HIV-Related Stigma Among African Immigrants Living with HIV/AIDS in USA

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Abstract

Recent advances in the fight against HIV have increased the life expectancy of those infected. Despite these, a number of barriers such as stigma continue to affect HIV prevention and treatment. Although the body of work on HIV stigma is growing, there is a paucity of literature on the experiences of specific sub-groups such as African immigrants living with HIV. Drawing on in-depth interviews with a sample of these immigrants in the US, this study examines their experiences of HIV-related stigma, its impact on their lives, and the means of coping and resistance they adopted. Like other persons living with HIV, study participants experienced interpersonal, internalized and institutional stigma. However, their experiences of, and responses to stigmatization are shaped largely by cultural/religious assumptions and perceptions about HIV learnt from their countries of origin and western media's construction of HIV. The study concludes with broader implications for further conceptualization of stigma.

Keywords: *HIV/AIDS, Stigma; Africa; Immigrants; Inequality; Discrimination; Immigration*

Introduction

1.1 Within the past decade, tremendous advances in the fight against HIV have resulted in declining mortality rates and improved life expectancy of those infected. Despite these advances, there continue to be strong social barriers such as HIV-related stigma that negatively affect HIV testing, disclosure, access to care, and health status of populations that may be at high risk of infection. African immigrants^[1] are one of such populations.

1.2 The number of African immigrants in the United States of America (US) continues to increase. There were about 800,000 (close to 3% of US population) African immigrants in US in 2000 (U.S. Census Bureau 2008), representing an increase of more than 166% since 1990 (Logan and Deane 2003). African immigrants represent a variety of linguistic, cultural, ethnic, class and religious backgrounds, reflective of their countries of origin. These immigrants come from West, East and Southern African regions, arriving either as students, spouses, refugees, independent or economic migrants who invariably tend to reside in urban centres.

1.3 The actual number of African immigrant persons living with HIV (AFIM-PLWHA) in US is unknown due to inconsistent reporting criteria in different localities. However, a recent analysis of 2003-2004 HIV diagnosis data from five US states and selected localities^[2] indicated that African immigrants accounted for 3.8% of overall HIV diagnoses, 41% among women and close to 50% among blacks in all the areas studied (Kerani et al. 2008). Though African immigrants constitute a small proportion of HIV prevalence in US, Kerani and her colleagues suggested that they might be disproportionately affected by the epidemic and therefore merit greater programmatic attention.

1.4 Although the literature on HIV-related stigma is growing, little is known about the experiences of specific sub-groups such as African immigrant persons living with HIV (AFIM-PLWHA), with the possible exception of a few studies (Foley 2005; Anderson and Doyal 2004; Rosenthal et al. 2003; Dodds 2006; Doyal and Anderson 2005; Othieno 2007; Doyal et al. 2009; Doyal 2009). These studies showed that African immigrants face several barriers in accessing HIV services, including lack of accurate information about how HIV is transmitted, prevented and treated, linguistic difficulties, legal status concerns, fear of the American health system, late testing/diagnosis of HIV, stigma, culturally-inappropriate HIV education and prevention strategies, as well as ethno-cultural beliefs and practices that negatively impact attitudes and

behaviours towards sexuality. However, none of these studies has focused exclusively on stigmatisation experiences and responses of African immigrants. Even when stigma is examined, it is rarely explored in the context of African cultural norms and values.

1.5 An examination of stigma within African immigrant communities demands attention to the cultural norms and values that undergird the discursive construction of, and responses to HIV in African cultures. This focus is important because it is these very constructions and responses that pre-condition negative attitudes and behaviours towards persons living with HIV/AIDS (PLWHA) in their countries of origin, and continue to do so in their communities of settlement abroad. Moreover, the reinforcement of these cultural values through continuing travel and contact with relatives and friends in their countries of origin, as well as the inability of American health education and promotion efforts to fully penetrate the tight-knit African immigrant communities have ensured the persistence of these stigmatising attitudes and behaviours. Given the impact that stigma can have on HIV testing and care, it is critical to examine the social construction of such stigma and how it can be addressed in various populations. Consequently, this study analyses the lived-experiences of AFIM-PLWHA, with particular emphasis on their experiences of, responses to stigma, and how such experiences and responses can be situated in assumptions and perceptions about HIV in their countries of origin and of settlement.

CONCEPTUALISING STIGMA

2.1 Since the emergence of the HIV epidemic in the early 1980s, PLWHA have been subjected to high levels of stigma and discrimination (Joint United Nations Programme on HIV/AIDS (UNAIDS) 2002). Goffman's conception of stigma as "an attribute that is deeply discrediting" (Goffman 1963, pg 3) has been central to the analysis of HIV-related stigma (Sandelowski et al. 2004; Parker and Aggleton 2003; Alonzo and Reynolds 1995; Deacon 2006). Following Goffman, analysts have conceptualised stigma as a 'blemish' of character resulting from immoral, promiscuous or disreputable behaviours. Consequently, PLWHA and the groups with whom they are associated tend to be constructed as the disgraceful 'other' whose needs are different from and inimical to those of the 'unblemished' (Zhou 2007).

