

Beyond Biomedicine:  
Sub-Saharan Africa And The Struggle For HIV/AIDS Discourse

by

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## ABSTRACT

This study aims to unearth monological and monocultural discourses buried under the power of the dominant biomedical model governing the HIV/AIDS debate. The study responds to an apparent consensus, rooted in Western biomedicine and its “standardizations of knowledge,” in the production of the current HIV/AIDS discourse, especially in Sub-Saharan Africa. As a result, biomedicine has become the dominant actor (in) writing and rewriting discourse for the masses while marginalizing other forms of medical knowledge. Specifically, in its development, the Western biomedical model has arguably isolated the disease from its human host and the social experiences that facilitate the disease’s transmission, placing it in the realm of laboratories and scientific experts and giving full ownership to Western medical discourse. Coupled with Western assumptions about African culture that reproduce a one-sided discourse informing the social construction of HIV/AIDS in Africa, this Western monopoly thus constrained the extent and efficacy of international prevention efforts.

In this context, the goal for this study is not to demonize the West and biomedicine in general. Rather, this study seeks an alternative and less monolithic understanding currently absent in scientific discourses of HIV/AIDS that frequently elevates Western biomedicine over indigenous medicine; the Western expert over the local. The study takes into account the local voices of Sub-Saharan Africa and how the system has affected them, this study utilizes a Foucauldian approach to analyze discourse as a way to explore how certain ways of knowledge are formed in relation to power. This study also examines how certain knowledge is maintained and reinforced within specific discourses.

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## Chapter 1

### BACKGROUND

#### **Rationale**

The morbidity and mortality caused by the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS) pandemic surpasses any other disease since the 1980s, ushering in an age of global crisis that has prompted worldwide attention (Greene & Katabira, 2011; UNAIDS, 2014; WHO, 2014). Drawing parallels from the Black Plague that overcame Europe in mid-14th century, researchers De Wall and Whiteside (2007) argue “[t]he HIV/AIDS epidemic is the biggest natural event in the history of our species for the last 500 years” (p. 1).

Beyond the pathology and the physiological intractability of the disease, the epidemic also carries and sustains a discursive magnitude and narratives that link certain disease risk factors with particular groups or cultures. Erni (2004) describes the disease as, “two parallel pandemics: a pandemic of the infection of the body on a worldwide scale, and a pandemic of the infection of cultural meanings of the human body” (p. 74). The study briefly examines both aspects of the pandemic mentioned by Erni, and how the two are derived not just from the observation of the virus under the lens of the microscope; but also from the sociocultural perception of the examiner and how that insight influences the current HIV/AIDS discourse in Sub-Saharan Africa.

## **HIV/AIDS Knowledge**

In the 30 years since the advent of the disease, the principle source of knowledge about HIV/AIDS in the world and particularly Sub-Saharan Africa is Western biomedical research (Clumek et al., 1984; CDC, 1981; Greene, 2007). Western experts from numerous disciplines, spanning mathematical epidemiology to biomedical, social, and behavioral sciences, have offered a variety of insights and means to combat the spread of HIV/AIDS (Kessel & Rosenfield, 2008). In the process, they have produced discourses about diseases in general and specifically HIV/AIDS in Africa. Simultaneously, images of Africa and Africans have been reproduced. This same knowledge system has informed policy and shaped the practice and design of health programs aimed at combating the spread of the disease globally (Gausset, 2001; Packard & Epstein, 1991, 1992; Ramin, 2007).

However, absent from the current literature is the indigenous knowledge of non-Western communities in Africa and elsewhere in the developing world (Green, 1999; Vaughan, 1991) that endures ninety-five percent of the global HIV/AIDS infection (UNAIDS, 2013). Critics explained this disparity as a product of Western hegemonic discourse construction of disease. In addition, critics also infer the phenomenon as a result of reinforced global North-South divide based on neoliberal ideologies of economics, politics, race, and power (Chomsky, 1999; Farmer, 2005; Goldin, 1994; Green, 1999; Harvey, 2006; Thérien, 1999). Regardless of one's rationale, the dismissal of indigenous knowledge and cultural values leads to gradual erosion of local expertise and treatment practices passed down from generation to generation.

Even in the displacement of indigenous medical knowledge, biomedicine is suffering from a major deficiency with respect to healthcare workers and access to healthcare facilities in the developing world and Sub-Saharan Africa in particular. For example, according to the World Health Organization (WHO) health report (2006) the continent is facing unprecedented healthcare shortages, “It has 11% of the world's population and carries 24% of the global disease burden. Yet the region has only 3% of the global health workforce and accounts for less than 1% of health expenditures worldwide” (p. xix). This situation can only be described as proverbial desertification of forests, “by planting one tree only to uproot thousands native species.”

Medical anthropologists such as Edward Green and others, who extensively examined this issue from the indigenous understanding of contagious diseases in Africa and elsewhere in the developing world, argue that intentional efforts by the Western powers and their medical system played a role in subverting other ways of knowing [or other knowledge systems] in order to preserve their own superiority. “The characterization of African and other health systems as supernatural becomes a rationale for making no effort to understand, let alone accommodate, existing ethnomedical beliefs and practice” (Green, 1999, p. 218). According to Green, the marginalization and exclusion is made possible through discursive characterization and representation, which portrays local knowledge as ‘folklore,’ ‘supernatural,’ and unworthy of occupying the same space as the science based biomedicine. This misrepresentation has ensured that local knowledge and indigenous voices have no place in the prevailing HIV/AIDS discourse. Devaluing indigenous knowledge is just one of the many forms through



which Western biomedicine tried to impose its preeminence and hegemony over African people and other marginalized groups, the process to achieve this end is often cloaked under the white-coat of science, development, and modernity. In doing so, this has left the production, translation, and institutionalization of knowledge to sole domain of one dominant power player. Thus allowing biomedicine to become the only legitimate paradigm in which the human body and life itself can be inquired.

As a way to critically examine the various factors contributing to the complexity of this discourse-laden epidemic and in effort to understand the struggles of power from those who subjugate and those who are subjugated, the study invokes the symbolic struggle for meanings in the ‘representation’ and ‘characterization’ in the realm of the global HIV/AIDS prevention efforts. This builds on an excellent body of work and analysis of a handful of scholars (e.g. Foucault, Richard Chirimuuta and Rosalind Harrison-Chirimuuta, Erni, Treichler, Stillwagon, Green, Sidel, and Vidal) arguing against the dominant undeviating biomedical account. Nonetheless, it is important to note, in order to resist or argue against the dominance of particular unfavorable or oppressive system it is essential to understand by what mechanism its dominance is expressed.

According to Michel Foucault (1982) analysis of power relations, power is an active process that is marked by interplay of those affected by it. Therefore the processes of establishing power relations ranges from “whether power is exercised by the threat of arms, by the effects of the word, by means of economic disparities, by more or less complex means of control, by systems of surveillance, with or without archives,

according to rules which are or are not explicit, fixed or modifiable, with or without the technological means to put all these things into action” (p. 792). Through this context the study explores how biomedical knowledge is formed in relation to power, and how that knowledge is maintained and reinforced in discourse as the only legitimate form of knowledge. In doing so, the study will layout the construction of the HIV/AIDS discourse and work to understand important guiding questions such as who controls, defines, and evaluates ‘knowledge’ in the context of HIV/AIDS prevention efforts in Sub-Saharan Africa and how is that knowledge used not to just reinforce power and dominance, but reinforce the priorities and motivations of the dominant actors?

Secondly, the study explores the need for broader understanding of the social construction of the HIV/AIDS epidemic by looking into the historical and social arrangements of groups through the lens of other diseases and by taking into account marginal voices of advocates and people of Sub-Saharan Africa. Finally, it explores the effectiveness of the currently mandated HIV/AIDS behavioral health prevention methodology by asking whose knowledge matters?

### **Bio-power**

The term discourse as laid out in this study is represented in every section of the paper. This is achieved by teasing out the important discursive practices that have contributed to the HIV/AIDS debate and by understanding the crucial factors and the roles each actor played in creating discourse. For instance, who is allowed to speak on particular subject, the manner in which they did the speaking, the historical connections,

and its outcome? Therefore, in the Foucauldian sense, discourse translates into defining the relationship between language and knowledge and how the two are closely interconnected to power. The actor that establishes what can be talked about also regulates what can be known. Likewise, the actor that establishes what can be known essentially controls not only the manner in which we should think but also how we make sense of our world through those thoughts.

Foucault (1998) goes few steps further from the control of the mind through discourse to the control of the whole body and ultimately life itself by introducing the concept of “bio-power.” Tracing its roots to the 17<sup>th</sup> century, this concept conveys the discursive practices of contemporary nations and states and the method in which they attain control over their subjects “an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations” (p. 140).

This should not be confused with his other categories of instruments of power such as ‘Sovereign power’ which he defines as “the right to take life or let live” (Foucault, 1990, p. 136), typically exercised in unequal relationship between the sovereign (king) and non-sovereign (subjects), power is given to the sovereign through symbolic rituals. Such power is not always indefinite, the subject can bring the sovereign’s life to an end. This is more of an example of power in the classical sense and has no bearing in this study other than to distinguish it from the other instruments of power.

