

## CRITICAL-RETROSPECTIVE ESSAYS

AIDS in Africa\*

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*HIV Exceptionalism: Development through Disease in Sierra Leone*, by **Adia Benton**. Minneapolis: University of Minnesota Press, 2015. 176 pp. \$22.50 paper. ISBN: 9780816692439.

*Letting Them Die: Why AIDS Prevention Programmes Fail*, by **Catherine Campbell**. Oxford, UK: International African Institute, 2003. 214 pp. \$24.00 paper. ISBN: 9780253216359.

*Scrambling for Africa: AIDS, Expertise, and the Rise of American Global Health Science*, by **Johanna Tayloe Crane**. Ithaca, NY: Cornell University Press, 2014. 224 pp. \$27.95 paper. ISBN: 9780801479175.

*Ancestors and Antiretrovirals: The Biopolitics of HIV/AIDS in Post-Apartheid South Africa*, by **Claire Laurier Decoteau**. Chicago: University of Chicago Press, 2013. 344 pp. \$32.50 paper. ISBN: 9780226064598.

*The African AIDS Epidemic: A History*, by **John Iliffe**. Athens: Ohio University Press, 2006. 214 pp. \$24.95 paper. ISBN: 9780821416891.

*Love, Money, and HIV: Becoming a Modern African Woman in the Age of AIDS*, by **Sanyu A. Mojola**. Oakland: University of California Press, 2014. 275 pp. \$29.95 paper. ISBN: 9780520280946.

*The Origin of AIDS*, by **Jacques Pepin**. New York: Cambridge University Press, 2011. 293 pp. \$27.75 paper. ISBN: 9780521186377.

*Religion and AIDS in Africa*, by **Jenny Trinitapoli** and **Alexander Weinreb**. New York: Oxford University Press, 2012. 276 pp. \$31.95 cloth. ISBN: 9780195335941.

can be told in a single narrative. While the continent accounts for a substantially disproportionate share of the global population living with HIV or AIDS,<sup>1</sup> the contours of the epidemic vary substantially across—and even within—its 54 countries. To make sense of this variation, researchers have devoted considerable attention to identifying the common and differential causal pathways of infection, barriers to treatment, and societal impacts of AIDS within African populations.

Traditional sociological perspectives have contributed to our understanding of the disease from relatively early on—for example, with a focus on social inequalities in HIV

### Introduction

It would be a vast overgeneralization to suggest that the story of HIV/AIDS in Africa

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<sup>1</sup> To avoid unnecessarily cumbersome writing, I follow the increasingly common convention of using the term “HIV” when explicitly referring to the virus, while using “AIDS” both to indicate the end-stage disease and as the catch-all term in lieu of repeatedly writing “HIV/AIDS.”

infection (for a review, see Heimer 2007) or AIDS-related stigma (Alonzo and Reynolds 1995). As the epidemic has matured, we have increasingly developed a reciprocal relationship between sociology and AIDS. In other words, while applications of existing sociological frameworks continue to shape explanations of AIDS, we have also seen the epidemic extend the boundaries of sociological theory and knowledge.

Here, I will follow a rough chronology to examine that reciprocity through recent developments in the sociology of AIDS. This chronology focuses on how we have come to understand the dynamic progression of HIV infection into AIDS in Africa, an understanding that has matured alongside the epidemic itself. I focus on four primary components: (1) the relatively recent reconstruction of a historical trajectory of AIDS's spread across the continent, (2) the primary explanations for HIV transmission patterns and corresponding prevention efforts, (3) the individual and collective experiences of people living with HIV/AIDS (PLWHA), with a particular focus on changes in population structure and the development and uptake of treatment regimens, and (4) the societal impacts of generalized HIV epidemics. Before getting into each of these elements, some descriptive overview will be helpful.

While initial scientific attention sprung from a cluster of cases in Los Angeles (CDC 1981), sub-Saharan Africa has consistently shown the highest prevalence and exhibited the most rapid growth in new HIV infections, until relatively recent plateaus (Bongaarts et al. 2008). Among the most quoted statistics about the global AIDS pandemic is that, as of 2013, while Africa accounts for only 15 percent of the world's population, it is home to roughly 71 percent of those who are currently living with HIV or AIDS (UNAIDS 2014). This has led many to question why AIDS is so much more pervasive in sub-Saharan Africa (SSA) than elsewhere in the world.