2.2 Although Goffman urged analysts to focus on a "language of relationships, not attributes" (Goffman 1963, pg 3) in their examination of stigmatised identities, his emphasis on the "spoiled identity" and "discrediting attribute" of the stigmatised person has shaped the analysis of stigma in individualistic terms (Parker and Aggleton 2003; Deacon 2006). This individualistic framework, influenced largely by social psychology (e.g., see: Jones et al. 1984; Crocker et al. 1998; Campbell and Deacon 2006) views stigma as an attribute of persons, and emphasises the perceptions and stereotypes of the stigmatiser as well as the impact of stereotypical behaviours on the stigmatised person. In so doing, the individualistic framework tends to ignore the social structural conditions that produce stigma, and instead, constructs stigma as "something *in* the person stigmatised, rather than as a designation that others attach *to* that individual" (Parker and Aggleton 2003, pg. 14).

2.3 By contrast, the sociological approach argues that stigma is not something that is inherent *in* individuals but results from "a complex social process linked to competition for power, and tied into existing mechanisms of dominance and exclusion" (Campbell and Deacon 2006, pg 412). Specifically, stigma engenders and thrives on difference: it elevates some groups as superior and relegates others as inferior. Thus, in order to understand the social forces that create and reinforce this difference, it is imperative to situate stigma along the axis of power, domination and control. This power in turn facilitates "the construction of stereotypes, the separation of labelled persons into distinct categories, and the full execution of disapproval, rejection, exclusion and discrimination" (Link and Phelan 2001, pg. 367).

2.4 Through the construction of stereotypes, stigmatisation enables people "to distance themselves and their self-defined in-groups from the risk of infection by blaming contraction of the illness on characteristics normally associated with out-groups, who are classified as deviant and 'other'" (Deacon 2006, pg. 420). Granted that the choice of the 'other' is rooted in social relations of power, and given that the 'other' is often the powerless, stigmatisation allows the designation of different groups of people (such as commercial sex workers, men who have sex with men and people from certain geographic regions) as being disproportionately at higher risk of HIV infection (Deacon 2006; Petros et al. 2006; Nelkin and Gilman 1988). Moreover, it is imperative that stigma theory take cognisance of what is at stake (e.g., the loss or gain of social status, life chances and good fortune) or what Yang and associates term 'moral experience' (Yang et al. 2007) in a given social world. Accordingly, stigmatised conditions threaten those issues that matter most to the sufferers and non-sufferers, prompting the latter to respond to the stigma by protecting themselves from the perceived threats.

2.5 Indeed, given the complementary roles of prejudicial attitudes as well as socio-structural forces in perpetuating differences, it is imperative to conceptualise stigma as a social construction, influenced by both individual predispositions and structural factors. As succinctly summarised by Mahajan (2008, pg

S71), “stigma exists when the following four interrelated predispositions and behaviours converge: (i) individuals distinguish and label human differences; (ii) dominant cultural beliefs link labelled persons to undesirable characteristics (or negative stereotypes); (iii) labelled persons are placed in distinct categories to accomplish some degree of separation of ‘us’ from ‘them’; and finally (iv) labelled persons experience status loss and discrimination that lead to unequal outcomes”. Thus, the interrelated components of labelling, distancing, discrimination - fuelled by the threat of an infectious disease to what is socially at stake - will be central to the analysis of stigma mechanisms in this paper.

METHODS

Recruitment of Participants

3.1 Currently, in the US there is no known sampling frame for African immigrants infected with HIV. This is partly due to the fact that not all localities routinely collect country of birth information during HIV testing. As a result, some studies of AFIM-PLWHA recruit participants from care settings such as public HIV/STD clinics or AIDS Service Organisations. This strategy however does not capture those who, for various reasons (such as fear of stigma or privacy concerns) seek care in private clinics or outside their immigrant communities. Consequently, I decided to recruit participants from this ‘hidden’ population by using purposive and snowball sampling techniques. I recruited the initial set of three participants who disclosed their status during a session at the National Association of People with AIDS “Staying Alive” Conference in 2006. I then asked those ‘seed’ participants to direct me to other AFIM-PLWHA. This second group of subjects also introduced other subjects for possible inclusion in the study, until a total of seventeen (17) participants were successfully recruited from various cities in the states of Pennsylvania and New Jersey.

3.2 In addition to being infected with HIV, a primary inclusion criterion was that participants had to have been born in Africa and lived there until they became adults before migrating to US. This restriction was necessary to differentiate the experiences of African-born immigrants (from those born in the diasporas), whose beliefs, attitudes and behaviours towards HIV and PLWHA are likely to be influenced by their previous exposure to the disease and its framing in Africa. After obtaining informed consent from the participants and assuring them of the confidentiality of the study, I arranged interviews at a time and place convenient to them. I offered them a choice of either a phone, face-to-face or email interviews. Most opted for combination of phone and email interviews, while a few preferred in-person interviews. The data collection, processing and reporting were guided by the relevant ethical guidelines^[3], which were adapted to protect the identity, confidentiality and safety of study participants. Thus, in reporting the study results, pseudonyms are used and no direct attributions are made to their countries of origin.

