

## **2. Representations of HIV/AIDS – An Historical Perspective**

In Paula Treichler's (1987: 32) oft-quoted but still pertinent observation, "the AIDS epidemic – with its genuine potential for global devastation – is simultaneously an epidemic of a transmissible lethal disease and an epidemic of meanings or signification." Indeed, Treichler's study of how AIDS was conceived in the early days of the epidemic in the United States revealed no less than thirty eight different framings of the virus, its causes and effects. The anxiety that produced this unstable epidemic of signification stems from what Sander Gilman (1988:1) identifies as "the fear of collapse, the sense of dissolution, which contaminates the Western image of all diseases." In Gilman's understanding, this fear of our personal or social collapse does not remain internal to us or our societies: "rather, we project this fear onto the world in order to localize it and, indeed, to domesticate it. Then it is not we who totter on the brink of collapse, but rather the Other. And it is an-Other who has already shown his or her vulnerability by having collapsed."

Gilman's influential work on the history and meaning of medical representations has demonstrated how for Western societies models of disease are part of our general security discourses. Driven by a sense of the self's fragility – whether that self by an individual body or a national collective – it is our sense of mortality that requires disease be bounded, contained and distanced. Moreover, argues Gilman (1987: 107), "it is in the world or representations that we manage our fear of disease, isolating it as surely as if we had placed it in quarantine. But within such isolation, these icons remain visible to all of us, proof that we are still whole, healthy, and sane; that we are not different, diseased, or mad." In this context, disease and its representation has historically always been a security issue, in which the fear of generalized collapse is regarded as a threat to the security of the identity of the self.

The intrinsic status of representations of disease as part and parcel of security discourses has been even more pronounced given the rise in the 1990s of the "emerging

diseases worldview" discussed in section 1. As Mayer (2002: 290) has argued with respect to viruses, their highly flexible nature means, "the virus embodies the key qualities of the global age, yet under markedly negative insignia. It discloses the flip side of global contact scenarios, giving vent to the fearful insight that the bright new world of compatibility, cosmopolitanism, and communication is only to be realized at the cost of systemic instability and vulnerability." In the words of Fernandes (2008: 66-67) conditions like HIV/AIDS and Ebola "offer a symptomatology of our present disquiet about globalization and the end of the supremacy of nation-states." Viral discourses thus have notions of insecurity in the form of systemic instability and vulnerability at their heart, and the onset of a new virus requires work in the world of representations to bound, contain and distance the danger from the fragile and mortal self.

When the US Centers for Disease Control (CDC) released a morbidity and mortality report in June 1981 that listed twenty-six cases of a previously unknown condition, the sexual orientation of its sufferers was marked as a key causal factor. As a result, over a year before the term AIDS was coined, the condition came to be known as 'Gay-related immunodeficiency' (GRID) and was understood as part of the larger family of sexually transmitted diseases (STDs) allegedly brought on by the life-style and practices of men who have sex with men. That AIDS was cast from the outset as a 'gay disease' in both popular, media and scientific accounts meant that its victims were viewed through the prism of the person afflicted with STDs generally, which is "one of the most potent in the repertory of images of the stigmatized patient" (Gilman, 1987: 89; see also Treichler, 1987, 42-51). This stigmatization was compounded when the CDC expanded its list of risk groups for AIDS to what came to be called the "4-H's" – homosexuals, heroin addicts, haemophiliacs and Haitians. This cemented the idea that the disease affected specific marginal groups because of who they were. Although a viral aetiology of AIDS had generally been accepted by May 1984, meaning the scientific analysis of the disease revolved around the nature of the viral agent, most public discussion remained focused on the perceived abnormal behaviours of marginal groups involved in the disease's propagation (Treichler, 1987: 44, 52).

Following Prins (2004: 933-35) we can identify three principal means through which AIDS was apprehended during the 1980s and 1990s. In the first instance, was *the medicalized* engagement in the US directed at drug users and men who have sex with men. Secondly was the *somatic* engagement, whereby the fear of widespread heterosexual transmission meant the virus was sexualized and linked to moral judgment. Finally came *the internalized* engagement in which the public scale and scope of the epidemic was denied in favour of a concern with individuals being directed to behave normally and responsibly. What the medicalized, somatic and internalized engagements fuelled was the transference of blame to victims via stereotypes (Prins, 2004: 935). What they obscured, amongst other things, was the importance of a political economy of public health in the life of HIV/AIDS. If, as Prins (2004: 938) argues, political economy is "the place where suffering and its alleviation collide with power," then attention to the political economy of public health would refrain from making "the prostitute" the poster girl of HIV/AIDS in Africa and India. In most media coverage of HIV/AIDS where sex as a medium of exchange is being discussed, the figure of the prostitute collapses a variety of conditions onto the stigmatized body of a person, such that they are always regarded as *infectors* rather than the *infected*, and the concern for their role as vectors of disease eclipses questions about their personal health (Sacks, 1996; Raimondo, 2003). Instead of ascribing a fixed identity to an individual a political economy framing would call attention to the "structural dysfunctions in the microeconomics of poor societies" that often push young women into sex work (Prins, 2004: 939). Instead, therefore, of seeing multiple partners as an expression of a supposedly innate, primitive, and insatiable sexuality, this could be understood as part of the domestic political economy with public health consequences.