Scholars from socio-medical, behavioral, and epidemiological perspectives have attempted to answer this question and have engendered frequent, intense debate about each perspective's explanatory power. Early speculation—often used to motivate

information-based intervention campaigns—posited a key role of ignorance (both passive and willful) in sustaining the epidemic. While seemingly plausible and providing a clear first intervention step, evidence in locales with high HIV prevalence demonstrates that “knowledge about the epidemic was not lacking” (Mojola 2014:7) because “there is little silence or denial” (Watkins 2004:674). The content of those conversations varies considerably, particularly between formal and informal contexts (Angotti et al. 2014). Below, I elaborate how these different understandings shape efforts for preventing HIV and caring for PLWHA. Others have claimed stigma is an important epidemic catalyst (Rankin et al. 2005). Here, the evidence is more mixed and will play a key role in the discussion below on societal impacts and treatment. Among highly informed populations, even those exhibiting low levels of stigma, the importance that a populace places on AIDS relative to other issues can shape the responses that they and their governments enact (Dionne, Gerland, and Watkins 2011). However, as will be shown in the sections below on prevention, care, and impacts, governmental actors and NGOs from outside the region heavily shape AIDS interventions across Africa.

## History & Disparities of HIV Infection

The human immunodeficiency virus rapidly replicates. This speed introduces numerous transcription errors into the virus's genetic code circulating in the body of any infected person, and the “errors” are transmitted between individuals. This variability has generated major strain differences in the population of existing HIV. HIV-1, type M is the predominant strain globally, but consists of many finer distinctions. For example, subtype B prevails in the United States, while C is dominant in southern Africa, and high viral variability—within the M class—is the norm in many central African countries. This rapid replication also supports the occasional recombinant form, incorporating multiple mutations. While this insight is not particularly new, researchers have recently leveraged these strain differences to trace large historical

trends in the global HIV pandemic (Iliffe 2006, Pepin 2011) and have used fine-tuned viral phylogeny for reconstructing infection networks that underlie particular epidemics (Lewis et al. 2008).

In *The African AIDS Epidemic* and *The Origin of AIDS*, John Iliffe and Jacques Pepin each draw on historical and current HIV viral strain distributions as a means to date HIV's transition to a human virus and to recreate the trajectory of its spread through human populations. Most researchers now accept that HIV-1 existed in low prevalence among humans by the 1950s in western equatorial Africa and, perhaps more remarkably, already displayed wide genetic variability. HIV-2 seems to have made the jump earlier; but because it is less virulent, its diffusion remained relatively constrained, keeping it mostly localized. Earlier cases of HIV were likely to have occurred by the 1920s but did not encounter conditions sufficient to produce widespread epidemics.

Among the first confirmed cases of HIV-1—by blood tests conducted decades later—is a case from Kinshasa, identified in a sample taken in 1959. The rapid viral diversification allowed researchers to reconstruct the pathways by which transmission seemed to have evolved from these origins. While Iliffe is a historian and Pepin a clinician and virologist, it is in tracing this historical trajectory that each of their respective works takes an increasingly sociological turn. As they trace the routes of epidemic growth across Africa—spreading mostly east, then south, from the initial human cases and accelerating in prevalence the further it went—the patterns by which HIV spread were markedly shaped by macro-structural characteristics that were distinct to the period. Primary among these were rapid demographic growth and cascading decolonization.

At the time of HIV's first documented human infections, the population of SSA was continuing to grow more rapidly than anywhere else, at rates unseen in any prior period in recent human history. This rapid population growth coincided with continued and/or increasing levels of (male) cyclical temporary occupational migration. Additionally, this period saw the beginnings of slow but increasing urbanization across

the continent. Riding on the backs of these population patterns, HIV traversed transportation and communication corridors across Africa, resulting in early concentration of the epidemic among urban—and to a lesser extent, more affluent—segments of the population. Complicating the effects of these population dynamics was a unique cluster of HIV's characteristics—its relatively inefficient transmissibility, its slow virologic development, and the fact that many of its subsequent complications mimicked (though amplified) morbidity and mortality events that were common to the area (e.g., tuberculosis in SSA). The combination of these population dynamics and HIV characteristics contributed to a unique feature of the HIV epidemic's spread across SSA: it was remarkably generalized before it was identified.<sup>2</sup> Iliffe concludes that this unique constellation of factors explains how “the fundamental reason why Africa had the worst AIDS epidemic was because it had the first AIDS epidemic” (2006:58).

These initial conditions provided a baseline from which the virus was able to accelerate its expansion as it spread across Africa; AIDS research began to expand correspondingly. Researchers documented that this period of rapid expansion was increasingly marked by diverging prevalence and incidence patterns—for example, countries such as Niger and Burkina Faso remained relatively unpenetrated (prevalence at or below one percent), while some countries, especially in the south (e.g., South Africa, Swaziland, Botswana), had population prevalence estimates that exceeded 20 percent.