Data Collection and Analysis

3.3 Data were collected through semi-structured interviews lasting between one to two hours, either by phone, email or in person. Phone and face-to-face interviews were tape-recorded and transcribed, while logs were kept of the email interviews. The interviews covered: (i) participants’ socio-demographic characteristics, (ii) how they migrated into the US - whether as refugees, visitors, students or economic/independent migrants, (iii) their general health status, HIV diagnosis, its meaning to them, disclosure, access to care, support, as well as (iv) their experiences of and responses to stigma. This paper is based mainly on the analysis of participants’ narratives about their lived-experiences of stigma; the additional information collected provided context to the findings.

3.4 A grounded theory approach (Strauss and Corbin 2007) was adopted to understand participants’ narratives. Such an approach is useful because of the recognition that knowledge and meanings are embedded in and emerge from people’s lived-experiences. This enables researchers to describe those experiences from the standpoint of those who experienced and are able to articulate them. Consistent with such a framework, data analysis began with a thorough review of the interview transcripts, followed by the identification of recurrent/emergent themes and concepts within and between transcripts (Boyatzis 1998; Creswell 2006). The analysis was iterative: the identification of new concepts and themes meant a re-examination of those identified earlier. This process allowed for empirically grounded findings reflecting shared understandings of the given subject.

Study Participants

3.5 Six men and eleven women, ranging in age from 28 to 54 years (mean age 35 years) participated in this study. With the exception of one participant who indicated he is gay, all others identified themselves as heterosexuals. Four of the women and two of the men reported they were married, while the rest indicated being single or involved in relationships. Participants also reported varying levels of education: four are university graduates while six completed some levels of college/technical/vocational education; three

completed high school, and the rest (four) had finished primary/elementary school. All participants indicated that they were employed at the time of the interview, with the exception of two who were on HIV-related disability and one who was unemployed. Most of the study participants stated they have been in the US for about ten years. Four have their permanent resident statuses (green cards), while the rest are temporary workers, visitors, students or undocumented residents. All participants reported being diagnosed after arrival in the US, either through routine or prenatal tests, partner-notification processes, or as part of mandatory immigration medical tests.

FINDINGS

Experiences of Stigma

4.1 The experiences of AFIM-PLWHA reported in this paper overlap with those of other PLWHA in the US (Ciambrone 2003; Mrus et al. 2005; Brown 2003; Green and Sobo 2000). What is distinctive about AFIM-PLWHA, however, is that their experiences of, and responses to stigmatisation are shaped by (i) their cultural and religious values, (ii) the meanings and assumptions about HIV and PLWHA in their countries of origin, as well as (iii) Western media's construction of HIV as an African or a 'black' disease.

4.2 Participants' narratives indicated they experienced stigma through (a) individual discrimination or social/interpersonal rejection (b) institutional (i.e., employment, immigration) discrimination, and (c) internalisation of stigma experienced from their environment. This section presents the analysis of participants' experiences of stigmatisation, indicating, their overlap with and differences from the experiences of other PLWHA in US.

4.3 Social and Interpersonal Rejection: Many participants shared poignant experiences of community gossip, distancing and harassment from friends and family after the disclosure or suspicion of being infected with HIV. These experiences could be better understood if framed within prevailing discourses about HIV/AIDS in Africa.

4.4 There is a widespread belief in many African countries that HIV infection results from deviant, social and religiously proscribed behaviours such as extramarital sexual relations, promiscuity, homosexuality and prostitution or from sexual relations with foreigners/outside (Ankomah 1998; Nzioka 1996; Mill 2001; Ulasi et al. 2009; Anarfi and Awusabo-Asare 1995). Given these perceptions, Dace (a 34 year old East-African woman) wondered how she got infected since she believed she is not a 'cheap' (promiscuous) woman, and went ahead repeating the tests at different places before finally accepting her status. Maccus (a 28 year old Southern-African man) claimed he is mystified by the source of his illness, because as a "straight" (heterosexual) African male, he was not "supposed to have this" [i.e., HIV], and his friend's reaction to his disclosure was: "where you get this shit – only gays and prostitutes get this..!" Similarly, Zada (a 36-year old West-African woman) shared her family's belief that she got HIV from "sleeping with a white man in America".

