other hand, 'HIV' itself may be too much to say. There are many codes for HIV to avoid saying it. One is indeed the 'three-letter disease'. Others are expressions like 'this thing', 'this torturing disease', and in high-prevalence contexts, 'our disease'. The character in 'Slim' uses the eponymous term, first used to describe the illness in Africa, instead of 'AIDS', because it describes precisely what is happening to him, and plays ironically on the value attached to thinness in the West. This character also insists on his own terms for other aspects of HIV illness: 'blackcurrants', in place of Kaposi's Sarcoma lesions, for instance (Mars-Jones 1992: 10). His lexical creativity allows him to keep hold of his own bodily reality and at the same time to grasp broader control of a disease process that he

cannot much affect, giving it his own meanings. Oscar Moore, describing two years of his 'life as an acronym,' also sketched out the 'secret fraternity of sickness' which build around the acronyms, conveying information, sympathy, rage and hope (1996: 3, 62). These are some of the more empowering functions that the slew of words, abbreviations and rhetorical play around HIV, generates.

Different forms of expression appear, of course, around other difficult health conditions like cancer (Sontag 1988), but they have been especially prolific within the HIV pandemic. We learn from them that indirectness can be helpful in allowing people to approach HIV issues obliquely (Squire 2007). However, indirectness can also be problematic. It can allow, through its imprecision, associations between HIV and areas of meaning such as sexuality, death and foreignness, that make it harder for people to understand HIV as an illness. In addition, with conditions like HIV, often characterised by privatised suffering and publicised silence, it can be very important for some people to talk openly and publicly, and for everyone to be able to talk openly in certain situations (Plummer 1995, 2001). Also, now that many people live with ARVs as well as HIV, the abjectification of HIV has diminished, so indirect ways of approaching it may be becoming less important (Abrahams and Jewkes 2012; Zuch and Lurie 2012).

At the same time, oblique strategies for approaching HIV continue, for a variety of reasons. People living with HIV and ARVs may have lived through a history of HIV as a 'death sentence' that does not leave them. Even those who became HIV positive more recently have heard about and imagine that history, which is also the present reality for perhaps 16 million people needing and not receiving treatment (World Health Organisation 2013; World Health Organisation/UNAIDS/UNICEF 2013). Such a history is also close to the present for people whose treatment is physically or psychologically difficult, or medically failing. An AIDS-free generation may be in sight, but it is not a reality even for the half of HIV positive people now also living with ARVs. And so acronyms remain important both as indirect strategies for addressing the difficulties of the pandemic, and, paradoxically, as indices of optimism.

The material in this book derives primarily from research participant interviews about experiences, expectations and requirements of HIV support in South Africa and the United Kingdom. In the early chapters especially, the book draws, too, on policy and cultural narratives of HIV, in the United Kingdom and South Africa, and at international levels. The

book's material also comes from listening to HIV volunteers and paid workers in South Africa and the United Kingdom, who, regardless of their status, are all citizens of an HIV-affected, HIV-defined world to some degree, and who discussed many of the same issues as the research participants. In addition, much of the book draws on insights from students who have participated in my 'HIV in the world' module at the University of East London over the past five years, who themselves come from many different country contexts across the pandemic, particularly from sub-Saharan Africa and the Caribbean, and who raise many similar issues to the research participants.

Often, students on the HIV module will say that the current policy picture cannot be right, and the figures must be wrong. They talk about all the people they know back home who don't have free treatment available locally, who can't get to treatment, who can't afford the fees the clinics charge, who fear someone will see them in the clinic, who have never told anyone their test result or received any medical help after their diagnosis, or who, even now, have never gotten tested but have just accepted their illness and likely death. In all this, they are frequently more pessimistic than workers in the HIV field, who are implementing change and measuring improvements, or indeed than my research participants, who, despite their extensive knowledge and understanding of the difficulties of three-letter lives, are well connected to treatment and education services. My students know, or sometimes are themselves, such people. They also know, or in some instances are themselves, people who do not access HIV services, do not know about services, do not know and will not consider their own HIV status. The continuing and new forms of difficulty around living with HIV and ARVs thus show themselves here too, in the conversations of people with close but often incidental connections to the pandemic.

The many directions from which the difficulties, as well as the hopefulness, of contemporary three-letter lives appeared, defined the shape of this book. The book starts from a general consideration of a possible end of HIV 'exceptionalism' and the beginning of a new 'particularity' about the pandemic. It continues by examining the different characteristics of HIV's contemporary naturalisation – its medicalisation, normalisation and marketisation - and how these characteristics at the same time denaturalise HIV. It then proceeds to explicate how HIV's particularities appear via its naturalisation and denaturalisation within two contemporary epidemics, in the United Kingdom and South Africa. In doing so, the book tries to describe and understand the new forms of HIV citizenship that are being articulated and performed within the current context of three-letter lives.