In the modern rearrangement of power, the old way would not make sense particular in the West, which Foucault establishes his understanding and analysis of

power. To make that jump, he notes a sweeping transformation had to occur, where the ultimate decider of life the sovereign was threatened. A good example is the American Revolution to resist the sovereignty of the British Empire or in Foucault's country of origin the French Revolution, both occurring in the 17<sup>th</sup> century. Foucault (1984) argues the birth of a new form of power where "power. . . exerts a positive influence on life, that endeavors to administer, optimize, and multiply it, subjecting it to precise controls and comprehensive regulations" (p. 259).

Foucault points out the shift, which he claims is observable through the ideology behind modern wars, and how they are waged or legitimized not in the name of the king, but rather for the protection and continuation of entire people. Paradoxically, through war both classical and modern states have exposed their subjects to death, but the difference now is that death is justified with preserving greater life, and the desire to save the greatest number. Foucault (1998) further explains this phenomenon as follows "the ancient right to take life or let live was replaced by a power to foster life or disallow it to the point of death" (p. 138).

With this historical understanding of the two periods, Foucault divides power into two basic forms, connected and interlinked in two poles of development. "Primary form," he notes is "centered on the body as a machine: its disciplining, the optimization of its capabilities. . . the parallel increases of its usefulness and its docility, and its integration into systems of efficient and economic control" (p. 139). The collective category for this he calls "disciplines: which is described as an 'anatomy-politics of the human body'" (p. 139). The secondary is biomedicine as a tool "focused on the species body, the body

imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality. . . life expectancy and longevity” (p. 139). The two are categorized as “biopolitics of the population” (p. 139). This research is interested in both the ‘disciplining’ and the ‘species body.’ These two concepts exemplify the HIV/AIDS discourse in the past 30 years from its discovery in the United States to the distancing of the disease to marginalized population and ultimately Sub-Saharan Africa.

The struggle for this broader understanding is personified by the likes of Paula Treichler and others who unswervingly speak to the epidemic. Treichler argues AIDS as lived “is metaphor, and this semantic work – the effort to make sense of ‘AIDS’ – has to be done” (Treichler, 1987). This statement is as true today as it was in the late 1970s, when Treichler and other social scientists started raising the question about the social construction of the disease. Treichler also stresses a dire need to explore the relationship between ‘signifiers’ and dominant discourse. It seems as though then, for Treichler (1987, 1999), the signifiers form the ‘reality’ from which we construct what is seen as ‘truth.’

Using this same pattern of discourse analysis noted by Foucault and Treichler, this study will explore the signifiers, which are themselves born out of the existing sociocultural dynamics of the dominant power writing the prevailing discourse. This is achieved through an in-depth examination outside the dominant assembly line of epidemiological and biomedical understanding of the epidemic and into the multidiscipline sphere of discourse analyses entrenched in the post-structural social theorists’ debates to affect social justice for the marginalized and powerless.

## **Historical and Socio-cultural Contexts and Analysis**

As Foucault emphasized, the precondition to understanding discourse is rooted at society's 'historical specificity' (Hall, 1985). This analysis starts by first examining the relatively short history of the HIV/AIDS epidemic that was delineated by the authority of Western biomedicine through epidemiological discourse which predated the disease itself. Historical inquiry dissects the different ways of knowing, the process of framing, and how meanings are produced and reproduced in language, institutions, and social practices that affects the lives of ordinary citizens (Hall, 1985, 1997).

## **Recognition and Naming of AIDS/HIV in the United States**

The first indication that there may be a new infection appeared in June of 1981, when five cases of an uncommon lung infection, in previously healthy, young gay men in the Los Angeles area were reported by the U.S. Centers for Disease Control and Prevention (CDC) in their Morbidity and Mortality Weekly Report (MMWR). Medical authorities devised for their expertise to protect the public from disease contagion narrowed the infection down to particular groups, where they identified in this case to homosexual men. Unfortunately, (US) society's perception on homosexual men had its own preexisting historical specificity that deemed them as outsiders and example of moral decay.

Additional investigation into the cases revealed that the infection was transmitted through sexual activity, consequently credited to the "sexual promiscuity" of gay men (Altman, 1982; Brennan & Durack, 1981). Using tools guided by biomedical research to

analyze epidemiological trends, the focus shifted to sexual behaviors and the practices of people deemed as “at-risk groups,” an epidemiologic term that would further alienate and marginalize more groups with the disease. The phenomenon was initially labeled by the CDC as the “GRID” or the gay-related immune deficiency (MMWR, June 8<sup>th</sup> and July 9<sup>th</sup>), however, despite the public health measures to bring about an end to the disease, the cases kept increasing and showing up in several major cities in the country.

This precedent gave birth to a period of discourse in which scientists and researchers led the first HIV/AIDS-related slew of accusations based on epidemiological construction of ‘othering.’ In the Foucauldian understanding of discourse the construction of certain discourse is guided, controlled and entrenched across various techniques of marginalization, exclusion, and control. The one who poses the power to dictates the rules of discourse construction is also controlling the power over the production of and the ownership of knowledge in general. In this case biomedicine and its various tools including the CDC have defined not just the knowledge of the disease but how the individual body who is distinguished as part of the infected group should live.

The public health authorities and society at large have interacted consciously or unconsciously to produce particular narrative to make sense of their environment, this is based on the historical discursive influence of the subject; therefore knowledge was drawn from the norms of the society in their previous discourses.

Naming AIDS as GRID by medical authorities left nothing to the public’s imagination and power was drawn from this discourse, which further fuelled popular opinions fed by existing stereotypes and negative stigmatizations of homosexuality.

Treichler (1999) makes an important point regarding the naming of the disease from the biomedical prospective "Names play a crucial role in the construction of scientific entities; they function as coherent signifiers for what is often complex, inchoate, or incompletely understood" (p. 167).

On the other hand, within the public discourse, naming the disease in such a manner, appropriated existing cultural and historical narratives and metaphors that produced many other names disparaging descriptions to explain the epidemic beyond the biomedical position. To the American public, the AIDS/HIV signified 'Gay plague' a punishment from God for the sinners, a 'Gay Cancer' meant to cleanse society for their moral failures, and the Sodom and Gomorra story of the 20<sup>th</sup> century (Fee & Parry, 2008; Goldin, 1994). Treichler (1987) indicates 38 cultural metaphoric narratives influencing society's perception of AIDS, where meaning was derived from the authorized GRID label of AIDs in the US in the 1980s.

The negative and disparaging connotation of GRID quickly changed with more findings, and the (CDC) will yet again include more groups to their risk group category. This time charged with epidemiological discourse of racialization of the disease to include people of African descent, mainly Haitian immigrants. The CDC Morbidity and Mortality Weekly Report (MMWR) publication in March 1983, quite clearly grouped Haitians together with homosexuals, heroin drug-users, and hemophiliacs, as the formation of the so-called '4-H club,' where the hemophiliacs would later translate into 'Hookers' (Fouron, 2013). The report reads as follows:



Current epidemiologic evidence identifies several groups in the United States at increased risk for developing AIDS . . . . Most cases have been reported among homosexual men with multiple sexual partners, abusers of intravenous drugs (heroin users), (patients with hemophilia) and Haitians, especially those who have entered the country within the past few years (CDC, 1983).

This sort of public health response acted as a precursor for social exclusion, scrutiny, and stigmatization of those infected with the virus. A system based on predefined parameters of cause and effect and constructs of risk reduction and disease containment, which rides on the backs of established authority. In the analytical and epidemiological framework of disease the interest lies not in the social and structural sources, but rather in the technical cause and effect. In this respect biomedicine has facilitated a unique system of procedures and techniques that controls the human body as nothing more than a product that can be shaped and molded to fit the desired ‘norm’ for society, Foucault defines this as “docile bodies”. The docile body is basically an individual who is processed in a ‘factory’ like manner handled and transmuted to fit the objective of the dominant power (Foucault, 1977a).

### **Biomedical as an Opposing Discourse to United States Historical Positioning of HIV/AIDS**

Regardless of who was suffering, for epidemiologists this was business as usual, a necessary biomedical process and the benchmark for collecting data required to

measure the link between exposures and effects. The selection criteria of risk groups is not restricted on just epidemiological data sets; rather behind every public health report and scientific publication there is a human with discursive history that informs his or her sociocultural perceptions and guides the individual's ability to make sense of their environment.

Whether the selection criterion was motivated by homophobia and or racism, it cannot be extricated from the Foucauldian concept of 'regime of truth' which gives these scientists the voice and power to make certain subject the 'truth' (Hall, 1997). Watney (1987) picks up on this point by arguing:

IV drug users, worker in the sex industry, black Africans, and gay men are carefully confined in the penal category of the "high-risk group," from which position their experience and achievements maybe safely ignored. In this manner a terrible ongoing human catastrophe has ruthlessly been denied the status of tragedy, or even natural disaster. (p. 72)

The stigma that Haitians and other people of African descent faced once they were implicated as the vectors of the disease was harsh (Deacon, 2006). Every form of discrimination became justifiable, from verbal abuse to physical assault and in some cases evictions from their homes and refusal for other members of the community to work or associate with Haitians (Farmer, 2006). On the economical scale, a small Island nation that depended heavily on tourism and the money expatriate and other workers sent home, no longer could depend on those prospects. On a larger scale, strict immigration laws closed the US borders to any Haitian immigrant and furthermore, authorities

controlled their movement and restricted the ones who were already in the country (Fouron, 2013).