4.5 Dace, Maccus and Zada's observations link HIV to promiscuity and deviant sexual relations. In addition to immorality, African discourses associate HIV and/or PLWHA with imminent mortality, as evident in labels such as *maiti inayotembea* (walking corpse) - used in Tanzania; *makizi yaku mochari* (keys to the mortuary) - used in Zambia; *menfese mute* (ghost) - used in Ethiopia; *Kakokoolo* (scarecrow) or *K'amuyoola* (was caught in a trap) – used in Uganda; and *basabasa* (promiscuous person) – used in Ghana (Mill 2001; Nyblade et al. 2003; Muyinda et al. 1997). In this vein, linguistic labels not only reflect community perceptions, but also typify stigmatising attitudes, including the inevitability of mortality. Consequently, being infected with HIV is not only a personal disgrace for which one is held responsible, but also a curse that is accordingly punished through distancing or shunning by family and community members.

4.6 Distancing and shunning takes many forms in African countries. Some of these include: isolating the PLWHA in separate quarters - where they eat and sleep alone, marking and separating their personal belongings from those of others, refusal by community members to buy food from a vendor or sit near anyone suspected of being infected with HIV (Sambisa 2008; Odimegwu 2003; Nyblade et al. 2003). Given these orientations, it is not surprising that participants reported several instances of shunning and distancing from their immigrant communities. Amber (a 30 year old Southern-African women) and Sabra (a 35-year old East-African woman) indicated that some community members shunned their company, while their friends started taking "protective measures", including "washing their hands" and providing "water or drinks in a dedicated cup or glass", after news of their infection spread around in the community. In fact, so severe is the stigma within African immigrant communities that people look for physical clues, such as sudden weight loss and skin rashes as a sign of HIV infection and a basis for stigmatisation. Thus, the physical side effects of HIV medications are not only visible reminders of the destructiveness of HIV, but

also the basis for gossip and distancing. Put differently, the degree of experienced (felt) stigma varies, and could be more severe for those with physical symptoms such as lipodystrophy and lipoatrophy^[4] - two visible signifiers of sero-status to anyone familiar with HIV infection and treatment.

4.7 If stigma is not manifested in distancing and shunning, it breeds fear and denial, as observed by Lamar (a 45 year old Southern-African man):

Our [African] communities do not want admit that HIV is here – them blame other people.... so you get HIV, you got to pretend, you know...not tell anyone here or back home. But I know the situation is changing ...in my home because many people are so affected, so it is becoming regular part of life there.

4.8 A number of participants traced the denial to the fact that HIV is a taboo subject in many African communities. For example, in Uganda, denial and silencing takes many forms. This includes insistence by family that an infected family member's health was improving when it is not actually the case, misattributing HIV symptoms such as skin rashes and weight loss to bedbug bites, witchcraft or poverty, and abbreviating, if not disallowing the tradition of showing relatives and friends the face or the body of the diseased, if death is HIV or AIDS-related (Muyinda et al. 1997). At the same time, a number of participants such as Lamar acknowledged that the experiences of stigma differ within various African regions, by stressing that the increasing HIV prevalence in Southern Africa might actually normalise and moderate stigmatising attitudes in those, as opposed to other, regions of the continent.

4.9 In short, stigma results in fears of disclosure, denial or a 'life in the shadows'. Life in the shadows represents a sort of self-imposed seclusion from the community. Just like distancing and shunning, seclusion reflects community censure against stigmatised conditions such as HIV. More importantly, such censure is a manifest recognition that HIV and its association with immorality and mortality is not only a defiling mark that causes an infected person's family to lose its face, but also limits the person's ability to be a fully functional member of his or her family, marry and procreate to extend the family lineage. In other words, it threatens core values and beliefs that are essential to the survival of African communities. It is no surprise then that a number of participants reported that they would rather hide their diagnosis from their families than face its associated censure and shame.

4.10 *Self-Imposed or Internalised Discrimination:* According to Last (2000, pg 56), 'internalised' stigma is "stigma internally imposed by the stigmatised themselves, who then pattern their behaviours to avoid the (possibly) imagined stigma of others". This 'internalised' stigma affects PLWHA in two ways. On the one hand, it has been linked to delays and/or avoidance of care seeking (Reidpath et al. 2005). Some participants expressed apprehensions about or refused to seek care because of fears of further stigmatisation, while others were compelled to seek care in nearby towns in order to avoid chance meetings with neighbours, friends or other acquaintances.

4.11 On the other hand, internalised stigma affects the identity of PLWHA. They feel reduced from a "whole and usual person to a tainted discounted one" (Goffman 1963, pg 3). As a result, they blame themselves for their illness and desire to keep it a secret. Candi (a 41 year old Southern-African woman) admitted that she felt like she was "carrying this bag of shit" that she "will give to anyone who gets close". Similarly, Jagger (a 42 year old West-African man) admitted his shame about his past:

I had my wild days, yes, I remember, in Mombasa, London, New York. I feel cursed. I am paying for my bad life. I try not to blame myself too much, but it gets to you, you know, man, it gets to you....

4.12 Jagger's feeling that his infection is a curse for past (sexual) misdeeds is in line with traditional African cosmology which views 'mysterious' diseases (such as HIV) as resulting from immoral acts and/or punishment from the gods (Caldwell et al. 1992; Mbiti 1990; Okpako 2006; Twumasi 1975). Consequently, the sick must silently and disgracefully carry the burden of their illnesses.