Chapter 2 in the book's first section, 'Living with HIV in the treatment possibility era', is called 'From HIV's exceptionalism to HIV's particularity'. It examines contemporary lives lived with HIV and ARVs in the context of medical, social and political gains within the HIV pandemic which promise to turn it into an everyday, rather than an exceptional, condition. It poses the 'acronym' optimism associated with this move away from exceptionalism, against continuing medical, social and political difficulties around HIV, as well as difficulties in the arena of personal beliefs and feelings. All of these difficulties still have powerful effects on the pandemic, and contribute to what the chapter calls its particularity. Chapter 2 goes on to describe the narrative approach to living with HIV and ARVs which I take in studying HIV support in the UK and South Africa, which allows for the particularities of lives within the pandemic to be registered. The chapter also describes how such studies, focused on the social, historical and personal particularities of epidemic contexts, may also allow for transfer or translation of understandings across contexts.

Section 2, 'Being naturalised, being left behind', examines the ways in which HIV has become part of everyday life, and the extent to which it has not, drawing both on my research studies, from the perspectives of people living with and affected by HIV, and on policy statements, professional position papers, corporate representations, and the discourses of HIV-related NGOs.

Chapter 3, 'Being naturalised', discusses ways in which the pandemic is becoming naturalised, made to seem an inherent, regular and inalienable part of the established order of power relations through processes of medicalisation, normalisation, and marketisation. It also examines how these processes undermine themselves internally and at the same time undo HIV's naturalisation, leaving lives lived with HIV to some extent outside or on the borders of naturalisation.

Chapter 4, 'When the drugs do work: The medicalised HIV citizen', explores the power of HIV's naturalisation through medicalisation, the benefits of that medicalisation, the constraints operating through medicalisation, which reduce and simplify ways of thinking about the pandemic, and the effects of some complex personal and cultural HIV narratives which try to redefine HIV citizenship in the biological field.

Chapter 5, 'A long-term condition: HIV's normalisation', focuses on the second major naturalisation process operating around the contemporary pandemic, which I call normalisation. Normalisation has many positive aspects to it, and yet its mainstreaming of HIV concerns can make the particularities of the condition hard to talk about or even to recognise.

Chapter 6, 'Investing in the pandemic: The marketised HIV citizen', examines the third naturalisation process in the contemporary pandemic, that of marketisation. This process increasingly structures arguments around prevention and treatment, and appears within personal as much as policy and popular accounts of the pandemic. It has become particularly prevalent since the financial crisis of 2008.

Medicalisation, normalisation and marketisation are processes of naturalisation that appear in many different contemporary fields. Chapter 7, 'Being left behind', goes on to examine some other denaturalising discontinuities in how the contemporary HIV era is lived, which derive from HIV's specific biological, psychological, cultural and socio-political characteristics. These discontinuities leave many people living with and affected by HIV, at some distance from the relatively hopeful HIV present. The chapter argues that both naturalisation and its failures lead to HIV being 'left behind,' and that this is an important element of HIV experience which requires continued attention.

Section 3 examines the particularities of HIV epidemics as they play out in different modalities of naturalisation in two national contexts, those of the United Kingdom and South Africa, drawing predominantly on interviews conducted largely in 2011 and 2012, respectively. Chapter 8, 'Living on: Three-letter lives in the United Kingdom', develops the analysis of narratives built up in the previous chapters, in relation to the particularities of the UK epidemic. To do so, it draws on the fifth round of my study of support used and wanted for living with HIV in the United Kingdom, in which 47 people, roughly half gay men, and half women and heterosexual men, took part in semi-structured interviews, mostly in 2011. The chapter discusses how narratives of medicalisation and de-medicalisation, narratives of normalisation and non-normalisation, and narratives of marketisation and of living outside markets, are enacted within the context of UK HIV citizenship. It is especially interested in how these three common narratives within the interviews, and their accompanying countervailing narratives, are inflected by what is often called neoliberalism. It examines

what the narratives can tell us about the adequacy of this term in relation to the multiple, ‘paraliberal’ ways people are developing of living with HIV and ARVs. It also investigates how the notion of living on a variety of HIV ‘borders’ of health, social and economic life, knowledge and resources (Derrida 1979) might be adapted to describe people’s active engagements with uncertainty and other difficulties.

Chapter 9, ‘Living with HIV: Three-letter lives in South Africa,’ examines how the particularities of the pandemic are lived out in a high-prevalence, medium-income country context. Here, ‘living with’ HIV increasingly seems to characterise research participant narratives as they trace the relations between different HIV statuses, and between HIV and other conditions, particularly in terms of resources needed, mobilised and developed. The chapter suggests that social resources of ‘living with’ HIV, or a kind of HIV conviviality, have come to have important effects, not just for people who are HIV positive or affected by HIV. At the same time, people living with HIV in under-resourced contexts face particular difficulties of being left behind in resource terms, as well as those difficulties of HIV knowledge and understanding which people living with HIV in higher-income countries also face.

Chapter 10, the last chapter in Section 3, reviews the particularities of contemporary three-letter lives as they have appeared in this book, and points to varieties of action and activism that may currently be available in everyday contexts such as those lived in by the interviewees in the HIV support studies. The chapter also suggests that the complexities and contradictions of living with HIV and ARVs, and their socially and historically particular forms, come into view in the long, involved, reflexive and often creative stories that people living with HIV co-construct in interview situations. They are persuasive accounts of the particularities of HIV, and of the processes by which its contemporary socio-political place is being negotiated.

To begin the book, I return now to the debate about current HIV optimism, how far concerns with HIV can be mainstreamed, and how we might be able to avoid separating and reifying the pandemic in an exceptionalist way, while still addressing its exceptional, particular characteristics.