Siedel (1993) does not see this occurrence of finger pointing by scientists as unique incident in the history of biomedicine isolated only to HIV/AIDS. He links this occurrence to ‘blame the victim’ mentality in which he argues, stems from long standing tradition of ‘Medico-moral’ discourse in the West. Siedel stresses:

AIDS in common with other sexually transmitted diseases, like syphilis involves ‘blaming others’ . . . . The location of blame for disease in immorality or ‘sin’ of the Other is part of the older, religious tradition of using sexual taboos and prescribed behaviors to reinforce existing sexual orders, and other order patterns in the interest of the well and powerful. (Siedel, 1993, p. 180)

Connecting this to Sub-Saharan Africa, as Siedel noted, it is important to acknowledge, how the morality factor in the initial response has not only contributed in the othering process, but also in its historical specificity in the way society made sense of their environment. Such acts have set the tone and the trajectory of the HIV/AIDS discourse in the next three decades. The emphasis biomedicine placed on predetermined “risk groups” mainly the homosexual population, intravenous drug users, patients with hemophilia, Haitians immigrants, and other minority groups has manifested in several discursive forms in the global arena, produced and reproduced by various actors, mainly the international prevention efforts, scientific and biomedical researchers, and in the policies of Western donors countries and their proxies.

The biomedical explanation for the origin of AIDS linked Haiti as the gateway for the U.S. epidemic, fueled by the so-called voracious sexual appetite of America gay men vacationing in the Island. This claim was countered by the possibility that Americans could have brought the disease while visiting. In either case, more studies for the index case of the infectious outbreak would broaden the place of origin and further distance it from the West and the U.S. to Africa and specifically to Zaire (Gilbert et al., 2007). This was validated with genetic subtyping experiments that outlined a map that showed the U.S. strain of HIV-B to Haiti and from Haiti to Zaire as the ground zero of the epidemic (Peeters, 1994).

The premise for this argument is that Africans who consumed primates in the central African forests in the form of ‘bush meat,’ tainted with Simian immunodeficiency virus (Chen, 1996; Peeters, 1994) suggested to originate from the sooty mangabeys monkeys that contained (SIVsmm) which according to Santiago et al. (2006) is the precursor of human immunodeficiency virus type 2 (HIV-2). The Haiti as ‘gateway’ narrative builds on the assumption that Haitian workers who worked in Zaire in the late 1960s brought the disease back home, where they had contact with American gay visitors (Gilbert et al., 2007).

Zoonotic transfers of viruses infecting primates in Africa to human hosts via consumption of bush meat is a bit uncharacteristic given the fact that Africans have lived with and consumed these animals even long before colonialism took place. So why would the jump occur now? Researchers have come up with many different hypotheses to answer this question. Clinician and epidemiologist Jacques Pepin worked in Africa since

the early 1980s, researching infectious diseases through historic data to explain the emergence of several infectious diseases, such tuberculosis, hepatitis, and syphilis. Analysis of data from tropical disease control programs of the colonial era in central Africa between 1930s and 1960s and other post-colonial period dating to 1990, implicated the colonial role in spreading infectious disease amongst the indigenous population while attempting to treat some of the tropical diseases prevalent in the area.

In 2006, Pepin linked asymptomatic cases of HIV-2 infection in Guinea-Bissau to the historical treatment of tuberculosis (Pepin et al., 2006). In a subsequent publication, Pepin and Labbe (2008) using data from 1945 to 1990 to show the prevention and treatment measures devised by the colonialist to prevent the spread of blood-borne viruses such as syphilis, hepatitis, and yaw disease including the use of harsh drugs such as arsenic-containing compounds. As a consequence, this had destroyed the resistance of otherwise common disease in the area that as result destroyed the otherwise stable relationship between the host and pathogen (Pepin et al., 2006; Pepin & Labbe, 2008).

Pathogens that may have otherwise interacted with their host without causing disease, in this case, the consumption of the bush meat tainted with SIV, could no longer have the same interaction. As Pepin and Labbe argue, “colonial medical campaigns were careless and often devised unsterilized syringe and needles, this facilitated the future of the epidemic” (Pepin & Labbe, 2008, p. 744). Where tropical disease prevention campaigns opened the window for the virus to interact negatively with its human host, the urbanization movements under colonial system opened the floodgates for mass human-to-human sexual transmission of the virus (Pepin & Labbe, 2008). In either case,

this discourse that still casts the blame to Africa and Africa's role in the origination of the disease is not without its share of criticism and questions of 'How' and 'Why' still remain unanswered.

Marginal voices of advocates and scholars from Africa and elsewhere pushed to fight the power differentials. Most prominent amongst them were the voices of Richard Chirimuuta and Rosalind Harrison-Chirimuuta, in their book, *AIDS, Africa and Racism* (1987). They challenged the prevailing biomedical account, which they argued depicted Africans as primitive peoples living in isolated tribes cut off from civilization with diseases that are uncommon in the Western civilized world. They further objected to the idea that linked monkeys with Africans as reminiscent of racist Western colonial medicine, which saw Africans as evolutionarily closer to monkeys. The other contested issue for them was the prevailing notion that Africans were sexually unrestrained, and a sexually transmitted disease would therefore spread more rapidly amongst them than any other people (Chirimuuta & Chirimuuta, 1997, p. 166).

### **Social Construction of AIDS**

Thus is the Western biomedical construction of the African origin of the AIDS discourse. Africa, just barely emerging from the strong grips of Western colonialism had little to add to the discourse. An African proverb symbolizes the uneven power and knowledge dynamic in this situation between the writers of discourse and the subject of discourse as follows: "Until the lions have their own historians, tales of the hunt shall

always glorify the hunters” (anonymous). Gilman (1998) notes the premise for shifting blame and the process of othering as follows:

We need to locate the origin of a disease, since its source, always distant from ourselves in the fantasy land of our fears, gives us assurance that we are not at fault, that we have been invaded from without, that we have been polluted by some external agent. (p. 262)

Discourse of ‘invaded from without’ played a critical role in shifting the epidemiological geography from San Francisco to Haiti and from Haiti to Zaire. Likewise, the epidemiological paradigm of risk groups, which justifiably received its own share of criticism shifted to a more watered-down categorization of ‘vulnerable groups’ and finally to the current language of ‘risk behaviors.’ No matter how the language shifts the discursive practices of biomedical researchers retains the absolute power to ‘validate’ particular perception of the truth.

What makes this research significant is the subject itself. HIV/AIDS discourse is a proverbial spider web. In the case of the spider web metaphor, there is one actor with multiple limbs weaving a complex web of silk strands, repeated and reinforced by one another to form the strongest net known in nature. The spider does not incorporate or collaborate with others to design its complex web. Likewise, the HIV/AIDS discourse controlled by the one dominant actor has so many thread like factors that are linked and interconnected to produce and reproduce the current dominant discourse, with little to no inclusion of other forms of knowledge or input. This is substantiated by the manner in

which some Western scholars particularly epidemiologist, anthropologist, and other so-called ‘expert of African cultures’ constructed and studied the disease.

Yeboah (2006) draws correlation between today’s HIV/AIDS discourse in Africa and the historical construction of biomedical discourse of disease in the continent as inherently racist. Yeboah asserts, “Sub-Saharan Africa's environment, its people, and their cultures were constructed as dark, barbaric, savage, hot, diseased, uncivilized, heathen, lost, and child-like” (Yeboah, 2006). This illustrates a discourse grounded on Western perception of race, driven by racial stereotypes and representation of existing xenophobia that is framed in epidemiological discourse.

To understand the abovementioned analysis that cites colonial characteristics of xenophobia and racism, it is critical to refer back to the discourse during the discovery of the epidemic in the West. Several defining moments can be traced to the initial response carried out by the biomedical field to not only make sense of the newly emerging infection, but also the technical nature it took to determine the description of the virus and its modes of transmission in the United States.

These historical assessments allow us to see the discursive practices that shaped the trajectory of the HIV/AIDS discourse in SSA. Stereotypes that sustain and reproduce on the established social hierarchies of the poor, the marginalized, and race cannot be extracted from their ‘historical specificity’ no matter how much equality is promoted. Western prevention and policy will forever be referenced to the historical specificity of the prevailing discourse of this period, so long as the power imbalance exists between the West and Africa (Schoepf, 2001).



This is not to overlook the optimistic global efforts to create a world where healthcare is understood as universal human right for all, and where racism and stigmatization is considered deplorable offense in society's past mistakes. These conceptions are so important that it is enforced by the Western and the global institutionalization of medicine, formalized both in the United Nations charter and the World Health Organization, as fundamental right. The charter states: "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (Chisholm, 1949; Hogerzeil, 2006; WHO Constitution, 1948).

Despite the ongoing efforts for a global social justice, the discourse of racism and othering can never be extricated from social practice regardless of what a theoretical charter guarantees. Barkan (1992) argues racism did not fade away from society simply because there is awareness of its danger, rather it went through a conversion process, "Racial differences are viewed in cultural terms, xenophobia has become more egalitarian, and the strife is no longer waged in the name of superiority. This transformation has been the retreat of racism" (Barkan, 1992, p. xii).