4.13 While some participants blame themselves for their infection, others believe they are not responsible for it. One participant reported that she got infected because she could not gather the courage to leave her sexually oppressive provider and husband, while others such as Gafna (a 33 year old East-African woman) saw themselves as powerless and 'undeserving' of the infection because they had led what they believed was a 'normal' life, and got infected by accident (e.g., through promiscuous partners). To these 'undeserving' participants, their shame results from lack of agency to escape from poverty and resultant sexually oppressive relations.

4.14 Beyond shame and self-blame, the transition from an "untainted" to a "spoilt" identity (Goffman 1963, pg3) results in identity dissonance. For PLWHA in particular, identity dissonance is a feeling that occurs

when a person is unable to assimilate the reality of living with HIV into their overall identity or what Rosenberg (1979) calls the 'self-concept' or 'self-picture'. The self-picture is the concept a person has of him/herself. It is mainly innate and consists of his/her capabilities, attitudes and beliefs that direct his/her behaviour. This self-picture therefore becomes the pivotal influence, defining a person's identity. When a PLWHA is unable to accommodate their experiences of living with HIV (the shame, the guilt, the physical changes) into their self-concept or self-picture, the resulting identity dissonance creates feelings of distress, inadequacy and reinforces the shame. Study participants expressed this dissonance in various ways. For example, Candi (a 41 year old Southern-African woman) claimed that:

It all started with the meds when I got the rashes. It was so bad I stayed in my room for weeks because you know when people see me they talk ...then doctors change my meds again! Then, my legs became small, and my face change so much. At that time, I don't look in the mirror. It was not me, Candi.

4.15 Candi's comments evoke the tension between her self-concept or self-picture and the 'spoilt' identity (from physical side effects) she has to live with as a result of HIV. Her decision to not "look in the mirror anymore" may reflect an attempt to deny the existence of the 'spoilt' identity. Other participants also noted the inconsistency between being infected with HIV and their socio-economic statuses. Jagger commented on this struggle:

I try not to blame myself too much, but it gets to you....hmmm, particularly when you know you are educated and should have known better not to have had sex without a condom...I feel ashamed, even friends will start wondering how a smart man like me would manage to get a HIV. They can't understand ...

4.16 Jagger's observations reflect the identity dissonance he was experiencing. His comments echo a common perception in African communities that HIV affects only those who are uneducated or poor, prompting educated participants such as him to blame themselves for their infection. Such self-evaluation partly reflects societal norms and expectations of their socio-economic status, since they view HIV infection as one indicator of status inconsistency (Gerschick 2000; Lenski 1966). Status inconsistency directly feeds the cognitive dissonance: Jagger's shame therefore resulted from his inability to reconcile his self-concept (of an educated man who should have known better about safer sex) with the new identity of living with HIV.

4.17 Ultimately, HIV imposes a 'master status' (Goffman 1963) on the normal identity of the person living with HIV, supplanting it with one constructed around biomedical markers such as antibody testing, CD4 counts and viral loads, influencing every decision of their lives – from disclosure, occupational choices, decisions on sexual partnerships and relationships, to future fertility. Candi (a 41 year old Southern-African woman) shared her experiences with physical symptoms of HIV:

After the news [diagnosis] everything was ok until I got the medications. Before then, I was normal.... just like everyone. But when I started medications, everything different. I did not understand why I have to take the meds everyday. Sometimes, I forget I have HIV until its time to take my meds, then I remember that I am not normal anymore. Then the rashes came later... I spent so much time in the clinic ..new tests, new medications, new side effects..... You see that's why I call HIV my *El-Nino*. Now when I think of me, my life, my body, my face, everything about me, I have to think of *El-Nino*: so, am I not *El-Nino*?

4.18 The above excerpt illustrates the shift in participant's identity from a normal person *sans* biomedical concerns to one that is 'medicalised' by constant reminders of ones illness. Undoubtedly, Candi's designation of HIV as (hurricane) '*El Nino*' metaphorically illustrates not only the potentially destructive but pervasive influence of HIV on their lives. So deep is the effect of stigma on their identity that participants such as Candi can no longer think of themselves as regular persons, but in relation to their HIV status - a unitary identity in which personhood is inseparable from their illness (Flowers et al. 2006). As will be shown in the last section of this paper, renegotiating these emerging identities constitutes a core part of participants' stigma management strategies.

4.19 Institutional Restrictions and Rejection : In addition, study participants reported instances of HIV-related stigma and discrimination from US institutions. For example, Lamar (a 45 year old Southern-African man) indicated that he experienced indirect discrimination when it was suspected that the cost of his medical care was somehow linked to sudden increases in his employer's insurance. He explained that he became concerned about his employer's and colleagues' comments whenever he became sick and missed work:

...they would ask me if I am on vitamins or if I was exposed to something on my recent trip

back home [Africa]...at the back of my mind, I kept thinking: they see an African man, they see disease...terrible! This boss stressed me out with harder projects....I left ...since then, I swore never to work for small companies...

