African achievers, structural barriers and 'The End of AIDS'

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Introduction

This paper explores three interrelated phenomena in relation to achievement in "ending" AIDS.[2] Firstly, it must be acknowledged that AIDS has, without doubt, been one of the worst health catastrophes ever to face the African continent as a whole. It has, however, also enabled some Africans to obtain global political recognition, to realise professional ambitions, to obtain upward mobility and to promote the future of science on the continent. Secondly, AIDS leadership, ambition and achievement are hegemonically viewed through the lens of 'ending' AIDS through technofixes and patient/community anti-retroviral (ARV) adherence. Thirdly, it makes the case that in a neoliberal context, it must be recognised that there are structural realities limiting the advancement of AIDS-related science and the capabilities of people living with, and affected by, HIV to end the pandemic. It is in this context that the socio-economic injustice which perpetuates the continued spread of HIV and ongoing AIDS-related death is occluded by heroic individualised narratives of the successful African scientist and the responsible, self-governing, resilient AIDS activist-leader.

The "End of AIDS" narrative and the ongoing pandemic

It has become common for intergovernmental organisations and scientists to refer to an 'end of AIDS' (*The Economist* 2014; Lancet HIV 2015; UNAIDS 2014). There is, however, a real risk that an accomplishment which is admirable and a conceivable future goal could be seen by important actors to be closer than it actually is.

To examine some recent statistics, according to UNAIDS, in 2017 globally, there were 36.9 million people living with HIV/AIDS (PLWHA); only 21.7 million of whom were on anti-retrovirals (ARVs); and, around the world 940 000 people died from AIDS-related illnesses (UNAIDS 2018).[3] In 2017, in eastern and southern Africa, there were 19.6 million PLWHA (the majority of those living with the disease globally); only 12.9 mil of PLWHA in the region were on treatment; 380 000 people in the region died from AIDS-re-

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2 By putting the "End of AIDS" in inverted commas, I am not expressing scepticism about it being medically possible, but rather concern about certain dominant – socially constructed – narratives about how to go about it.

3 The 2018 report contains this data from 2017.

lated illnesses; and, an estimated 800 000 people became HIV-positive (UNAIDS 2018).[4]

The persistence of the AIDS epidemic must be understood as a product of historical and contemporary social injustices. In southern Africa, social drivers of HIV incidence include phenomena such as: the migrant labour system; high female unemployment and sexism, which are linked to multiple, concurrent sexual relationships, many of which are transactional in nature; and, homo- and trans-phobia.

There are now an array of HIV prevention technologies which can be deployed to end new HIV infections. One of these is Truvada, which can be used for pre-exposure prophylaxis (PrEP). For PrEP to work, a person must take Truvada daily in order to radically reduce their chances of acquiring HIV. PrEP has been hailed as an important advance in terms of HIV prevention, especially as regards "key populations" (including MSM and transgender people). In order for it to be effective, people who wish to take it should, ideally, also be tested for Sexually Transmitted Infections (STIs) in addition to regular HIV testing, and this means that health facilities providing the intervention must be "safe spaces" for those who wish to use this prevention method to discuss their sexual health. Unfortunately, universal access to PrEP has not been realised, as African LGBTIQ NGOs have pointed out (AVAC 2016). In Africa, a key barrier to LGBTIQ people being able to access ARVs for PrEP is the ongoing criminalisation of same-sex sexuality.

There are social and structural barriers to people taking ARVs such as the high prices of drugs and underfunding of the Global Fund to Fight AIDS TB and Malaria (GFATM). In such a neoliberal climate, there are artificial constraints on funding for AIDS programmes in Africa. This provides the grounds for the unethical rationing for health resources to become the norm. To be more precise, in such a context, healthy people who desire to take PrEP (to prevent HIV acquisition) are potentially competing against PLWHA for access to the drugs, which they need to stay alive.

AIDS leadership and achievement

Global recognition of African activists' and scientists' leadership in "ending" AIDS has been refracted through the prism of transnational media, corporations, international scientific organisations and multilateral institutions. One can state this while not bringing into question *both* the importance of the work of scientists aiming to develop a vaccine or functional cure *and* the principled and brave work of African AIDS activists who have pressed for universal access to HIV treatment.

Instead, we must critically examine the modalities of media production, corporate marketing (Nike [RED], which is discussed below) and branding and political messaging (by the UN and donors) around the end of AIDS in an African context. As we shall see,

[4] This report is also referred to in note 3 and it contains this data from 2017.

the dominant hero-driven, "techno-fix" framing of the "end of AIDS" obscures the ways in which socio-economic injustice drives new HIV infections and AIDS deaths.

The idea of "ending" AIDS is, essentially, premised on the universal adoption of a range of biomedical interventions and the African scientist-doctors who have been most widely recognised in Western media have been those promoting these approaches. For instance, in an article published by *The Economist* on the 2014 Melbourne International AIDS Conference entitled "Is the End in Sight?," it was relayed that that Salim Abdool Karim had outlined a range of methods which could be used to substantially reduce new HIV infections, including: counselling and consistent and correct use of condoms; voluntary male medical circumcision; and "treatment as prevention" (*The Economist* 2014). Unsurprisingly, the article failed to mention the challenges facing physicians, nurses, community health workers and those affected by, and living with, HIV in implementing these measures. In particular, we must note here its silences around the reasons for the high price of Truvada (long inflexible patents) or the ways in which HIV services are severely impaired by health systems crises in African countries (such as shortages of health care workers and the imposition of user fees).