This is also echoed by Martin Barker (1981, 1984). In his study of racist discourse in the United Kingdom, he introduced the concept of 'new racism' and points out two principals grounded in its formation. The first, unlike the archaic racism construct, is not restricted to enslavement of human and it does not display outward forms of discriminations. Instead, its functionality dominance of other cultures is exercised through an obscure means and it thrives on the concept of otherness. The second

principal replaces the old notion of biological difference based on genetics to differences between cultures or nations, without any distinction between the two.

The old understanding of race is now veiled as differences in culture or ethnicity. Barker calls this phenomenon ‘pseudo-biological culturalism’ (Coombe & Little, 2005, p. 7). He notes the idea is constituted in human nature as part of the othering process. “It is part of our biology and our instincts to defend our way of life, traditions and customs against outsiders - not because these outsiders are inferior, but because they belong to other cultures” (Barker, 1984, p. 78).

### **HIV/AIDS in Sub-Saharan Africa**

In its gradual development, epidemiological representation and classification of risk group utilized during the onset of the epidemic in the homosexual community and other minorities in the U.S., takes a life of its own as it was transplanted for Africa and the so-called ‘African pandemic’ characterized for its heterosexual transmission where the risk groups in this case, included ‘prostitutes’ ‘barmaids’ and ‘long-distance drivers.’ This construct vilified women and men who were away to provide for their families and homes as disease carriers that were polluting society.

The African continent inherits both the origin of the disease and severity of its outcome disproportionately. The World Health Organization (WHO) estimates the global HIV/AIDS infection rate at nearly 75 million people and mortality at 36 million people since the advent of the disease. Statistics show that a startling 25 million infected people, more than two-thirds of the world’s HIV cases, are found on the African continent. Africa

is also home to 88% of the world’s HIV-positive children. The majority of these individuals live in Sub-Saharan Africa, where the disease claims 1 in every 20 adults. In the 2012 global report data, an estimated 1.8 million people in the region became newly infected and an estimated 1.3 million adults and children died of AIDS (UNAIDS, 2013). This accounted for 75% of the world’s AIDS related deaths just in that that year (UNAIDS Global AIDS Response Progress Reporting, 2012).

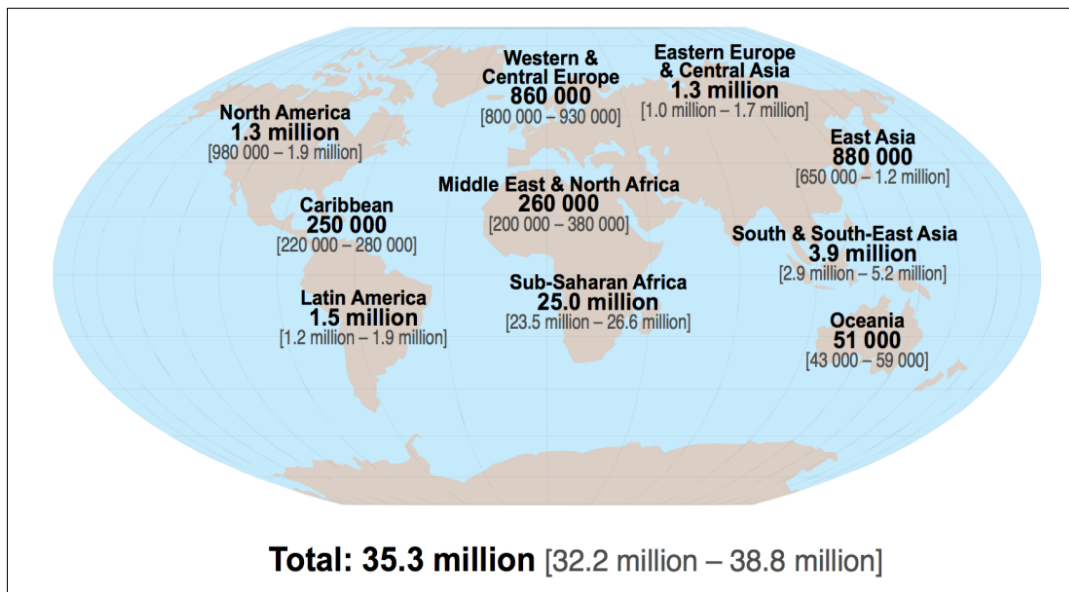


Figure 1. A global view of adult and children living with HIV in 2012. Source: UNAIDS (2014)

Figure 1 clearly depicts the spread of HIV/AIDS in every corner of the world in general and in Sub-Saharan Africa (SSA), which is disproportionately affected. Surprisingly, given the high prevalence of the disease in SSA, very little knowledge comes from this area. The most significant source of knowledge about HIV/AIDS in SSA in the past three decades has been the product of Western scientific research. This disparity in both the disease and knowledge calls for immediate understanding of their

structural causes, a notion that is so essential and yet absent in much of the current HIV/AIDS discourse.

Historically and long before the advent of HIV/AIDS, the African continent was consistently portrayed as a hub for disease, hunger, and poverty. Western-driven portrayal that has not changed much today is vivified by images of poor Africans and cries of unavoidable ill fate of diseased bodies of children and adults alike in almost every form of media. This perception is further exacerbated by some Western scientists who have solidified in discourse the otherness of Africa and Africans, citing ‘cultural barriers’ to prevention of diseases and ‘promiscuous’ sexual nature of Africans fuelling the high prevalence rate in the continent. It is equally important to note, with respect to Africa, the current biomedical discourse predates the onset of the HIV/AIDS epidemic.

As I have established in my analysis, the discourse of HIV/AIDS merely picks up on historical biomedical discourse of racist colonial era, utilized by foreign occupiers as a tool to enforce political, social, economics, and to drive their own interest (Vaughan, 1991; Watney, 1994). As a result, some researchers and medical authorities in the name of Western biomedicine have managed to impose their own form of colonization on indigenous populations of Africa, by fettering community’s knowledge, promoting xenophobia, and medical prejudice, and ultimately looking out for their own advancement in the scientific realm, while doing little to nothing in the process to advance the interests of the communities struggling with disproportionate health issues (Packard & Epstein, 1992).

Biomedical researchers, behavioral and social scientists, as well as, doctors, and international non-governmental organizations (INGO'S) have all contributed to shaping the public health programs in developing countries and the prevention policy of the HIV/AIDS epidemic around the world. Moreover, biomedicine has acted as the undisputed and principal means of delivery and response to public health and global health issues in the industrialized Western countries who are the custodians of the discipline, and also in the developing countries who fall on the receiving end of the discipline.

### **North-South Inconsistencies in the Prevention Models**

Although the prevalence of HIV/AIDS epidemic is without a doubt the highest in Sub-Saharan Africa, the disease is also disproportionately affecting minority groups in the West particularly the United States. In what seems a bizarre mirror image of statistics, Africa, a continent that makes up 12 % of the world's population, has almost 70% of the world's HIV cases. Conversely, the U.S. has a small population of African Americans who are disproportionately affected by HIV/AIDS.

Reports from the U.S. Center for Disease Control (CDC) indicate that African Americans account for more new HIV infections and more HIV-related deaths than any other racial/ethnic group. African Americans represent only 12% of the U.S. population (U.S. Census, 2010) but accounted for 44% of new HIV infections in 2010 (CDC, 2013) and an estimated 44% of people living with HIV in 2010. This group also accounted for half of the newly progressed AIDS-diagnosed cases in 2011. African Americans lead in

the national estimates of new HIV infections in the U.S. and are designated by the CDC as one of the most affected subpopulations across gender, with males comprising 72% of the new cases and females comprising 29% of the new cases in 2010 (CDC, 2010).

Remarkably, several meta-analysis that have examined HIV risk behavioral factors among men who have sex with men, showed although black men are more at risk for HIV than their white counterpart they have reported the same or fewer risky behaviors (Millette et al., 2007). Furthermore, these studies determined black men were not more prone to have unprotected anal sex, participate in commercial sex work, or have sex with identified positive partner. Additionally, black men reported fewer sexual partners and lower intravenous drug use than their white counterpart (Millette et al., 2007). Likewise, black women indicated less or similar risk factors as their white counterpart (Farley, 2006).

This disparity is further corroborated by studies that looked at sexual and drug behavior patterns across gender between African Americans and Whites in the United States. The result indicated racial disparity in both HIV and other sexually transmitted infections (STD's). These studies concluded even when African Americans and Whites had the same risk behavioral factors, African Americans were more likely to getting HIV and other STI's and lead in more new HIV infections and more HIV-related deaths than any other racial/ethnic group in the U.S. (CDC, 2013; Hallfors et al., 2007).

This comparison illustrates two salient points. First, African Americans were incorporated to the Western system by force and enslavement and cannot be pushed to the side of the 'third world' argument to explain such disparity. The holistic explanation

then from Foucauldian viewpoint is that health issues can only be understood within a framework that acknowledges influences social and structural sources as well as cultural, economic, historical, and political factors. The parallel this study draws from whether in Sub-Saharan Africa or forcibly relocated populations of African people everywhere have experienced institutional practices and racialized history that contributes to the disparity of the HIV/AIDS epidemic. Ford and Airhihenbuwa (2010) argue, “racism produces rates of morbidity, mortality, and overall well-being that vary depending on socially assigned race” (p. 30). This shows a link between racism and health disparity that can no longer be ignored.