4.20 Although Lamar had no direct proof of discrimination due to his medical condition, he felt vulnerable, especially in a small company that was sensitive to fiscal constraints, and within a larger societal context that perceives him (and his African community) as a carrier of HIV. Other participants reported service-related barriers such as limited access to quality treatment, mistreatment and insensitivity by health care workers because of their condition. Udela (a 35 year old East-African woman) shared her experiences of discrimination in a care setting:

Imagine...you get there [clinic]...because you have HIV. But you speak little or no English....they get interpreter...you pray she no come from your country...you feel you no belong...you feel you different because you not be able to talk by yourself. Some staff even laugh at you... Them nurses are so ignorant..they gossip me, one said: "her viral load is high....you know she is new here....just from [Africa]...we have to be careful..I hear their HIV is different".

4.21 Similarly, Nada (a 44 year old East-African woman) recalled how her doctor broke the news of her diagnosis to her:

He came in, looked at me some way, and asked where I come from.... [laughs] hmmm...yes, [nods head] first question he asked me. I told him, and then he said: "there is lot of HIV cases where you come from...in Africa"

4.22 Admittedly, negative attitudes by caregivers have been reported in US and elsewhere (Abell et al. 2007; Ohnishi et al. 2008). However, as the experiences of Udela and Nada show, negative attitudes tend to be discriminatory when they deride language difficulties of patients and associate their HIV status with their countries of origin, thereby reinforcing their sense of being different (or 'other'). Undoubtedly, the institutional discrimination faced by AFIM-PLWHA is intrinsically bound with their immigration status. For most participants, HIV diagnosis meant confronting immigration restrictions, especially the 'HIV Entry Ban', which restricts immigrants who test positive for HIV from lawful admission into the US unless they are able to obtain limited waivers (United States Citizenship and Immigration Services 1993). Until its recent repeal by the US government (U.S. Department of Health & Human Services 2009), the 23 year-old "HIV Entry Ban" had been the clearest indicator of institutional discrimination against PLWHA. More importantly, for AFIM-PLWHA, this immigration restriction had, for many years, foreclosed a return to their countries of origin (due to stigma and concerns about medical care) and prevented their fuller integration into US institutions. Consequently, almost all participants in this study indicated that although they face a distinct hierarchy of needs, resolution of their immigration status is a priority.

4.23 Indeed, the institutional stigma participants experienced has to be understood in the context of mainstream western media's portrayal of HIV. With almost daily barrage of sensational headlines and pictures of infected children, buttressed by statistics that indicate that sub-Saharan Africa carries the heaviest burden of HIV/AIDS, the western media has succeeded in giving AIDS an 'African face' (Michira 2002; Downing 2005). Such portrayal of HIV tends to perpetuate the stereotypical myth that HIV/AIDS originated from Africa, and reinforces the association of HIV/AIDS with the continent. It is in the context of such discourses about HIV and Africa that stigmatising attitudes and behaviours take place. Thus, participants' experiences underscore the fact that stigma is a social process, involving distancing and discriminatory attitudes (by the privileged) towards the "other" (here, people of African origin) thereby perpetuating social inequalities and exclusions (Deacon 2006; Joffe 1999). Viewed in this way, one cannot but agree with Parker and Aggleton's (2003, pg.17) assertion that "stigma arises and stigmatisation takes shape in specific contexts of culture and power". Such power is usually lodged in, wielded and executed by the full apparatus of the state (Das et al. 2001; Yang et al. 2007).

4.24 Participants' experiences of stigma (whether individual, institutional or internalised) need to be situated within a broader framework of stressful life events that define their life as migrants. Some of these events include accommodation and language difficulties, poverty, family separation, and challenges in navigating social and medical services in the US. Unlike other PLWHAs in the country, AFIM-PLWHA have to confront these problems *in tandem* with their HIV status, as observed by Pancho (a 35 year old male of East-African origin):

Like last time I go to clinic and the counsellor ask if I can join support group. I tell him that dem people no understand me. I come here with no papers, no job, my family back home, and I be African with HIV. HIV one more problem for me You see, we all get this disease, but we feel it different.

4.25 The above excerpt shows that variations in experiences of stigma are related to socio-economic, cultural and other differences. Put differently, for AFIM-PLWHA, their reality of life with HIV intersects with other social disadvantages related to their status as migrants from Africa. It is such multiple realities, or layers of disadvantage that intensify their differential experience of stigma, and set them apart from other PLWHA.

Managing and Challenging HIV Stigma

4.26 The foregoing analysis has shown that living with HIV and its inherent stigma entails a “biographical disruption” (Bury 1982, pg 167), fracturing the everyday lives and identity of those infected (Flowers et al. 2006). However, study participants did not passively accept this “disruption”. Instead, many of them chose to confront and resist the stigma through specific strategies aimed at bringing more meaning into their lives. Some of these strategies are: (i) keeping their illness a secret (ii) selective disclosure to friends and family, and (iii) public disclosure intended to challenge stigma and normalise life with HIV.

