

Troubled normalities: “Living on” and “living with” HIV in the treatment possibility era

[BOOK REVIEW]

Squire, Corinne (2013) **Living with HIV and ARVs: Three-letter lives**. Houndmills: Palgrave Macmillan. ISBN 978-0-230-28423-4 hbk. Pages vi + 275.

Dumisa Sofika

School of Psychology,
University of KwaZulu-Natal,
Pietermaritzburg

In **Living with HIV and ARVs: Three-letter lives**, Corinne Squire delves into very touching issues related to living with HIV in the treatment possibility era and what some have come to call the era of a possible AIDS free generation. Conducted in two settings, the UK and South Africa, the author looks at how HIV has come to be naturalized (seen as a natural, manageable and understandable part of our everyday biological, social and economic environments). This naturalization has been brought about by the medicalization of HIV, which because of scientific and medical breakthroughs in HIV, sees ARV treatment as especially important to the treatment and management of HIV. Naturalization also occurs through the normalization of HIV, where HIV is presented as a regular and unproblematic part of everyday health and social relations, and through marketisation where participation in market economies has been presented as a solution to living a normal healthy HIV lifestyle for the HIV positive.

This virtual and discursive presentation of HIV and ARV treatment as potentially problem free undermines the complexities of three-letter lives which are often un-narrated. We can see this for example in the proliferation of medical knowledge that is meant to liberate HIV positive people from death, delivering them (and us) from uncertainty to the certainty of a prolonged life. The old “knowledge is power” maxim can now be translated to “medical knowledge is power to live”. Yet to live as an HIV positive person entails something more than access to knowledge, which is in itself problematic (access to knowledge often requires resources that are not equally available to everyone). We can see how it confers control and responsibility on the HIV citizen without questioning the ability for citizens to act on this responsibility,

or questioning the limits and extent of responsibility between citizens and the state or other vehicles or mechanisms of power.

In **Three-letter lives**, we are confronted with accumulating evidence of how in the face of optimism and in the context of progress, HIV is slowly taking a backseat, pushed to relinquish its seat at the forefront of politically and socially sensitive issues, for what are stated to be far more pressing social concerns such as crime and poverty. In public health discourse, HIV is normalized as an everyday illness, no different from other chronic illnesses, with HIV positive people enticed with the possibilities of living a normal life. And HIV positive people can live a normal life, or some semblance of a normal life. It is not to argue that they cannot. Yet HIV is not just another chronic illness, there are deeply particularized aspects of three letter lives that evade, that resist its normalization as just another chronic illness. If there is any normality in HIV, it is a troubled normality, reflected in the normalizing discourses that participants participate and implicate themselves in, but that sometimes veil the troubled voices, the troubling features of living three letter lives. These are the tensions, the contradictions and ambiguities represented in the normative and counter-normative narratives of HIV's naturalization, and expressed in participants' stories of their three letter lives that the book deals with. Corinne Squire looks at the particularities of living with HIV and ARVs in this climate of growing optimism arguing that this framing often undermines deeply particularized aspects of living with HIV and ARV treatment.

The narratives that Corinne Squire engages in with her participants show us that as much as we can say that to live three-letter lives is to live a normal life, that is not entirely true. HIV citizenship is still confronted by issues that other forms of citizenship are not confronted by. The particularities of three letter lives take place in the context of neoliberal markets in which normal citizenship and HIV citizenship have to be constantly negotiated, weaving in and out of each other. In the global financial crisis which has had a severe impact on health budgets, HIV positive people are often the worst affected by reductions in health funding which means that social support services are reduced, NGOs and CBOs that provide support are shut down because of lack of funding, and the downscaling of HIV remittances. At a policy level, according to Squire "health for all" has meant a diversion of funding for HIV to focus on health in more general terms. Medical practitioners are under pressure and this means that HIV positive people may often compromise their own health needs over those that are deemed to be more important.

Medicalization of HIV has resulted in a flourishing of HIV knowledge in which HIV is treated only in medical terms. This has resulted in the creation of an expert HIV patient who is well informed and well versed in HIV. What has resulted has been the shifting of responsibility to HIV patients for their wellness without due regard of the difficulties that this knowledge may pose for some HIV positive people. HIV positive people are entreated to take full responsibility for their lives through the acquisition of knowledge even though the acquisition of this knowledge, and whether people are able to act on it, is often in question. We are confronted by an even direr situation: the marketization of the HIV citizen. Marketization is meant to normalize the HIV citizen by incorporating him/her into normal everyday relations of consumption. But even here we have a problem since HIV tends to be concentrated around people who are resource-constrained and so that means that they are never fully incorporated into this normalization. Alternative and less marketized means of dealing with the side effects and stress of living with HIV are often less discussed than conventional Western medicine. We are confronted with how HIV positive people are "being left behind", a useful phrase for looking at what happens when naturalization is forced onto people without really taking account of some of the personal difficulties that this poses for people living with HIV.

How are HIV positive people supposed to live then? This is a question that is tackled by the book. We are faced with a situation where people either have to “live on” with HIV in contexts like the UK that have a longer treatment history, or “live with” HIV in resource low and middle-income settings such as South Africa. “Living on” refers to survival in spite of the precarious nature of living three letter lives. In the UK, it encompasses “living on” with the loss of loved ones and therefore a constant reminder of the effects of HIV on people’s personal lives. Somehow, infected people must still find a way to live on with this perpetual sense of loss and the sometimes unstated but present fear of impending doom over their own lives. “Living on” involves a strategic rejection of certain aspects of one’s HIV positive identity while simultaneously facing HIV related feelings of depression and HIV complications. “Living with” HIV in South Africa entails resourcefulness and negotiation in the context of poverty and resource constraints. Resourcefulness may mean skipping ARV medication in the absence of food to supplement the medication, it entails finding new strategies for social and psychological support amidst lack of access to these resources, it means having to endure the sometimes ravaging side effects of ARV medications on already weak and impoverished bodies. In South Africa, living with HIV also means living with the severe cash constraints that make living a healthier life almost impossible.

The book shows us the complexity of living three-letter lives in this era of a possible AIDS free generation. This is a complexity that HIV naturalization, in its optimism and progressive zeal may often gloss over. It glosses over the uncertainty that faces HIV positive people, on the borders of scientific and medical progress, at the helm of fluctuating global markets that they have no control over. It means that social and economic uncertainties that have a direct and indirect bearing on the lives of HIV positive people are sometimes placed on the periphery of medical progress and discourses. As much as medical and public health, and even media discourses can claim through medicalization that HIV positive people have control over their wellness, there are a host of things over which HIV positive people have no control. It glosses over the dents and threats to personal and other forms of security that encounter people living three letter lives. This book will enable us to consider issues of social justice, where we are forced to take account of the context of ambiguity that HIV positive people have to live with as part of their three letter lives in this era of optimism.