Second, the answer for the underlying causes of the health disparity in Africa does not lie solely in the ‘Africa’s promiscuous sexual nature,’ but rather the historical discursive manifestations and the social measures that molded them into the (false) *status quo*. Seidel and Vidal (1997) conscribe this phenomenon to ‘culturist discourse’ where culture is blamed for program failures:

[t]here is a problem with trying to account for the relative failures of health interventions on the grounds that they have encountered a ‘cultural problem’. A form of cultural relativism is becoming more apparent. This is further sustained by a tendency towards ethnocentrism displayed by some researchers who are convinced that, if an argument is made out for culturally-based resistance, the problem has no solution. They argue that the reason is to be found in conceptions and health practices different from

those developed in the industrialized countries. (Seidel and Vidal, 1997, p. 52)

Previous research indicates that the Western linear model of knowledge equaling behavioral change alone does not constitute effective prevention and that a failure of program uptake occurs even in the cases where Western biomedical knowledge of the disease exists (Airhihenbuwa & Obregon, 2000; Barden-O'Fallon et al., 2004; KNBS & Macro, 2010; Lema, Katapa, & Musa, 2008; Sennen, et al. 2005).

In response to failed efforts of some prevention programs, a number of Western researchers have become more concerned with the negative implications of African culture, rather than making an effort to actually understand the root cause of this pandemic in Sub-Saharan Africa. In some cases, the lack of program adaption was blamed in part on what has been labeled as Africa's inherent flaws and cultural norms that promote sexual promiscuity. A prime example of racial ideology that rationalizes and explains away disease inequality on what is termed as 'Africa's inferior cultural differences' this is exemplified in the works of Caldwell and Caldwell 1987, 1989, and 1999 also by Hrdy, 1987 who takes the same position as Caldwell by asserting the claim "Most traditional African societies are promiscuous by Western standards."

### **Historical Limitations of the Sexual Behavioral Health Approach**

Behavioral-change-theory-based programs have been utilized extensively as intervention approach to reduce sexual risk behaviors and a means to prevent sexually transmitted infections and HIV/AIDS globally. These programs were also deemed the



most effective prevention and reduction route of the pandemic by national and international health governing bodies (NIH, 1997; UNAIDS, 2013). Furthermore, concerted efforts of the international community have funded and applied targeted behavioral health change theories to induce behavioral change in select groups identified as ‘at risk’ in Sub-Saharan Africa and other developing regions of the world. This has been typically carried out by the expertise of the international health governing bodies and the local public health sector of each country.

Today, despite the numerous advancements in the biomedical field short of cure vaccine, the theoretical framework remains the same and the methodological focus on the psychosocial behavioral health change theories of prevention has not changed much since their first use. Furthermore, there is astounding support amongst the biomedical and behavioral health researchers on efficacies of these programs. For instance, in February 1997, scientific consensus conference sponsored by the National Institutes of Health (NIH) summoned a group of scientist from a wide array of disciplines including a non-Federal, non-advocate, 12-member panel representing the fields of psychiatry, psychology, behavioral and social science, social work, and epidemiology. In addition, 15 experts in psychiatry, psychology, behavioral and social sciences, social work, and epidemiology were tasked to review existing data on the effectiveness of HIV behavioral health interventions. The group declared, “[b]ehavioral interventions to reduce risk for HIV/AIDS are effective and should be disseminated widely” (NIH, 1997).

In 2008, similar conclusion was reached by the Global HIV Prevention Working Group, an international panel of about 50 prominent public health experts, clinicians,

biomedical and behavioral health researchers, assembled by the Bill & Melinda Gates Foundation and the Henry J Kaiser Family Foundation to advise on the global HIV/AIDS policymaking, donor decisions, and campaign for effective response to the epidemic. In their report the groups argued, “[i]n all cases where national epidemics have been reversed, broad-based behavior changes were central to success,” (GHPWG, 2008).

The collective assertion of the previously mentioned Western experts who claim the panacea for curbing the transmission of HIV/AIDS is through the sexual behavioral health change programs for people deemed as risk groups. This reinforces the perception of sexualization of disease and echoes the same themes of the ‘docile body’ that can be shaped and manipulated to conform to the accepted or dominant norm at the beginning of the epidemic. In this case, the cultural construction of HIV/AIDS to predefined groups is relatively rooted in the historical discourse of epidemiologists in the history of biomedicine and subsequently in the discovery of HIV/AIDS on a group of homosexual men and other minority groups in the US. However, this premise takes a life of its own in its reproduction in the developing world and especially in Sub-Saharan Africa.

There are two broad sets of assumptions here, one is the continues practice of epidemiological exclusion, which gave the epidemic a geographical patterns exemplary of North-South divide; type one pattern, represented the wealthier West, including the United States and Western Europe, where the spread of the disease was associated mainly with homosexual behaviors and intravenous drug. The other pattern is type two, which affects the poorer nations of the world, exemplified by Africa and Latin America; in this

case the disease was linked on heterosexual behaviors and practice (Kiple, 2003; Quinn, 2001).

The second broad assumption is the inductive generalization or reasoning of some Western researcher and so-called experts of African culture, who in the tradition of scientific empirical evidence took a small sample of any given population in Africa to make broad claims that suggests strong link between the rapid spread of HIV/AIDS and what they termed Africa's promiscuous sexual culture across the continent (Hrdy, 1987; Lopez et al., 2006).

Consequently, sexual behavior change remains a major focus of HIV prevention efforts in Africa today (Wellings, 2006). The intention of these programs are posited as well-meaning and are theorized by their Western designers to reduce the impact of HIV/AIDS on the most affected communities by increasing knowledge through awareness of the disease, its modes of transmission, risk factors for infection, and to ultimately prompt positive attitudes towards behavioral change.

### **Research Questions**

This analysis is guided by the following questions to explore how biomedical discourse functions to generate the HIV/AIDS othering and serves to maintain the status quo.

1. What are the intended and unintended impacts of Western biomedical discourses and related public health policies in HIV/AIDS prevention efforts in Sub-Saharan Africa?

2. What are the ways in which those discourses and policies hinder the global efforts in the prevention of HIV/AIDS?
3. Who controls, defines, and evaluates 'knowledge' in the context of HIV/AIDS prevention efforts in Sub-Saharan Africa and how is that knowledge used not to just reinforce power and dominance, but reinforce the priorities and motivations of the dominant actors?

## Chapter 2

### SIGNIFICANCE OF THE STUDY

#### **Intellectual Merit**

Glanz and her team (2008) clearly articulated the correlation between theory and practice, “[t]he best theory is informed by practice; the best practice should be grounded in theory” (p.24). This raises two questions: 1) do evidence-based practices influence the behavioral change theory based intervention programs in Sub-Saharan Africa? 2) Has the Western knowledge-based behavior model produced measurable behavioral change in the general population? In attempting to answer these questions, the study uncovered the disparity goes beyond the disease and into the realm of scientific literature and the scarcity of evidence-based practice of the currently mandated prevention programs.

This study seeks to address a major shortcoming in the HIV/AIDS literature by using a critical social theory approach to analyze existing literature and the discursive magnitudes of ideologies that influence them. Previous studies have emphasized a quantitative approach and hegemonic epistemology (Western) of HIV/AIDS prevention in Sub-Saharan Africa (SSA). While the Western biomedical studies are very important to understanding the pathology of the disease, these studies cannot tell the realities on the ground. It appears that the limitation of the Western perspective is that there are potential inconsistencies. There are also conceivable biases due to prior assumptions and expectation about culture. This study will also tease out any conceptual dilemmas, particularly those that can lead to dominance or subjugation of a one-sided approach.

This approach deconstructs the concerted global prevention efforts as one that is

contentious and promotes the superiority of medical knowledge in the developed world to the cultural considerations of the developing world. In other words, the so-called “developed world or the first world” dictates treatment and prevention methodologies to the “developing world or the third world,” which is always at the receiving end and at mercy of the other. This perpetuates the inequality between these two “worlds.”

The ultimate contribution of this study is to forge alternative and less oppressive social discourse and offer potential measures that can help us learn from the past and contribute to the future, as well as provide a context with which to analyze the diverse global intervention efforts of HIV/AIDS. Challenging inequality needs the shovel that unearths where its social conquest occurred in the first place then following the factors that are interlaced to contribute to such disparities, this will also establish another level of checks and balances directed towards the status quo.

### **Societal Impact**

The global community’s effort to fight HIV/AIDS has arrived at a significant juncture. With Sub-Saharan Africa leading in the global reported cases of adult and children living with HIV in 2012 at 25 million people (see fig 1.1-UNAIDS global report, 2014), it is crucial to address this issue and find effective, culturally relevant prevention programs. With no vaccine in sight, the overwhelming mortality and morbidity reported figures in the past 30 years of this epidemic are only one part of the story, the devastation caused by HIV/AIDS extends beyond the data and even beyond the disease, as it undermines communal social order by destroying the traditional African family structure

that cared for children (Cluver et al., 2011). Consequently, leaving an estimated 17.8 million orphans and vulnerable children globally unattended, having lost one or both parents (UNICEF, 2013); close to ninety percent of these children inhabit sub-Saharan Africa and tragically of these affected group; additionally, 3.4 million are infected with HIV/AIDS (UNAIDS, 2013, 2014).