4.27 It has been documented that PLWHA in many African countries, as elsewhere, endeavour to keep their illness a secret (Anarfi and Awusabo-Asare 1995; Nyblade et al. 2003). Accordingly, a number of participants such as Nada (a 44 year old East-African woman) reported going to various lengths (e.g., hiding her medications, attributing HIV-related illnesses to less-stigmatising ones) to hide their status from the community. Others like Candi (a 41 year old Southern-African woman) adopted more creative strategies such as wearing pants or using cosmetics to hide some of the bodily changes associated with antiretroviral therapy. Both Nada and Candi's efforts to hide their illnesses are typical attempts by PLWHA to maintain control over the stigmatising effects of their illness.

4.28 Instead of hiding or covering up their illness, some participants chose to disclose either to attract sympathy and support or to avoid and neutralise its associated fears and shame. Baileys (a 54 year old East-African woman) reported that she decided to disclose to selected friends and family members after a close friend died of AIDS without disclosing her status to them. Pancho (a 35 year old East-African man) also overcame his initial fears about disclosing his status to a potential partner from his country of origin, then ultimately disclosed to and married her. These examples point to the risks and apprehensions about disclosure, particularly within tightly knit African immigrant communities, where rumours circulate with high velocity. As a result, many participants resorted to strategic disclosure: a disclosure that is more guarded and guided by weighing its longer-term implications.

4.29 Some participants supplemented strategic disclosure with sero-sorting their friendship ties. To these participants, having friends who either are infected with HIV or have favourable attitudes towards HIV and PLWHA constitutes a buffer against stigma. Jagger (a 42 year old West-African man) indicated that he decided to “hang around only people who were like me or who would accept me”. Here, the principle guiding disclosure is homophily: people with similar attitudes and experiences are more likely to be supportive of each other. Thus, in some respects, the experiences of, and responses to stigma by infected persons are partly influenced by the structure and composition of their personal networks (Shelley et al. 2006).

4.30 Unlike the above strategies, the next two strategies involve challenging the stigma in a much more proactive manner. The first of these strategies is termed ‘deviance disavowal’ (Davis 1961). This process involves externalising the illness and convincing oneself and others that even though one is infected with HIV, one is just as normal as other people. Sabra (a 35 year old East-African woman) boasted of her accomplishments despite being infected with HIV:

Look me. I look good. I work. I normal like you. I have this sexy boyfriend, who love me, even when he know I positive. HIV not make me who I am!..no, no no...! I still me...strong and beautiful.

4.31 The second set of strategies involves open or public disclosures. Two participants indicated they disclosed not because of sympathy or support but to affirm their dignity and pride about their sero-status. In response to questions about the reasons and timing of their disclosure, one participant explained:

You asked me why I disclosed. It's not because of pity... Sympathy? Hell NO !! I am too strong for that. I disclosed because I want to educate my people that HIV is real – that regular people can have the disease, but they can have regular lives if they get treatment...I disclosed in my church.... I stood there, and told how I got the disease, ...jaw-dropping huh ...it felt good. I can now walk with my chin high, instead of hiding (Wally a 51 year old Southern-African man).

4.32 Another participant perceived disclosure as an active response to stigma. Imbued by her early

experience with HIV, and religious faith, she viewed disclosure as entailing positive activism against the burden of stigma, as she explained below:

I had to deal with HIV since I was young - back home, it is hard to find someone who has not lost a brother, a sister, a friend or a neighbour to HIV. Because of this people are getting more open, instead of living in fear. If we don't come out and disclose, who would fight for us. Look at them gays, feminists, blacks, they all fought for their rights...Nothing comes easy. If we all hide, the stigma will continue. Because of my disclosure, my employer now can talk openly about HIV (Baileys, a 54 year old East-African woman).

4.33 The narratives above indicate that participants' stigma management strategies varied along a continuum from coping/silence to public disclosure. Their choice of a strategy however varied by a participant's social context and experiences. Participants (such as Candi) facing strong familial or community stigma preferred the coping and silencing strategy. Others such as Pancho who felt more comfortable with their illness adopted deliberate and selective disclosure to friends and family. Open disclosure strategists (such as Baileys and Wally) have transcended the fear of stigma (because they've seen the suffering of others with HIV) in order to educate others and champion an effective fight against the disease.

DISCUSSION AND CONCLUSION

5.1 This paper examined the lived experiences of, and responses to stigma by African immigrant persons living with HIV (AFIM-PLWHA) in the US. The paper has shown that AFIM-PLWHA experience stigmatising attitudes and behaviours in their interpersonal and institutional relationships. As a result, many reported internalising these stigmatising attitudes, with negative consequences on their welfare and health. In addition, stigmatisation affected their integration into the larger US community, marginalised them from their ethnic communities and foreclosed their return to their countries of origin, where they are likely to face further stigma. To counter the negative consequences of stigma, some participants chose to hide their illness from friends and family, while others elected more public disclosures in order to normalise the disease and confront its negative connotations. Thus, although stigmatisation is often associated with (and results in) disadvantages for the stigmatised, paradoxically, it can strengthen the stigmatised when it is resisted.