Three primary features were vital to documenting this period of HIV expansion: identifying when prevalence/incidence rates were going to plateau and/or reverse, altering the strategies for generating such estimates, and documenting the (changing) socio-demographic disparities of HIV infection. Incidence captures the rate at which uninfected members of the population

<sup>2</sup> A “generalized” epidemic indicates one that has spread to more than one percent of the region's population and typically is not restricted within small subsets of the population (e.g., “high risk” individuals).

become *newly* infected, while prevalence provides a point estimate of the proportion of a population currently infected with HIV—whether recently or from an old infection. These distinctions matter because their ability to capture epidemic dynamics across the period was changing due to concomitant changes in other features—especially treatment availability. Mathematical estimates of epidemic dynamics often focus on incidence, because the point at which an epidemic will cease growing (or begin to decrease) is identifiable from the reproductive rate of infection ( $R_0$ ), which enumerates how many new cases each existing case is expected to generate (Anderson and May 1991).

Unfortunately, incidence is notoriously hard to estimate for many infectious diseases, especially HIV because of its features mentioned above. As a result, prevalence estimates have been much more common (Ghys, Kufa, and George 2006), despite simultaneously incorporating incidence and survival components. While survival post-infection without treatment is relatively consistently estimated at approximately nine years, as treatment regimens were introduced in this period, they substantially altered survival trajectories—also altering the relationship between incidence and prevalence (Hallett et al. 2008). These measurement difficulties notwithstanding, it appears that HIV incidence in SSA experienced a plateau/decrease during the mid-2000s. Over the same period, prevalence has plateaued, or increased at a slowed rate. These prevalence changes reflect a combination of the incidence trend and increasing availability of treatment—elongating survival possibilities for PLWHA.

A methodological sea change occurred during this period, which further complicated temporal trend interpretation—the transition away from relying on antenatal clinic data as the primary source of epidemic estimates. Early in the period of epidemic growth, the most ready source of testable samples was from women attending clinics at or before giving birth. Because of high fertility, this was thought to provide broad access to the potentially at-risk population—sexually active persons. However, as estimates increasingly relied on population-level estimates, it became clear

that antenatal data was overestimating the scope of the epidemic (Mwaluko et al. 2007). This forced re-interpretation of longitudinal trends in the epidemic trajectory, and some modest (delayed) adjustments to estimates of when the plateau in new infections is thought to have occurred (Ghys et al. 2008).

While it was important to document how many people were (newly) infected, as surveillance efforts increased, it became increasingly apparent that socio-demographic subsets of the population varied considerably. I describe some of these differences now and examine their sources in the sections below on transmission/prevention and treatment. Gender provides perhaps the most entrenched HIV disparity in SSA—women have experienced elevated incidence and prevalence rates compared to men since the 1990s, a discrepancy exacerbated for those in the youngest age cohorts (Mojola 2014). While the early period demonstrated some infection preference toward those in advantaged socioeconomic positions, as the epidemic has matured, it has increasingly mirrored the disadvantages of poverty that are observed for most health outcomes (Farmer et al. 2001). Similarly, while genetic evidence points to early urban concentration, as the epidemic spread the urban/rural disparity shrank, and in a few cases even reversed (Iliffe 2006). Research has noted ecological-level differences by religion—for example, countries with more Muslims have lower prevalence (Takyi 2003). Translation of religious disparities into individual-level models has produced mixed evidence (Trinitapoli and Weinreb 2012). Religion is one among several factors that correspond to researchers' shifting their focus beyond the individual level to identify community-level factors that generate these and other disparities.

## HIV Transmission & Prevention

HIV transmission in SSA occurs predominantly through heterosexual sex. There are two very different approaches for examining why this is so. Social-behavioral work tends to focus on the *risk factors* associated with potentially contracting HIV, while epidemiological work—especially that concerned

with formal modeling—asks about factors that influence the *reproductive rate* ( $R_0$ ). While some factors similarly shape both, others influence risk factors or  $R_0$  differentially. Take, for example, the fact that women consistently exhibit higher incidence and prevalence rates than men. From a risk-factor perspective this stems from factors that differentially *elevate* women's risk; for example, biologically women are approximately two to three times more susceptible to infection than men from a single penile-vaginal sexual encounter (Fox et al. 2011). Thus, if comparing a man and woman who are each currently infected and exhibit exactly the same frequency of sex, with the same number of partners—from an  $R_0$  perspective—the woman would be a less efficient transmitter of the virus, generating *fewer* secondary infections.

Sociological work on HIV gender disparities tends to focus more on gender-based risk factor differences. Sanyu Mojola's *Love, Money and HIV* and Catherine Campbell's *Letting Them Die* address several of the most consistently identified factors elevating women's risk: age-heterophilous partnerships, "transactional sex," and power differentials that reduce condom usage. In her ethnography of Kenyan women, Mojola argues that age heterophily in the formation of romantic partnerships—and its combination with "transactional sex"—substantially

genders HIV risk factors. Age heterophily describes the pattern of women partnering with men who are (sometimes substantially) older. This differentially shapes HIV risk because at almost every age group, men's HIV prevalence is lower than for corresponding women. Thus, by selecting older partners women are at substantially elevated risk of finding a partner who is already infected.