This already dire situation is further exacerbated by the link between the epidemic and economic development in Africa, pushing the continent into deeper disparity that affects growth, income, poverty level, social stability, human welfare, security, and any prospects for future economic development. Evidenced by studies that showed broader negative consequences of HIV/AIDS epidemic in both human loses and financial economic development, Dixon et al. (2001a, 2002) examined the pandemic's effects on the economy in an effort to understand the future development capacity of the continent and the cost effectiveness of prevention and treatment programs in use.

This research team (Dixon et al., 2002) discovered low labor and productivity in nations hit hardest by the disease, coupled with low exports, and increases imports, making trade a one way market. Dixon and colleagues note as a result of these factors, the continent experiencing a reduced average national economic growth rates of 2-4% a year. Furthermore, the long-term impact, given the rapid spread of HIV/AIDS throughout the years, coupled with the lengthy delay time of the biological progression of the disease between the initial infection phase and the onset of the vicious symptoms, has contributed to great economic and social disparities that threaten to erase any sign of progress,

leaving the most affected countries permanently behind the North-South divide (Mimiko, 2012).



## Chapter 3

### THEORETICAL FRAMEWORK

It seems a befitting and somewhat cruel irony that this study applies the post-structuralist work of Michel Foucault, who has given us so much to make sense of HIV/AIDS, yet this irony is not lost in the fact that Foucault himself died in the height of the epidemic due to AIDS-related illness on June 25, 1984 (Edkins & Vaughan-Williams, 2009). This only illustrates the many lives the epidemic has robbed us of. Michel Foucault (as cited by Hall, 1997) defines discourse as:

[A] group of statements which provide a language for talking about – a way of representing the knowledge about – a particular topic at a particular historical moment. . . . Discourse is about the production of knowledge through language. But. . . since all social practices entail *meaning*, and meanings shape and influence what we do – our conduct – all practices have a discursive aspect. (p. 44)

Within this definition, it is important to note the existing variations in the use of discourse analysis in the social theories and their applicability in this study. These variations depend on the school of thought one subscribes to, in the linguistic applicability, discourse is the identification of text either spoken or written, and therefore, meaning is derived from the language.

In the Foucauldian school of thought, however, discourse is beyond the limits of just the text or the language, it is rather a conceptual way in which everything is subject to examination, from knowledge, power, linguistic texts, societal practices, as well as

representations, which is a paramount concept in understanding or placing discourse.

Stuart Hall elaborates this point in his analysis as follows: “Systems of representation are the systems of meaning through which we represent the world to ourselves and one another” (Hall, 1985, p. 103).

Foucauldian discourse analysis operates beyond the understanding of the text or the language, but the societal conditions that worked to produce their outcome. In this respect, Foucault’s conceptualization of discourse encompasses number of areas while paying close attention to how language and representations come to construct meaning in our understanding of the world. Likewise, how what we hold as knowledge or truth is derived from power, and how that power is regulated to reinforce the status quo by the dominant groups. For instance, when any prevailing discourse is created, the knowledge that informed it is not spontaneously generated by the subject, rather it came to be because the subject is directed and functions inside the boundaries of the existing discourse. This is set by what Foucault called ‘regime of truth,’ which is the historically specificity and conditions that produce discourses in particular times and culture (Hall, 1997).

Furthermore, the subject of particular discourse cannot be separated from discourse itself, because it is regulated by the discourses that superseded it. It must also adhere to the specific agreements of the group where it derives its power and knowledge. However, the subject has the ability to inform particular knowledge and thus operate as an entity through which power is imparted. Yet, it cannot survive without its driving mechanism, which is power and knowledge. This is to say; the knowledge acquired in

this process operates to further strengthen the implementations of power or group dominance (O'Farrell, 2005). Accentuating all is the historical specificity in which meaning is drawn from and the function of different outcomes, because the perception of the group is defined and rooted in their social context (Hall, 1997).

In the case of AIDS, throughout the history of the epidemic and especially with WHO's mandate to do more in the Global South, biomedical knowledge about how the epidemic spreads, and what measures are applicable in its prevention, become grounded and dominant in the discursive practices of global health. This is solidified and vivified through a discourse that makes 'true' specific practices such as behavioral change and KABP studies. Additionally, powers to legitimize the prescribed measures are drawn from the economic power and the ability to fund selected prevention approach over others. This often leads to power struggle between Western Biomedicine with its authority to impose its own definition of health and disease modality and the indigenous community who often feel left out of the discourse concerning their own life and body. This refusal to be the 'docile body' clashes with the conformity expectation of the dominant system.

### **Mbeki and the Politics of Life**

This brings us to President Thabo Mbeki is product of his environment, it is clear that the stance he took during his administration in denying the causative agent of AIDS as HIV has led to the loss of many lives and stopped the clock on prevention and treatment efforts. But to simply blame him would not contribute much to this paper either. Rather the approach this study takes is to briefly understand what shaped his

representation of the topic and how he drew meaning from those representations to shape his denial of the link between the first stage of the infection and its progression to AIDS. But before any such attempt is done, clarification is required factors of influence. First, the claim that President Mbeki based his assertion on indigenous African medicine is not entirely accurate. According to Green (1999), there is no cherry-picking between Western concept of HIV/AIDS in the African etiology of disease, to suggest that would contradict the healers understanding of the “‘utushishi’ the insect causing AIDS” (163). The idea to disprove the accepted scientific facts about AIDS and its causative agent HIV comes from the infamous American scientist turned dissident Peter Duesberg and his associates David Rasnick and Charles Geshekter (Belata, 2000; Kalichman, 2009; Schneider & Fassin, 2004). It seems as though, what President Mbeki is guilty of is his exercise of power over the body and by determining what in his perception of the collective good represented the preservation of life for his people. Furthermore, the influences of dissident theories, which disputed the connection between HIV and AIDS and the alleged ‘dangers’ of Azidothymidine (AZT), this paved the ground for the ban. By banning AZT President Thabo Mbeki and Health Minister Manto Tshambalala-Msimang disallowed life of thousands of patients that could have used the life saving drugs.

## CHAPTER 4

### DISCUSSION

#### **Whose Knowledge matters? Deconstructing Dominant Discourses of HIV/AIDS in Sub-Saharan Africa**

From the discovery of the first cases by the U.S. Center for Disease Control (CDC) in the early 1980s to present day the field has continued to evolve, but in the absence of a cure vaccine, dominant biomedical, psychosocial, and behavioral change research, and educational models for HIV and AIDS interventions have been advanced to deliver the framework for studying and describing the relationships between behaviors and health outcomes. In many cases Western researchers who dominated the field felt pressured to produce solutions for the pandemic, driven by competition for resources, desire for accolades, and ultimately a mentality that stressed ‘lives had to be saved.’ In that frame of mind, grave errors were committed in the name of biomedical science and to present day that lack the necessary measures needed to test their efficacy and have essentially remained unproven (Gausset, 2001).

Fassin argued, “[t]he state of ‘anthropological emergency,’ and the desire to save lives lowered the level of ethical, theoretical and methodological self-control of the researchers” (cited in Gausset, 2001, p. 23). Besides the cavalier nature in both design and assumptions, there are other major complexities. Primarily, there is no singular approach or theory governing HIV/AIDS behavioral intervention. However, there is a large body of literature on constructs in the behavioral sciences that have been developed to recognize, analyze, and prevent the spread of HIV/AIDS risk behavioral factors. These

conceptual models include the health belief model (HBM) (Rosenstock, 1974, 1990) the theory of reasoned action (TRA) (Fishbein & Ajzen, 1980), the theory of planned behavior (TPB) (Ajzen & Madden, 1986), social cognitive theory (SCT) (Bandura, 1994), and the AIDS risk reduction model (ARRM) (Catania et al, 1990).

Each of these behavioral models attempts to explain the distribution and the prevention of the disease across human groups. They were designed to play important roles in informing policy, health promotion, and disease prevention (Glanz et al., 2006; Lawrence & Fortenberry, 2007). In practice their large number and extreme reliance on multiple constructs within the different theories to explain human behavior has contributed to so much confusion in the field (Bandura, 2000). Most of the studies utilizing these constructs are either disease or factor-specific. In both instances, they lose sight of the interconnectedness among factors and diseases, and more importantly, underlying sociostructural causes of the inequalities in the spread of the disease.

One of the most comprehensive critiques is offered by Bandura (2000), who ironically is the father of a widely used theory in the HIV/AIDS prevention arsenal, the Social Cognitive Theory (SCT). Upon observing the cavalier nature of how researchers were designing new behavioral health theories and the redundancy in several constructs of existing theories, Bandura (2000) argued “fractionation of predictors and theoretical disconnectedness” (p. 2). He further cautioned:

[p]roliferation of conceptual models of health behavior tends to spawn cafeteria style research. Constructs are picked from various theories and strung together in the name of theoretical integration. This practice

multiplies predictors needlessly in several ways. Similar factors, but given different names, are included in new conglomerates as though they were entirely different determinants. (p. 2)

Additionally, Bandura spells out several other limitations in the design and the conceptualization of the numerous constructs forming the various theories of behavioral health. He also challenges the design and the process majority of biomedical researchers took to create the existing discourse, an argument in line with Fassin's initial analysis (as cited in Gausset, 2001, p. 23).

On the supporting side of the behavioral health theories, Glanz et al., (2008), asserts:

The most successful public health programs and initiatives are based on an understanding of health behaviors and the context in which they occur.