That these representations are not fixed is demonstrated by the transformation in the US of attitudes towards people who are HIV+ or suffering from AIDS. By the late 1990s HIV/AIDS had lost its stigma to such an extent that people who are not infected can identify with the disease, through the wearing of the red ribbon, for example. Although the sexual

behaviours attached to AIDS are still stigmatized, a combination of activism which turned HIV/AIDS into a cause at the heart of gay liberation, celebrity calls for a normalization of social attitudes, and recognizable “faces of AIDS” in the media and popular culture have meant that, in North America at least, identification with the domestic victims has trumped the blaming of stereotypes (Gilman, 2007).

The role of stereotypes in the representation of disease is to ensure the security of the self by locating danger outside us. As Gilman (1987: 100) observes, “the desire to locate the disease is the desire to be assured that we are not at fault, that we have been invaded from without, polluted by some external agent.” Given this, the de-stigmatization of HIV/AIDS in North America is likely to have been made possible, at least in part, by the fact that there was a ready location for this desire to externalize danger. AIDS had been labelled an “African” or “Haitian” disease from the earliest days of the epidemic, although this characterization had been subsumed by the original focus on drug users and men who have sex with men. Once attention turned away from the latter groups, the former came under greater scrutiny – which was a cruel irony for the Haitians, given that it is likely they contracted HIV from seropositive North American tourists (Gilman, 1987: 102). This focus on Africa is now central to the international policy environment of HIV/AIDS. Africans – an homogenizing term for a continent of 900 million people in 57 countries and thousands of cultural groups – are routinely understood as a single population with problems. Constructed as “an abstract target group for global help” by the various practices that have internationalized, institutionalized and medicalized HIV/AIDS, they are deemed to be the source of the pandemic and therefore made subject to the agents of change in the developed world (Seckinelgin, 2008).

None of these considerations alter the fact that HIV/AIDS spread rapidly in sub-Saharan Africa and remains perhaps the region’s biggest social problem. However, the search for an explanation for the high rates of HIV prevalence, morbidity and mortality underplayed a range of standard epidemiological cofactors in disease transmission (such as malnutrition,

migration, gender relations, poverty and the lack of public health care) and emphasized individual sexual behaviours marked as “promiscuity” (Stillwaggon, 2003: 811; Stillwaggon, 2006). The prioritization of the behavioural paradigm thereby transferred the early concerns with the medical and somatic representations of HIV/AIDS in North America and Europe to Africa despite a lack of direct evidence to support its basic contention. In her aetiology of the argument about behavioural factors, Stillwaggon (2003: 812) notes “most assertions about African sexuality cite the same sources, which are based on ethnographic reports of varying reliability, many of which date from the early twentieth century.” Of particular importance here is the work of John and Pat Caldwell of the Australian National University, who, in a term that echoed 19<sup>th</sup> century racial science, deemed Africans to be *Homo Ancestralis*, a single group separate from *Homo Sapiens*, and identified by an exceptional and exotic sexuality. Although many noted investigators have looked to “local cultural practices” as an explanation for high HIV prevalence in the region, as Paul Farmer (2001) concludes, “most such claims are splendidly unsupported by serious research” (see also Nguyen and Stovel, 2004: 10).

Given the multiple citations to their research in both academic articles and policy documents, the Caldwells produced a particularly powerful instance of what Barnett and Prins (2005: 18) have called “factoids.” These are, they write, “the intellectual viruses of quick and dirty synthetic studies. They are soft opinions that have hardened into fact. The term describes pieces of data that look credible at first glance, but which are insecurely grounded in evidence. They achieve this status as a result of a form of pyramid selling by recycling through publications, grey literature and reports of meetings.” Given that the Caldwells’ sources on African sexuality were “often old, biased and unreliable” (de Waal, 2006: 21), and their perspective lacked cultural nuance, historical specificity and an appreciation of dynamic traditions (Reid and Walker, 2005), the persistence of their claims made them factoids par excellence.