Romantic partnerships the world over often involve provision of gifts and money—more often from men to women (Poulin 2007).<sup>3</sup> Mojola shows how such relational norms are governed by increasing globalization and commodification of wants among Kenyan women. As such, "transactional" partnerships are simultaneously likely to increase the number of partners women have, exacerbate the age heterophily described above (as age increases men's capacity to support such relationships), and reduce the woman's control over the sexual encounter (e.g., ability to require condom use).

Negotiating condom use has been frequently posited as a potential intervention, seeking to elevate women's control over the risk they encounter within sexual partnerships (Sinding 2005). However, as Campbell notes in her account of a (mostly failed) community-level intervention among commercial sex workers in a mining community in South Africa, commercial sex workers often exhibit higher HIV prevalence than their clientele. In that case, condom promotion is more likely to reduce  $R_0$  for women who are currently infected than to shape their risk factors.<sup>4</sup> Despite the potential for protecting the clientele, Campbell echoes others' findings (e.g., Tavory and Swidler 2009) that condom use is especially resistant to behavior change. The failure in the intervention Campbell documents was especially surprising given both its "harm reduction" orientation and its putative development as an intervention from *within* the targeted community.

<sup>3</sup> Two qualifiers are important in using the term "transactional sex." First, the practice is not unique to Africa. Second, each of the authors who employ the term "transactional sex" explicitly does *not* equate it with commercial sex work. Relationships involve exchanges, some of which are financial. In these books' settings, the levels of existing disadvantage and ongoing gender inequalities compound the implications of the transactions. A quote from Decoteau helps illustrate this conceptual distinction from the literature, "It is important not to misconstrue the practice of 'transactional' relationships. They are usually enduring, they often involve cohabitation and the sharing of child-rearing responsibilities, and women exercise agency in choosing their partners. . . . greater freedom than [in] marriage" (2013:180). Mojola goes even further to contend that financial exchange is perceived by many of the young women in her study as a vital component of romantic relationships, a perspective summarized as "love = sex provision" (2014:87).

<sup>4</sup> This discussion slightly over-assumes the likelihood of individuals' knowing their HIV status. I will address the implications of HIV testing more explicitly in the section on PLWHA.



Researchers have identified a number of other behavioral, biomedical, and socio-demographic factors that influence HIV's risk factors and/or  $R_0$ ; the incidence plateau described above is occasionally interpreted as improvements in one or more of these factors. An important behavioral aspect is *concurrency*, which is having multiple sexual partnerships that overlap in time (Halperin and Epstein 2004). Early modeling efforts demonstrated that small amounts of concurrency in a population could lead to rapid increases in HIV's  $R_0$  (Morris and Kretzchmar 1997). In other words, beyond how many partners one has,  $R_0$  estimation also requires knowing how those partners are temporally sequenced. Part of the reason concurrency is thought to be especially important for HIV transmission is its unique virologic development. HIV is most concentrated in the human body—and therefore most likely to be transmitted—in the first several weeks after infection, then again once it has progressed to AIDS; between these, HIV has a long “latent” period where viral load is low and transmission much less likely (Wilson et al. 2008). As such, concurrency increases the likelihood that additional partners overlap with the early period of high infectivity just after infection—increasing the probability of a newly infected individual passing HIV along to their concurrent susceptible partners (Wawer et al. 2005). Concurrency is also one of the more misunderstood concepts in HIV literature; a number of researchers have modeled concurrent relationships as a risk factor for contracting HIV. This is an inaccurate use of the model, however, as concurrency only predicts elevated population-level risk and increases in  $R_0$ ; it has no direct implications as an HIV risk factor beyond those associated with having large numbers of partners (Goodreau 2011).

Important biomedical interventions address reducing mother to child transmission (MTCT), circumcision, reducing other STIs, and identifying/eliminating iatrogenic transmission sources. Nevirapine provides an example of successful interdisciplinary integration that produced the development and increased accessibility of an effective means to prevent MTCT (adams and Light 2014). Absent treatment, HIV-infected

mothers can transmit the virus to their children in utero, during birth, or through breastfeeding (Newell 2001). Mothers' primary treatment can have the secondary benefit of decreasing transmission probability before and after birth. Nevirapine was developed as a single-dose intervention that halves the likelihood of transmission *at birth* (Guay et al. 1999). Recent experimental evidence shows that male circumcision reduces both the risk of contracting (Auvert et al. 2005) and transmitting HIV (Wawer et al. 2009), though the subsequent scale-up of targeted circumcision interventions has not been without some controversy. Comorbid sexually transmitted infections other than HIV elevate HIV risk factors *and*  $R_0$  (Pepin 2011), leading to the treatment of other STIs as a key component of community-based HIV interventions (Campbell 2003).