Therefore, interventions to improve health behavior can be best designed with an understanding of relevant theories of behavior change and the ability to use them skillfully. (p. 57)

Despite the recognition by Glanz and other biomedical researchers that claim theories of behavior change must be viewed within the context of behavior and decision making to successfully get people to change their behaviors, there are a number of problematic issues arising from this conceptualization. This concept is based on an individualist model of human behavioral change focusing on behavior as a means to determine disease and monitors individuals that are classified as part of the at-risk groups.

This perception is grounded on unspoken cultural biases toward a linear and individualistic emphasis that does not take into account the norms of collective cultures. Sadly, this standard of behavioral assessment to determine disease risk factors becomes the principal guide for public health policies in the HIV/AIDS prevention programs globally. It is further reinforced by the one-sided belief that Western biomedical prevention techniques would lead to increased knowledge levels about health problems and drive attitude changes in favor of healthier lifestyles cross culturally

This is evident in the adoption of the globally mandated UNAIDS programs and the research tools it employs, such as the Knowledge-Attitude-Belief-Practice surveys (KAPB), which are designed to link pathological changes caused by the onset of an infection to limiting factors such as knowledge, lifestyle, and behavior of the individual. The linkage assumes that healthy individuals can overcome disease susceptibility through knowledge, and that knowledge has the ability to modify individual behaviors and lead to healthy lifestyles in all cases. Green (1999) argues against the value of the KAPB surveys and classifies them as nothing more than tools used to assess negative cultural differences and stereotypes of native knowledge and health systems. The methodology he argues was designed to:

Prove native health beliefs wrong (or childish) with superficial KAP surveys, then lead the natives out of the darkness and get them to what we want them to do, calling this “behavioral change,” “health facilities utilization,” and “treatment compliance.” He further goes on to say “There is little recognition or acknowledgement (aside from some



anthropologists) of the fallibility and malleability of biomedical models of illness and treatment regimens and of the fact that these models are themselves are culturally constructed. (p. 219)

The premise that knowledge leads to behavioral change is a topic of debate, especially in the HIV/AIDS prevention arena. Some scientists acknowledge the overall impact of education on disease as something that will contribute to general reduction of risks and ultimately lead to behavioral change outcomes, while acknowledging its limitations (Airhihenbuwa, 1999; Parker, 2003).

Airhihenbuwa and colleagues (1999), on the other hand, in several publications noted the complete and utter flawed nature of behavioral health theories. Even the tools used to measure such strategy are ineffective, particularly in the developing world. They further assert that the models of behavioral health currently utilized in preventions, tend to frame health and disease from individual Western biomedical perspective rather than on the social context within which that individual exists.

The construct 'Knowledge' is typically measured to determine to what extent certain group's knowledge matches to the Western biomedical models. Therefore, the criterion for meeting whether or not the group is knowledgeable is derived from preselected questions, such as: What is HIV? How does it transmit? How many partners do you have? Do you wear a condom? Or, when was your first sexual debut? Any deviation from the expected biomedical answer is deemed folklore or flawed cultural belief of the group.

In this context, knowledge is considered a prerequisite to shifting attitudes and lastly, it acts to modify behaviors that lead to unhealthy practices. To the contrary, a large body of research in Sub-Saharan Africa has shown even when knowledge of the disease occurs it does not translate into behavioral change or risk reduction practices (Barnett & Whiteside, 2002). Nevertheless, the appeal for this tool is attributed to its simplicity; therefore, it provides public health organizations in the developing world, requiring no special skills to conduct the interviews beyond a simple training. The quantifiable data yield is also seen positively both for the relatively quick time it takes to gather the data and in the analysis phase of the project. However, there are debates regarding the usefulness of the data collected.

The point of contention between the two groups is that the opposing group sees KAPB Surveys as problematic in its lack of context in which the questions are not only formulated, but also when the answer deviates from the template it does not explain the reason for the nonconformity other than the usual ‘blame the victim’ assertions. This approach excludes the effects of social and structural causes of the disease and reduces the overall human experience to cognitive behavior (Airhihenbuwa & Obregon, 2000; Barnett & Whiteside, 2002; Green, 1999). Thus it impedes on the possibilities of an answer or even a potential remedy. Consequently, it solidifies the status quo and marginalizes the very individuals the programs were designed to help.

## **Dehumanizing and Xenophobic Subtexts In The HIV/AIDS Discourse**

The consensus among many of the international health governing bodies is that stigmatization of people with HIV/AIDS goes beyond the disease. The essence of the stigma comes from pre-existing conditions of society's in-built discernments of racial, ethnic, and sexual minorities. Selective targeting of women and other 'sexual minorities' mainly the homosexual population further exacerbates the situation. These historical perceptions contribute to the current explosion of the infectious disease. The global report from Joint United Nations Programme on HIV/AIDS (UNAIDS, 2004) revealed the daunting obstacle they faced as follows: "In many countries stigma and discrimination remain important barriers to understanding how marginalized groups of society are coping with the epidemic" (p. 17).

Some Western scientists have not made the road to prevention any easier, either by blaming victims or using the pretext of African culture as a "barrier" and as a means to justify the lack of program uptake, they have concocted and at times distorted data using biomedical tools to reduce the complex interactions between the disease and African society to mere incompatibility of the Africans to adopt to the 'sophisticated' Western knowledge (Ahlberg, 1994; Fassin, 1999; Gausset, 2001; Preston-Whyte, 1999; Sobo, 1999). Such scientific inhumanity of our modern time can be seen in the work of many so-called Western biomedical experts who were devised to pave the way for research in the understanding of how cultural systems shape sexual practices relevant to HIV/AIDS transmission and prevention (Gausset, 2001).

It is beyond the scope of this paper to list all the actors that have contributed to this discourse, however, two Australian demographers who have extensively worked in the HIV/AIDS arena and carried the label of expert, John and Pat Caldwell, in their research (Caldwell & Caldwell, 1987; Caldwell, Caldwell & Orubuloye, 1992; Caldwell, Caldwell & Quiggin, 1989), exemplify as among the most prominent actors of the generalized notion of Africa as the ‘special case,’ different in context and understanding of disease geography from anywhere else in the world (Schoepf, 2004).

With no supporting evidence they claimed HIV/AIDS disparity in Africa arises from the “hypersexual behaviors of Africans” (Gausset, 2001). Behavior which they claimed is due to weak marriage ties, the occurrence of polygamy, the limited role of the mother in the education of her children, the rejection by women to partake in sexual contact at the end of pregnancies, and overall African religious beliefs that prescribes and dictates the rules of fertility and ancestral lineage focus that makes it acceptable for sexual promiscuity to occur, thus fueling the current high rate of HIV/AIDS in the continent (Caldwell & Caldwell, 1987).

Furthermore, they go on to suggest future research needs to treat Africa as a whole as an ‘alternative civilization.’ They argue “Such social research [to contain AIDS] is likely to reveal a coherent society – indeed, an alternative civilization – very different in its workings, including its patterns of sexual behavior, than outsiders prescribing cures and even offering sympathy and support often realize” (Caldwell et al., 1989, p. 185). They further divide the disease along racial lines by dehumanizing Africans by claiming Africa as “the domain of Homo Ancestralis” (Caldwell & Caldwell, 1987, p. 410), a new

subhuman categorization based on their suggested African ancestral beliefs, which dictates the hyper sexuality of Africans (Stillwaggon, 2003).

This dominant viewpoint in biomedicine is in line with Western stereotypical and prejudicial perception Africans predates HIV/AIDS pandemic and echoes a similar theme of colonial tropical medicine. Stillwaggon (2003) extensively reviewed the legacy of Caldwell and Caldwell's work from 1988 to 2001. She uncovered the tremendous influence these scholars had on other research regarding the sociocultural framework of AIDS in Africa. Stillwaggon notes, under the guise of scientists and with the authority of biomedicine they wrote xenophobic cultural misrepresentation of Africans as undifferentiated "hypersexualized" promiscuous people. Their perception of Africans not only influenced research, but also informed the prevention policy. (Is this a quote?)

The Caldwell's and Quiggin (1989) further ridiculed anyone who dared to disprove their racist mentality by alleging such notion of 'perceived racism' is hindrance to the important work that must be done to contribute to the behavioral prevention strategies of HIV/AIDS in Africa. In an attempt to further humiliate their critics, they cite Miller and Rockwell (1988, p. xxvi) who contradicted their (1987) publication, by saying: "there is no evidence that Africans are more likely to be sexually promiscuous than people from any other continent." [...] "there is a tendency to look for factors that explain promiscuous sex lives, but in this is a serious risk of projecting age-old Western stereotypes and prejudices about sexuality onto African cultures" (as cited on Caldwell, Caldwell, & Quiggin, 1989, p. 186). In similar fashion the Caldwell's also attack Brokensha and Waite (1988) who also opposed the Caldwell's by saying, "Most of the

stereotypes were based on myths . . . [T]here was nothing inherent in African practices to support the notion that sexual excesses were widespread" (Brokensha & Waite, 1988, as cited in Caldwell, Caldwell, & Quiggin, p. 186).