The problematic nature of the Caldwell's factoids is highlighted by the fact that there were, even at the time their research was being regularly called forth, a number of scientific assessments that directly challenged the tenets of the behavioural paradigm. For example, a 1992 World Health Organization (WHO) survey concluded that "it becomes more and more clear that morbidity and mortality due to these infectious diseases are as much a function of the state of human development than they are the virulence of the micro-organisms which are their biological cause" (Quoted in Schell, 1997: 132). A 1995 WHO survey contradicted the view that the HIV/AIDS pandemic was fuelled by extreme promiscuity and a 1999 UNAIDS survey of four African cities questioned the correlation between various measures of partner exchange and HIV prevalence (Stillwaggon, 2003: 811).

At the same time, the evident problems with the thesis of an innate, exotic sexuality and natural promiscuity should not prevent a consideration of how particular sexual practices, made possible by the political economy of which they are a part, contribute to the pandemic. The epidemiological study of Halperin and Epstein (2004), for example, suggests that concurrent sexual partnerships could be significant in explaining the extensive heterosexual transmission of HIV in southern Africa. The authors are careful to note that various demographic surveys and studies show that on average African men do *not* have more sexual partners than men elsewhere, and that African men and women have similar, if not *fewer*, numbers of lifetime sexual partners than heterosexuals in western countries. What is different, then, is that some African men and women have two or three concurrent partnerships that can overlap for some months or even years. Significantly, Halperin and Epstein note that while most of the women in these concurrent partnerships are *not* prostitutes (leaving aside the essentialization of identity in that term) these relationships have a transactional dimension related to gender inequality and poverty.

However, one counterintuitive feature of the pandemic in southern Africa is that HIV prevalence is highest in the relatively wealthy countries of the region, and within those countries it is highest amongst the wealthiest citizens (Swidler and Watkins, 2007: 147). In

this context, while highlighting the importance of “transactional sex” – the exchange of sex for material support – Swidler and Watkins argue that their fieldwork in Malawi demonstrates that concurrent relationships are common, not because of a desire for sex or money per se, but because of a social commitment to patron-client relations:

We believe that the pervasiveness of multiple sexual partnerships is better understood as driven neither by men’s nature nor by women’s poverty. Rather, these partnerships are but one form of a complex system of social insurance that mitigates uncertain risk by binding patrons and clients – at every social stratum and in many of life’s activities – in a web of ties held together by an ethic of redistribution and reciprocity. Even if a man’s libido were low or a woman were not poor, forging ties of dependence through transactional sex might make sense, just in case (Swidler and Watkins, 2007: 157)

Similarly, a particular relationship to ameliorating risk, rather than an innate or exotic promiscuity, is understood as enabling high rates of infection in Catherine Campbell’s ethnography of a South African gold mining community. Campbell’s study revealed how underground miners who faced danger through their labour, while living in all-male hostels far from their families (arrangements that were part of apartheid’s forced labour migration), constructed their identities by practicing a macho sexuality which functioned as a diversion from the foreseeable threat of injury even if it meant they knowingly increased the likelihood of future HIV infection (C. Campbell, 2003: ch.1).

What these more nuanced accounts of sexual networks suggest is that the problem with the behavioural paradigm is that it has come to be largely understood as synonymous with assumptions of an innate and exotic sexuality, downplaying in turn the way sexual practices are historically specific and part of a wider economic and social context (see Hunter, 2005). As such the term ‘promiscuity’ – evident even in some of these accounts (see Epstein, 2004), and which connotes the casual, frequent and morally questionable changing of sexual

partners – is singularly ill equipped to encapsulate what is at stake in this issue. That these crude notions of African sexuality persist, and are propagated in the absence of scientific support, speaks to the continuing power of colonial stereotypes of Africa in the European imagination. Although few proponents of the behavioural paradigm argued openly in terms of race, suppositions of racial difference were made in terms of cultural characteristics allegedly common to hundreds of millions of people in numerous and disparate cultural groups. These permeated the social science literature on HIV/AIDS in Africa throughout the first fifteen years of the pandemic, echoing the long established representation of Africa as a distinct and exceptional place populated by people with an exceptional sexuality (Stillwaggon, 2003: 811-812). The end result was another instance of what Mayer (2002: 1) has called “Africanity,” the artificial concoctions of Africa which “attest to the fact that at least in one respect the gigantic project of colonialism did work: forcing most diverse regions, traditions, and cultures in Africa into one symbolic system, colonial rule brought about an imperialist framework of representation that is still effective today.”<sup>1</sup>