A longstanding biomedical concern has been what role, if any, iatrogenic sources (i.e., transmission stemming from medical treatment) have played in HIV transmission. Pepin contends—though he admits that *direct* evidence does not exist—that it is likely that early expansion of the virus was accelerated by the use of contaminated needles. Moreover, before a reliable antibody test was developed and put into widespread use, transfusions were an occasional route of infection (most notably among a cluster of orphans in Romania). A small group of researchers contends that the extreme inefficiency of the sexual transmission of HIV (approximately 1:1000 chance per coital act) points to a continued contribution of iatrogenic sources in sustaining the African pandemic (Gisselquist et al. 2003). However, the overwhelming consensus remains that in SSA, HIV is predominantly spread through heterosexual sex, though sexual transmission among men who have sex with men is receiving increased attention (UNAIDS 2014).

Part of the reason sexual transmission remains a difficult point of intervention is continued high (if decreasing) fertility in SSA, which has a complicated relationship to both population-level HIV prevalence and individual HIV status (Trinitapoli and Yeatman 2011). Within marriage, both men and women often share a strong desire for children, removing two primary HIV prevention recommendations (abstinence and

condom use). As Mojola details through some especially poignant quotes from her focus groups, this has led to an increased focus on marriage as a potential risk factor for HIV. Moreover, the cyclical migration patterns described above can lead men to provide bridges between HIV risk pools in their occupational locations and their home villages. Mojola shows how the changing nature of fishing communities around Lake Victoria sustains these dynamics on a somewhat accelerated time-scale.

Intervention efforts have increasingly focused on the community rather than individual level, with varying success. In *Religion and AIDS in Africa*, Jenny Trinitapoli and Alex Weinreb—recognizing SSA residents' near-ubiquitous religious involvement—explore how religion influences HIV prevalence rates and associated behaviors. They find that religious organizations can substantially alter behavioral HIV risk factors (e.g., abstinence, fidelity, and condom use) and that increased individual religiosity is itself a mostly protective factor. Perhaps more intriguingly, they find that those community and individual-level protective factors combine in unique ways: in communities that are marked by low aggregate religiosity, there is virtually no individual-level association between religiosity and HIV status; but in highly religious communities, women's increased religiosity is associated with *lower* HIV infection probability, while the relationship is inverted for men—that is, higher individual religiosity is associated with *higher* HIV risk.<sup>5</sup> Religion is but one of several potential community factors that play an important role in shaping the HIV risk environment, and it will also factor into the discussions below of treatment and societal impacts. Another particularly promising community-level intervention coincides with what is known as venue-based sampling (Weir et al. 2003). The aim is to recruit clusters of individuals from places that are associated with higher population-level risk, rather than singling out individuals' risk behaviors for designing interventions (Yamanis et al. 2010).

## Living and Dying with AIDS

While it is not the focus of any of these books, AIDS has significantly reshaped African population dynamics. As with the epidemic itself, those changes vary widely. As mentioned above, without treatment post-infection survival is around 9 years (Ghys, Zaba, and Prins 2007). Since most HIV expansion in Africa occurred before broad treatment availability, life expectancy dropped substantially (approximately 16 years across Africa [UNAIDS 2006]). Those in their prime child-bearing years were the hardest hit (Heuveline 2004), leading to a vast number of AIDS orphans, who, on top of losing a parent, suffered other substantial life disruptions, such as forced residential mobility (Ford and Hosegood 2005).

Treatment offered the potential for ameliorating at least some of these effects. In much of the world, as highly active antiretroviral (ARV) therapy (HAART) became available in the mid-1990s, HIV rapidly transitioned from being viewed as a death sentence to being seen as a manageable chronic condition (Harden 2012). In *HIV Exceptionalism* and *Ancestors and Antiretrovirals*, Adia Benton and Claire Laurier Decoteau demonstrate the more complicated story of ARV accessibility in SSA—beginning with the delay of HAART's availability in SSA by approximately a decade after its development (Crane 2013).<sup>6</sup> While ARV scale-up has vastly improved—approximately 37 percent of PLWHA are now on treatment (UNAIDS 2014), the majority of PLWHA remain without access to treatment.

A person's HIV status must be known to start therapy. The scale-up of HIV testing was therefore a key intervention point (Angotti et al. 2009), even before widespread ARV availability. The implication was that by knowing their status, people could take steps to protect their partners from infection. Moreover, to accelerate prevention of MTCCT, testing became practically mandatory for receiving antenatal care in settings of high prevalence (Angotti, Dionne, and Gaydos 2010). While HIV testing is now relatively widely available, roughly half of those

<sup>5</sup> This raises the question of causal direction.

<sup>6</sup> For a stand-alone review of Decoteau's *Ancestors and Antiretrovirals*, see p. 654 [ed.].

infected still do not know their status (UNAIDS 2014).