Abdool Karim is undoubtably an admirable, highly accomplished scientist, who agrees with the need to address the structural barriers to ending AIDS. He is, indeed, a major scientific leader in Africa and the worlds of medicine and public health globally. A study authored by Quarraisha Abdool Karim and himself along with other collaborators entitled the CAPRISA 004 study showed that Tenofovir gel applied vaginally before and after sex could reduce HIV incidence by 39% (Abdool Karim et al. 2010). When Quarraisha Abdool Karim presented the results of the study she received a rare standing ovation at the 18th International AIDS Conference, which is organised by the International AIDS Society (IAS) in 2010 (NAM AIDS Map 2010). Salim Abdool Karim is the recipient of numerous prestigious awards including one from The World Academy of Science (TWAS 2018).

However, the structural barriers to scientific AIDS innovations being implemented on the ground is indicated by another trial called VOICE where women were to either use the Tenofovir gel or an ARV tablet (tenofovir or Truvada) daily faltered as most of the participants could not adhere to taking either the gel, or the drug, daily (Marrazzo et al. 2015). This is an example of the ways in which there are socio-economic barriers to health care interventions being rolled-out on the ground: these include the various reasons why patients don't take drugs even when they are rendered readily available. Doctors, nurses, and community health workers at the 'coalface' of providing ARVs need to also be provided with a platform to highlight their work and the socio-economic and health systems reasons hindering it.

The celebrity or 'captured' AIDS activist

We must situate our critique of narratives of the heroic, individual AIDS activist in a context where global media coverage of AIDS is disproportionately dominated by celebrity humanitarianism and corporate "compassionate" brands (Richey and Ponte 2011). For instance, Harry, the Duke of Sussex (a British royal family member), receives far more international media coverage for the work of his AIDS NGO Sentebale than the more 'mundane' work of NGOs like the Treatment Action Campaign (TAC) and Médecins Sans Frontières (MSF). It is certainly for this reason that the International AIDS Society heavily promotes celebrity humanitarians' participation in their international AIDS conferences (IAS 2018).

In the case of corporate "compassionate" branding/marketing, Kenworthy et al. have critiqued the (NIKE) RED "Write the Future," which provides a vision of the End of AIDS which avoids a discussion of the structural injustices underpinning new HIV infections and AIDS deaths (2017). By way of description, in the advertisement, school children are taught a lesson on the end of AIDS as driven by patients dutifully taking ARVs, sports stars (including Ivorian football player Didier Drogba) tweeting about "ending AIDS" and, of course, people buying their sports shoes. Kenworthy et al. have argued that dominant "end of AIDS" discursive frames "have material and financial consequences [...] [including] a general avoidance of discussions about long-term financial commitments by donors and governments to comprehensive treatment, health systems building, and patient-centred health modalities" (2017).

An interesting point to make here is that through such initiatives, AIDS has become a site of brand-building, the collection of moral legitimacy and legacy-building for *African* celebrities (such as Drogba). So, we cannot resort to easy dichotomies of "Great white saviour/celebrity" and passive African recipient: African celebrities also use the "end of AIDS" narrative to build their own brands. When one examines "the AIDS world" in the context of dominant corporate brandings and framings of the issue, it becomes clear that there is social contestation over who, in fact, is an AIDS activist. The malleability of the term enables people with a wide range of agendas to receive social recognition.

Few Africans feature among those recognised by powerful media outlets based in the global North as "leading" activists. For instance, a 2016 article in *Esquire* magazine which highlighted "13 Faces of AIDS Activism" focusing on "some of the most prominent people, living and dead, with the most impact in the history of AIDS" only mentioned Zackie Achmat alongside 10 Americans (such as Liz Taylor and Magic Johnson), one Irishman (Bono) and one British person (Elton John) (Firger 2016). Mentioning the media celebration of Achmat's achievements does not imply a critique of the man himself, merely the representation of him as the *sole* important African AIDS activist in the history of the pandemic. Achmat was an important founder, spokesperson and leader of the TAC in its first decade. The TAC was, in turn, vital in pushing for a drastic expansion in ARVs

provision in both South Africa and developing countries around the world.

Recently, as activists (many of whom have worked with Achmat) have considered barriers to the "end of AIDS," they have also described what might be termed as the end of radical and high-impact AIDS activism. An interesting recent phenomenon which has emerged is activists' critiques of those deemed to have been 'captured' by the desire to accumulate wealth through developing networks of patronage in the "AIDS world." The idea of their being an "AIDS world" made up of UNAIDS, international donors, researchers, and NGOs is nothing new.[5] What is more recent is the idea of a reduction in the radicalism of transnational AIDS activism.