These claims are shared by others who analysed historically rooted racist biomedical discourse of African or black hypersexuality. Gausset (2001) suggests, when it comes to the global HIV/AIDS prevention methods, there exists undisputed 'double discourse.' The first views culture as a barrier to prevention. The second tries to work with any existing barriers. He draws a conclusion from this dichotomy as follows:

In the West, one respects different cultural and sexual behaviors and one tries to make them safer without fighting against them; in Africa, one adopts the opposite attitude and one tries to eradicate what are identified as 'cultural barriers' to AIDS prevention. (p. 511)

Guasset (2001) asserts that the double standard is also widespread in biomedical facilities in Africa, which coincidentally have exposed people to HIV risks and even transmission of the disease. In cases involving unsanitary practices leading to transmission in facilities such as hospitals and clinics, the prevailing discourse does not instruct people to stop going to those facilities, rather efforts are put in place to improve the facilities and the blame does not go beyond the specific act to suggest inherent responsible on biomedicine.

On the other hand, in cases where cultural practices are implicated inducing factor of the transmission, it is labeled as a barrier and the system is too quick to instruct people to stop practicing those perceived negative cultural practices (Gausset, 2001). This

paradigm not only denies the local interpretation of disease, but also aggressively participates to erase existing local knowledge of the community. Thus, by reinforcing the hegemony of exclusively Western understanding of disease and treatment it shifts racism of biology to racism of culture.

Paul Gilroy (1987) in his book, *There Ain't No Black in the Union Jack*, puts forward a complementary argument regarding 'cultural racism' by voicing his frustration with the British elites and scholars who held vague views on racism to justify cultural supremacy, to which he noted, they no longer profess to ascribe to the old biological theories of scientific racism based on genetic differences of groups. Just as in earlier example of Barker's (1981), Gilroy concurs with the notion of 'new racism.' The word racism is obscured and instead replaced with culture or ethnicity to represent otherness from the dominant group. This new form of racism or cultural racism as Gilroy and others warn (Baker, 1981; Balibar, 1991; Gilroy, 1987, 1993; Taguieff, 1987) tends to forget the social and historical factors of the human experience that formed the discourse. Gilroy (1987) notes "Racism is not akin to a coat of paint on the external structures of social relations which can be scraped off if the right ideological tools and political elbow grease are conscientiously applied to the task" (p. 12).

### **Control of the Body and Life**

The West, with its resource-established biomedical system of healthcare that works for its own public health needs, was also utilized to write the policies and programs from their own perspective with slight adjustment for the outside population.

Accepted as the standard form of knowledge, the system has marginalized and eliminated any other forms of indigenous knowledge. Consequently, healthcare decisions rest in their own hands, measuring and designing theories and constructs of behavioral change based on their judgments and using psychosocial demographic questionnaires to reach important decisions that affect communities.

These communities have little to no control contribute or construct effective policy or programs based upon their traditional knowledge. Therefore, all too frequently traditional systems, such as indigenous health systems, are either destroyed or discredited and replaced by the dominant biomedicine discourse. Often these decisions, made by Western experts, follow utilitarian ethics. In the case of the HIV/AIDS, the prevailing attitude seems to be, “Let’s throw these at them and hope that it produces result for all,” instead of weighing the benefits and burdens of a particular program for the target community.

This philosophy appears to be based on the idea of the greatest good for the greatest number. Such attitudes in the past have given rise to atrocities in the history of public health. For example, individuals thought to pose public health risks were forcibly quarantined, incarcerated, and had their civil liberties taken away all in the name of the greater public good.

A well-known case here in the U.S. is the Tuskegee syphilis study, where disenfranchised groups were taken advantage of and used as guinea pigs for medical tests and observations (Reverby, 2010). The study was initiated in the 1930s as an examination of the natural progression and history of untreated syphilis in African American males; it



continued until 1972. The subjects were recruited without informed consent and furthermore deceived to believe that they were receiving free treatment for their so-called “bad blood” which is a term the group identified particular ailments in their environment and were not informed that they had syphilis or that they were being studied as a sub group (Cohen, 1999).

Access to other options for medical treatment was restricted and the group basically became a property of the biomedicine, and served as a sample for people of African descent in a laboratory shelf. For years after penicillin was discovered in 1947 treatment was never afforded to them because the objective for this clinical work was to “observe the natural progression of untreated syphilis” (Cohen, 1999; Epstein, 2008; Reverby, 2009). Instead the only incentive given to the group appealed to their economic disparity, which assured they would come back for the promise of free food, transportation, treatment for the so-called bad blood, and burial fees.

Pine et al., (1997) in their publication, recreated characteristics of biomedical research practices reminiscent of Tuskegee syphilis studies to a lesser extent. This involved medical experimentations conducted by major institutions in the United States such as Columbia University and other medical schools funded by taxpayer’s dollars. The study utilized biomedical racialization and victimization of minority children from African American and Hispanic families. The study used dangerous biochemical markers to analyze possible predispositions of violence in minority children who had siblings incarcerated in the juvenile detention system. The target group was justified as “young boys who show clinically significant aggressive behavior or who are raised in a social

environment that is conducive to the development of chronic aggression” (Pine et al., 1997).

The racial undertone is evident in both their selection of minority children as prime control groups for ‘aggressive behaviors’ and in their hypothesis, which claimed social upbringing as a precursor to ‘chronic aggression.’ Even worse, the children were subjected to the now banned drug commonly known as ‘fen-phen’ or fenfluramine, which was linked to cause heart defects (Connolly et al., 1997). Likewise, structural sources such as knowledge and socioeconomic disparities of the two minority groups who were perceived by researchers as inherently violent due to their environmental upbringing played a major role for their targeting.

These scientific abuses based on racialized attitudes by Western biomedical personnel have historical reoccurrences for people of color. Given the historical malpractice of biomedicine, bioethics needs to be more prevalent in examining biomedical research, pharmaceutical companies, and other institutions vested in the HIV/AIDS prevention in Sub-Saharan Africa as well.

As a result of this and other atrocities in the name of biomedical research, several measures to protect human subjects and vulnerable groups were enacted. In 1974, the formation of the National Research Act by congress established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research to guide biomedical research in human subjects (Beauchamp, 2008; Field & Berman, 2004; Reverby, 2009). Further measures were put in place following the horrific abuses of Tuskegee to protect people from dangerous and unethical experimentation.

## **Limitations of the Study**

In the future, I hope to incorporate local epistemology and other marginal voices, which struggle to liberate themselves from the hegemonic biomedical paradigm. In order to compliment or detract from previous studies, I hope to conduct ethnographic research in the local communities by following the “emic” approach, which allows me to examine the behaviors of individuals in their cultural context. Taking this approach will help design better prevention methods that are tailored to the culture of the individual rather than the human race in general. Emic prospective will also allow me to incorporate local experts.

## **Conclusion**

Among the crucial lessons gained in this study is the unearthing of widespread inconsistencies that exist between the notion of biomedical ‘truth’ - based on scientific proof and impartiality - versus the reality of life in Africa. The African reality shows evidence of a biomedical discourse built on domineering and discriminative cultural practices and beliefs. Following the research questions as a guide, the study first illustrated who controls, defines, and evaluates knowledge in the context of HIV/AIDS prevention efforts in Sub-Saharan Africa and how that knowledge is used not to just reinforce power and dominance, but to reinforce the priorities and motivations of the dominant actors. Secondly, the implication of monological and monocultural practices and their intended and unintended impacts in public health policies of HIV/AIDS prevention efforts in Sub-Saharan Africa was highlighted. Lastly, through the work of

Michel Foucault and other social scientists, the study demonstrated how the concept of bio-power and biomedicine are inextricable given the patterns of discourse before and after the advent of the of HIV/AIDS.

Western biomedicine has shown its power to produce, distribute, administer, and regulate HIV/AIDS knowledge in contemporary Africa. Where boundaries of a state used the exertion of power in the past, contemporary Western states employ technologies as an extension of Western governmental influence and dominance. Throughout the paper it was demonstrated what may have been well-intended humanitarian effort to display a side which exhibits a negative unintended consequence. Foucault's description of bio-power and the concept of "people as species" who are subject to the states control is applicable in this context, not just for Africans and Africa as a generalized entity, but to all people afflicted with challenging disease that were generalized and categorized as at risk groups.

The take-home message is that there are arrangements and systematic processes that facilitate this type of knowledge or limit it. In the Foucauldian reasoning, it falls under the definition of 'regime of truth.' Foucault argued:

Truth isn't outside power. . . . Truth is a thing of this world; it is produced only by virtue of multiple forms of constraint. And it induces regular effects of power. Each society has its regime of truth, its 'general politics' of truth; that is, the types of discourse which it accepts and makes function as true, the mechanisms and instances which enable one to distinguish true and false statements,

the means by which each is sanctioned . . . the status of those who are charged with saying what counts as true. (Foucault, 1980, p. 131)

Finally, this study will serve to inform future researchers to be cognizant of the interplay between history of Western biomedicine in the African continent and its diaspora and the despondent link of racism whether ‘old’ or ‘new,’ colonialism, and the socio-historical context that formed them to define any disease. To reiterate the cautionary call of poststructuralist advocate scholars, to say, disregarding and forgetting, the root causes of injustice will not erase the visible effects of its outcome. If this review of existing HIV/AIDS discourse and conceptual models for prevention and treatment can help identify where the program disconnect lies, then a thorough follow-up investigation in greater detail to determine their efficacy will aid in the construction of a sound and effective conceptual model for newly infected populations. Consequently, this will also aid in addressing the clear link between the disease, racism, and economic disparities in the developing world, particularly Sub-Saharan Africa.

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