Benton's participant observation among AIDS NGOs in Sierra Leone documents an encouragement to "live positively," an encouragement that leads to testing not only to provide access to treatment and support mechanisms and to protect one's partner(s) from infection, but also to encourage (public) status disclosure as an aid to the continued reduction of AIDS-related stigma.<sup>7</sup> However, her encounters within NGOs providing material and social support to PLWHA demonstrate that not all their members—not even necessarily those in leadership—embrace this perspective. Testing has also led to an increasingly common push to make treatment available sooner (i.e., not waiting until CD4 levels are below 200), as a means of reducing viral load in infected individual's bodies (Crane 2013). This has the dual effect of elongating the symptom-free period for PLWHA and allowing "treatment as prevention" by reducing the probability of secondary infection(s).

Building from the concept of "biomedical citizenship,"<sup>8</sup> Decoteau shows that simply making HAART available is not sufficient to guarantee its benefits for all who need it.<sup>9</sup> While early claims posited African populations' limited capacity to properly adhere to treatment regimens,<sup>10</sup> this perspective has been resoundingly rejected, with

adherence rates in audit studies in SSA having occasionally outpaced those in the United States and elsewhere. Additionally, with the introduction of generic drugs, treatment regimens have been simplified into a single pill combining the multiple drug cocktails initially necessary. Decoteau argues that biomedical citizenship is marked by the individualization of responsibility that has come with neoliberal policies in post-apartheid South Africa. Correspondingly, failures in treatment are often blamed on the individual's shortcomings. This view ignores the fact that putatively "freely available" treatment still incurs costs in time and money for regularly attending clinics where the drugs are provided. Treatment therefore often reinforces, and exacerbates, SES-based infection disparities. Moreover, stock-outs of drugs are not infrequent at the under-resourced facilities many rely on. Decoteau's critique of saddling primary responsibility for ARV adherence on PLWHA leaves the distinct impression that treatment approaches—at least in South Africa—are not sustainable and, even if able to achieve wider coverage, still would not produce the optimal effects that they might with more comprehensive interventions.

Berkeley biologist Peter Duesberg's HIV denialism is notorious; he believes that HIV does not cause AIDS, but that AIDS results from a simplex of other conditions which deplete the immune system. Former South African President Thabo Mbeki was heavily influenced by these ideas, leading to strong criticisms of South Africa's weak response to AIDS during his presidency. This much is well known. But Decoteau also describes how Mbeki's denialism has deep roots in other, often ignored, factors. In particular, the recent legacy of apartheid generated mistrust of postcolonial interventions from external governments and western NGOs that led Mbeki to view HIV-related "biomedicine as a racialized science masquerading as objective epistemology" (Decoteau 2013:91). In other words, avoiding western biomedical HIV interventions was one element (among many others that were more politically and ethically palatable) of his political strategy to fully establish South African autonomy (sometimes referred to as traditionalism). While critics have often

<sup>7</sup> How HIV status disclosure shapes stigma is believed to have been changing rapidly since the increasing availability of ARVs.

<sup>8</sup> Crane and Benton both explore a similar concept, labeling it "therapeutic citizenship."

<sup>9</sup> Other concerns about ARV treatment in SSA concerned the efficacy of treatment regimens developed largely based on subtype B, given the viral heterogeneity pervasive in Africa. Crane (2013) suggests this has not influenced their efficacy to date, but warns that as treatment advances become increasingly targeted to molecular aspects of HIV, generalized efficacy of treatment may wane.

<sup>10</sup> Most notorious among these was the claim by Andrew Natsios—who at the time was head of USAID—that people in SSA "don't know what Western time is" and therefore couldn't be expected to follow the complex administration of HAART. This story has been so widely circulated—and repudiated—that it appeared in four of the books reviewed here.



claimed this prioritized indigenous treatment approaches to HIV *in lieu* of biomedical ones, Decoteau's evidence from PLWHA in the two settlements she studied reveals a common "hybridity" wherein individuals draw on both biomedicine *and* indigenous treatments to improve their health—for HIV and other conditions.

Biomedical and individual orientation to AIDS treatment is common in the literature, but many of these studies ignore a substantial element of AIDS's consequences and care. The communities within which PLWHA live—disproportionately their kin—also regularly contribute to AIDS treatment. Several common examples: household members nurse PLWHA through opportunistic infections, community acquaintances assist with transport for obtaining medications, extended family members often bear the primary responsibility for caring for AIDS orphans.<sup>11</sup> Jenny Trinitapoli and Alexander Weinreb (2012) also document the common practice of religious leaders simply visiting, spending time with, and offering assistance to members who are ill. In addition to the relevance of this form of care for the treatment of PLWHA, it also speaks to the ongoing discussion of AIDS-related stigma. In regions of high prevalence, estimates suggest that one (or more) in three households have been directly impacted by HIV, and many more engage in these forms of care. This has led some researchers to begin questioning how stigmatized HIV can genuinely be, if people are so regularly engaged with PLWHA—often by choice.<sup>12</sup>