Veteran AIDS activists such as Vuyiseka Dubula and Sipho Mthathi (both formerly of the TAC) have critiqued some activists as having become self-serving and comfortable in their donor-funded jobs (Spotlight 2018).[6] Here we see a critique of AIDS activism being used as a site of accumulation and the obtainment of a middle-class social status. In sum, it has been argued that

> Some say that the civil society AIDS response is 'captured' by donor money and agendas, in other words the new 'activists' are those who fly business class to New York, Geneva and Moscow, speak sweetly at roundtables, shout a few Amandlas and board their flights back home to their donor funded jobs. (Spotlight 2018, 1)[7]

Unsurprisingly, given the relatively small number of AIDS activists, they do not name exactly who is the object of their critique, however, advocacy as a site of individual "success" is clearly a site of reflection and tension. One element of this debate is generational in nature, so, for example, it has involved older AIDS activists reflecting on their own legacies and how to guide younger activists.

The structural realities behind the continuation of AIDS

While leading AIDS doctors/scientists and AIDS activists are often treated as celebrities, less international media attention has focused on the reasons why some people living with HIV cannot take their drugs consistently or effectively. Mark Heywood, a prominent South African AIDS and social justice activist has argued that UNAIDS had yet to discover that there was "elephantine truth hiding in the room next door": the reality that without dealing with social injustices and inequalities and the "real social determinants of HIV and AIDS," progress in arresting the epidemic will, eventually, stall (2016).

An example proffered by Heywood in this article is that of the link between

5 The idea emerged from key informant interviews I conducted with AIDS activists who were actively campaigning on the epidemic in the 1990s and early 2000s (Mbali 2013).
6 They are quoted in this article, which is a collection of excerpts from interviews with key activists.
7 This quote is derived from the introductory paragraph of same article referred to in note 6 above.

unequal access to quality education and the incidence of HIV and teenage pregnancy in young women in secondary schools in South Africa. Per capita expenditure in Limpopo, a province wracked by poverty and corruption, is R1 117 per annum (less than 80 USD) whereas that spend in one private school in Johannesburg is in the region of R200 000 (or 14 285 USD per annum). In poor schools, HIV and teenage pregnancy exist at high levels; by contrast, in rich schools, both are practically non-existent.

A further instance of this type of critique is that levelled by MSF doctor-activist Eric Goemaere. He has argued that the much more effective roll-outs of ARVs have had the consequence of reducing death rates, however, those who continue to die are mostly those who develop drug resistance or interrupt their treatment (Spotlight 2018, 2-3). Goemaere has gone on to highlight the fact that these "defaulters" face a new kind of AIDS-related stigma, whereby they are blamed for their own AIDS-related deaths (Spotlight 2018, 3). There are a myriad reasons why people interrupt their HIV treatment: there are frequently drug stockouts in South Africa; it is expensive to afford public transport to attend clinics and hospitals; some patients move unexpectedly; some have mental health issues (including drug dependence) or major social problems such as homelessness or gender-based violence against women; and, some face trans- and homophobia.

Measuring whether AIDS is "ending" requires PLWHA to be counted. They are counted through testing, but not all of them want, or are able, to be tested for HIV. For instance, in eastern and southern Africa, 19% of PLWHA do not know their HIV status (UNAIDS 2018, 27). Are those who do not want to be tested for HIV passively refusing to "end AIDS"? In the "AIDS world" there is a danger that they could be presented as the exact symbolic opposite of the brave AIDS activist living with HIV who successfully adheres to treatment. Without careful reflection on the risks of further stigmatising PLWHA, there is a real risk that some of them could be described as those who stand in the way of reaching the UNAIDS 90-90-90 target by 2020 (UNAIDS 2014).[8]

Conclusion

Individual African activists and scientists have played a critical role in reversing the tide of the AIDS epidemic on the continent. In collaboration with their colleagues from the global North, African scientists have shown that from a technical, scientific stand-point "ending AIDS" is feasible. The plaudits received by scientists such as Salim Abdool Karim and activists such as Zackie Achmat are richly deserved. Dominant understandings of AIDS leadership are, however, filtered through the prism of the transnational media, corporations, international scientific organisations such as the IAS and multilateral institutions such

8 The 90-90-90 UNAIDS target is for 90% of PLWHA to be tested (diagnosed), 90% of those placed on ARVs, and 90% of those on ARVs to be virally suppressed.

as UNAIDS. Seasoned AIDS activists with a focus on Africa have recently expressed a concern that the radical content of advocacy on the pandemic may be being hollowed-out and being replaced with donor-driven and accumulation-focused "activism." Similarly, they have drawn our attention to the structural realities behind the ongoing pandemic, including socio-economic injustices. Doctor-activists on the ground who advocate for their patients' right to access to health care have also cautioned us against the further stigmatisation of those PLWHA who have interrupted their ARV treatment for socio-economic reasons. Ending new HIV infections and AIDS deaths is a collective, global undertaking. In the "AIDS world" it must be emphasized that leadership in ending the pandemic must go beyond the work of influential individuals: in each affected country, it will require society-wide leadership, including social movement strengthening, fundamental health systems restructuring and serious efforts to address socio-economic inequality.

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