There are, of course, a number of African voices that have contested the reinvigoration of these colonial discourses, most notably that of South African President Thabo Mbeki. Although the Mbeki government’s stewardship of the HIV/AIDS crisis in South Africa deserves serious criticism (Prins, 2004: 935; de Waal, 2006: 34-45), the opprobrium his perspective has attracted also suggests the difficulties faced when challenging established representations. These issues were evident around the 13<sup>th</sup> International AIDS conference held in Durban in July 2000. In advance of the conference some 5000 scientists (including 400 African researchers) issued “The Durban Declaration” in an effort to secure the claim that “HIV causes AIDS” (*Nature*, 2000). Their document revealed that the controversy centred on how causal responsibility for the pandemic could be ascribed. The scientists argued that despite the role played by factors such as malnutrition in determining the risk of the disease, “HIV is the sole cause of the epidemic.” In contrast, Mbeki – while associated with some scientists who claimed erroneously that HIV was not the etiological agent of AIDS – did not dispute in his opening conference speech that HIV was the viral source of AIDS. However, he

put greater emphasis on the non-viral co-factors when it came to explaining the scale and scope of the pandemic. As he declared, “this is the story: the world’s biggest killer and the greatest cause of ill-health and suffering across the globe is listed almost at the end of the International Classification of Diseases. It is given the code Z59.5 –extreme poverty” (Mbeki, 2000). This was an effort to move the discourse of HIV/AIDS from “the mono-causal clinical to a complex conjunction of the scientific, clinical, political and economic” (Fernandes, 2008: 91). As such, there was no need, as Paul Farmer (2001) concluded, to “excommunicate [Mbeki] for pointing out the obvious – that inequality is the major co-factor in this epidemic, as in most epidemics. And that inequality’s origins are neither fated nor mysterious” (see also Whiteside, 2002 on the relationship between the pandemic and poverty).

Furthermore, the clash between Mbeki and the Durban Declaration highlighted how the researchers associated with the public statement were not averse to crossing from the scientific to the populist in their own arguments (Fernandes, 2008: 94). The Declaration, while stating that the disease recognized no geographic boundaries, nonetheless posited a specifically African geographic origin for HIV/AIDS. Having done so, it then revived colonial stereotypes by suggesting promiscuity needed to be the major focus of the public health priority of prevention. This was achieved by the priorities accorded various preventative policies. Before either blood screening or retroviral drugs were mentioned, the Declaration highlighted the fact that “the sexual spread of HIV can be stopped by mutual monogamy, abstinence or by using condoms.”

While this may be true, this primary emphasis on preventative strategies flows directly from the behavioural paradigm, narrowly construed and statically constructed. This emphasis on voluntary behaviour change has been the leitmotif of the global public health response to HIV/AIDS. Although various states have implemented divergent strategies, the centrality accorded voluntary behaviour change is a shift from earlier public health strategies that privileged coercion, compulsion and collective action by state authorities (Baldwin, 2005). Interestingly, sub-Saharan African countries “have without exception stuck faithfully to

the liberal script" of individual responsibility, placing their faith in "the discipline of good epidemiological citizenship" – an approach that explains the Bush Administration's activist response to HIV/AIDS in Africa (de Waal, 2006: 48, 64) – that fits with broader neo-liberal development scripts (see Manzo, 2003).

(a) Questions for photographic practice

Despite HIV/AIDS being an 'epidemic of signification', this review has demonstrated that a few of the many possible modes of representation came to be sedimented as dominant modes of understanding in the 1980s and 1990s. Given this historical context, there are a series of questions for photographic practice:

- (i) How has the desire to contain, bound and distance disease been photographically represented? Have photographs of HIV/AIDS done more than replicate colonial stereotypes, particularly in relation to Africa?
- (ii) How have photographs of HIV/AIDS embodied the emphasis on the medicalized, somatic and internal frameworks for the disease?
- (iii) To what extent do photographs of HIV/AIDS replicate the idea of the essentialized vector (such as the prostitute) or the stigmatized patient?
- (iv) Have photographs of HIV/AIDS supported the central assumptions of the behavioural paradigm of disease causation over and above the role of co-factors associated with development issues?

- (v) How can photographs represent in context the dynamic, culturally nuanced, and historically specific sexual networks that contribute to the HIV/AIDS pandemic?

#### NOTES

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<sup>1</sup> On the colonial history of representing Africa, see Brantlinger (1985), Jarsoz (1992), Campbell and Power (2008). On the figure of the virus as important to the colonial tropes of "Africanity," see Schell (1997), and Mayer (2002: ch.7).