### Societal Impacts of AIDS

In addition to AIDS's individual and population-level impacts, research increasingly documents how HIV has altered organizations and the political economy of the regions

hardest hit by the epidemic. While religion's influence on AIDS has increasingly captured scholars' interest, especially in Africa, it also provides an example of how AIDS is altering organizations in the regions that are heaviest hit. For example—far from ignoring AIDS—Trinitapoli and Weinreb (2012) find that religious messages have increased their focus on sexual morality. Other common patterns (e.g., individuals switching their religious affiliation) have also changed trajectories over this same time period, though how directly AIDS is shaping those changes is less empirically clear.

The NGO-ification of AIDS-belt countries has been an increasingly documented—and critiqued—phenomenon (Watkins and Swidler 2012). In Benton's *HIV Exceptionalism and Scrambling for Africa* by Johanna Tayloe Crane, the authors provide accounts—and detail the corresponding limitations—of how external donors and researchers have become increasingly central to AIDS responses in Africa. Benton describes how HIV has simultaneously become "the largest vertical public health program in history" (Benton 2015:x) and exceptionally horizontally integrated. Verticality in NGO organization indicates the top-down orientation of program prioritization, which in part stems from the external sources of funding; estimates suggest that as much as 40 percent of Africa's health funding is earmarked for AIDS, largely because of its reliance on external donors (for example, The Global Fund sponsors approximately 20 percent of all HIV funding worldwide [Benton 2015:45–46, 27]). Benton also argues that this verticality can occasionally lead NGOs to see donors as the primary audience for their intervention efforts, rather than the populations for whom those interventions are developed.

The horizontal "creep" of AIDS interventions derives from well-intentioned holistic approaches to improve AIDS-related outcomes, addressing not just biomedical, but financial, social, and emotional aspects as well. This expansion has had the subsequent impact of making policies beyond medical care (for example, housing and food supplement programs) increasingly subject to the ebbs and flows of HIV donors' resources and aims. Both Crane and Benton's data include a prominent example: at times health clinics' HIV-positive patients have access to common

<sup>11</sup> Iliffe succinctly summarizes how important caring for AIDS orphans is often perceived to be: "for the family the shame of not caring is worse than the shame of AIDS" (2006:103).

<sup>12</sup> By no means should this be read as indicating that AIDS-related stigma has been completely eradicated. I simply raise the issue to point out a recent uptick in scholarship questioning just how pervasive stigmatizing views and behaviors are in practice.

drugs (like pain killers) that are occasionally simultaneously unavailable to other patients in the same clinic who do not have AIDS. A particularly harsh critique of this horizontal expansion is the claim by some that HIV NGOs have become increasingly interested in sustaining their organizations' funding and infrastructure, independent of the contributions they make. Benton shows that Sierra Leone, despite its relatively low population HIV prevalence of 1.5 percent, is subject to this exceptionalism and expansion, just like regions with much higher AIDS burdens.

Ample funding for AIDS research has had similar far-reaching effects, leading high-prevalence settings to be increasingly heavily researched (Biruk 2012). Crane's book is embedded in a long-standing research project in Uganda that combines clinical treatment for research participants; she shows how this approach raises two potentially substantial limitations. First, research like this increasingly leads to the postcolonial reality that "laboratories take on new meaning as sites of extraction and exchange" (Crane 2013:106). That is, while research can contribute benefits for patient care, capacity building, and development, each of these elements comes with unique trade-offs that are complicated to negotiate—a tension that, Crane argues, "both generates and relies upon inequalities, even as it seeks to end them" (2013:7). For example, is the research project primarily there to gather data or to treat patients (see the stock-out example mentioned above)? And are the HIV-positive Ugandans involved in the project primarily conceptualized as research subjects, HIV patients, or individual members of a society heavily impacted by HIV (i.e., is their identity as HIV positive prioritized only by the project)? Second, many of the practices employed (clinical or research, technical, and infrastructural), were developed in the United States and other non-African locales.<sup>13</sup> As examples, ARV treatment and

attempts to develop an HIV vaccine are built on knowledge of HIV subtype B, which only accounts for a small fraction of global HIV cases and only negligibly factors into the distribution of African HIV.<sup>14</sup> Moreover, Crane argues that once these humanitarian, postcolonial relationships are established, even if the specific elements are revised over time (e.g., a new focus on ARV development based on other subtypes) it is difficult for those who start out on the receiving end to subsequently attain fully collaborative partnerships.