5.2 The analysis underscored the fact that stigmatisation is a social process that is framed by ongoing discourses about HIV. The rejection, silencing and distancing that participants experienced in their interpersonal relationships need to be understood within African cultural values and assumptions that construct HIV as a death sentence, acquired through immoral and culturally prohibited sexual relations with outsiders. Paradoxically, the rejection and discrimination participants experienced within mainstream US institutions could be situated within western media's discursive presentation of HIV/AIDS as a black/African disease. At the confluence of these two representations is the externalisation of HIV – i.e., the fact that outsiders, often constructed as the 'other' – are responsible for the spread of HIV. The significance of 'otherness' lies in the fact that historically, infectious diseases are frequently traced to the 'other' categories of people, be they those of a different race, class or ethnicity and sexual orientation. But granted that illness is inextricably linked to poverty, which tends to be a defining characteristic of the 'other', 'otherness' will become the inexorable basis, in fact, a justification for the experience of social inequalities, stigmatisation and blame.

5.3 Additionally, this paper showed that stigma can be layered: that is, stigma reinforces (and is reinforced by) existing systems of negative social representation and disadvantage, similar to feminist notions of 'double or triple oppression' (Deacon 2006). More importantly, this layering is related to power. As Link and Phelan (2001) showed, the privileged and those with power have the influence and authority to attach labels to the marginalised. The stigma tends to stick, and the cycle of stigmatisation continues, so long as structural and historical socio-economic disadvantages render stigmatised persons powerless to resist their marginalisation. Consequently, one cannot but agree with Deacon's (2006, pg. 4) succinct observation that 'stigma and discrimination often follow the fault-lines of existing social marginalisation or social exclusion'.

5.4 At the same time, the analysis has underscored the variations in the degree of experienced stigma, depending on participants' gender, educational status, extent of physical symptoms, and culpability/responsibility for infection. In particular, some of these variations depend on the level of stigma in participants' countries of origin, as pointed out by participants such as Lamar and Baileys. For example, recent decreases in HIV prevalence in Uganda are partly attributed to the various anti-stigma and HIV prevention efforts adopted by the country within the last six years (Low-Beer and Stoneburner 2004). Consequently, there is an acknowledgement by some participants that the complexity of responses to stigma is directly related to more accommodating attitudes in their countries of origin.

5.5 Underlying participants' narratives is the recognition that HIV affects their identity, changing it from an "untainted" to a "spoiled" one (Goffman 1963, pg3). The shame and self-blame of infection internalised by participants, the presence of therapy-related physical side-effects, and subsequent attempts to reclaim some of their lost physical identity through cosmetic applications, are not only constant reminders of the invisible and visible effects of HIV, but also serve as harbingers of stigma. At the core of this internalised stigma is the tension between what Goffman (1963, pg 2) calls the "virtual social identity" (i.e., how a society characterises a person because of their illness) and the "actual social identity" (the person's actual attributes) of the infected person. The resolution of this tension is key to stigma management strategies adopted by participants.

5.6 In spite of these insights, one limitation of this study was that it was not representative – participants were recruited using purposive/snowball sampling techniques – and involved self-selection bias. In fact, given cultural, religious and regional differences among African immigrants, it is plausible that the study has not totally captured the diversity of their experiences and responses to stigma. Nevertheless, some of the findings are consistent with those from other studies dealing with AFIM-PLWHA elsewhere (Rosenthal et al. 2003; Anderson and Doyal 2004; Dodds 2006; Beier 2005; Erwin and Peters 1999; Komer 2007), despite their methodological and contextual (e.g., health policies in different countries) differences. As such, this study's findings might be reflective of broader structural and contextual issues that frame their experiences and responses to stigma. Consequently, there is need for more research to tease out the variations in immigrant experiences of health-related stigma, as well as validation of instruments that assess the various layers, components and dimensions of stigma, particularly, within marginalised communities.

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Notes

¹African immigrants, as used in this paper refers to African-born persons

²Selected areas are California, Georgia; Massachusetts; Minnesota; and New Jersey; King County, WA; New York City; and the portion of Virginia included in the Washington, DC metropolitan area. In total, these areas represent 47% of African-born population in US (U.S. Census Bureau 2008)

³American Sociological Association (American Sociological Association 1999) and World Medical Association's Helsinki Declaration (World Medical Association 2008).

⁴Lipodystrophy refers to abnormal fat distribution manifesting in enlarged stomachs and breasts or 'buffalo' humps at the back of the neck, and lipoatrophy refers to localised loss of fat tissue, resulting in gradual muscle wasting in the face, arms and legs.

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