### Moving Forward

What has the reciprocal relationship between sociology and AIDS taught us, and where should these lessons lead us next? It is perhaps obvious, but worth reiterating, both that this review is not comprehensive and that much of what we have learned varies (sometimes considerably) across contexts. Given that caveat, I highlight a few aspects that are particularly common in the literature and/or were important contributions of the books examined here.

Like most health conditions, HIV exhibits a variety of socio-demographic disparities—differentiating both the risk factors for potentially contracting HIV and how many secondary infections each case produces. Women's elevated prevalence and incidence compared to men is among the most documented—and growing—of these disparities. This contradicts the frequent refrain of focusing intervention efforts on a small number of women—especially commercial sex workers—thought to be catalysts of the epidemic. As generalized epidemics in SSA (and elsewhere) continue to become increasingly female-skewed, it will become even more important to develop broad-scale interventions that engage full populations and not just those presumed to

<sup>13</sup> One example is recommendations for when to commence treatment that are based on CD4 counts. In settings where the capacity for measuring CD4 levels is rare, this points to a mismatch between existing recommendations and their potential implementation (Benton 2015:125).

<sup>14</sup> Not only does this work focus largely on subtype B, but since the samples it relies on are built upon the earliest attempts to isolate the virus, the variants of subtype B that are actually in circulation in the population today are decreasingly reflective of the strain being used in these efforts.

be “high risk” (Moody, Morris, and Adams 2014).

Epidemic dynamics across the world, or within any particular context, do not take place in a vacuum; whether a region’s epidemic expands or stagnates can be dependent on sexual behavior and partnering patterns in neighboring locales. NGOs and other foreign funding agencies have shown equally strong influences over the nature of AIDS responses in Africa.<sup>15</sup> This provides another example of how postcolonial ties between Africa and western countries foster dependent relationships that externally shape governmental, financial, and health outcomes across SSA. Moreover, consistent with neo-institutional organizational theories, these externally developed strategies frequently encounter difficulties of improper fit when attempting to integrate into African contexts.

Sociological and demographic research has produced numerous models accounting for social influences on health. AIDS provides a compelling case for expanding this view to not only consider health as an outcome, but also as a “right-hand side” variable shifting social norms. The examples in Trinitapoli and Weinreb of AIDS’s impact on religion and Benton’s description of horizontal NGO expansion from HIV services provide exemplary models for future work to consider such effects.

In addition to the important ways sociology and AIDS have each shaped our understanding of the other, these books also point to a number of unanswered questions for each. Scientific research funders, especially for health, have increasingly prioritized interdisciplinary approaches to solving our most pressing problems. HIV/AIDS provides a theoretically rich case for leveraging those benefits, as scholars from across the social, physical, and biological sciences, along with practitioners of many stripes, have perspectives that uniquely inform AIDS understanding and response. However, these efforts have thus far demonstrated

mixed results; for example, integration underpins some important developments in PMTCT, while sustained disciplinary segmentation between clinical and basic researchers hampers our reactions to newly developing drug resistance (Adams and Light 2014). This provides an important critique for literature on interdisciplinarity, encouraging a more carefully theorized perspective on how and when we can expect to best reap its benefits.

While some improvements have been observed (like transmission plateaus), SSA is far from out of the woods with respect to AIDS’s societal impacts. This combined with the postcolonial structure of many of the responses documented above raises the question of how “weak” states can (continue to) improve their responses to HIV/AIDS. Even as new cases decline, increasing treatment availability may lead prevalence figures that have plateaued to begin growing again as PLWHA survive longer (Bongaarts et al. 2008). How can the states where this occurs learn from previous responses to build the infrastructure necessary to care for these populations? Their responses must address AIDS-specific aspects such as access to care, but also should ensure—as PLWHA increasingly transition to experiencing AIDS as a manageable chronic condition—that they have the opportunity to remain (or become for the first time) fully participating citizens. Given the patterns described above, the role of external governments and NGOs will likely need to be reconceptualized to optimize these possibilities.

A final practical consideration is how much of what we have learned about HIV transmission and AIDS responses in SSA will be usefully portable to other contexts. Because of disproportionate AIDS prevalence in SSA, it has also been more thoroughly documented than most epidemics elsewhere. There are other regions (e.g., portions of Eastern Europe and Central Asia) and segments of other populations (e.g., African American women) where epidemic growth has not plateaued, or is even increasing (UNAIDS 2014). It remains to be seen whether these settings can leverage the proximate causes of gender disparities to reduce the rate of epidemic spread, or if the NGO-ification of AIDS responses will be echoed

<sup>15</sup> This should not be interpreted as minimizing the importance of the many bottom-up HIV intervention strategies (Watkins 2004), but merely indicates the comparative organization and deeper resources of external efforts.

elsewhere—or if it can be improved upon. At minimum, the lessons from SSA seem worth bearing in mind as we continue to develop and scale up responses elsewhere and continue to seek improvements in Africa.

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