



Review Article

An Intersectional Perspective on Stigma as a Barrier to Effective HIV Self-management and Treatment for HIV-infected African American Women

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Abstract

Among those who are HIV-infected and striving to live well with HIV, African American women have poorer health outcomes and represent a higher portion of those women who die from HIV-related causes. These health inequalities have been associated with the presence of social determinants of health such as stigma. This analytical review asserts that stigmas precipitated by gender, race, and class in the context of HIV-related stigma constitute substantial barriers to active engagement in HIV self-management, care, and treatment for HIV-infected African American women. The utility of the intersectionality framework for analyzing how these various stigmas interact to create unique deterrents to effective treatment and active self-management of HIV among African American women and for serving as a foundation for intervention development is presented.

Keywords: African American women; Engagement in care; HIV; Intersectionality; Self-management; Stigma

Introduction

African Americans living with HIV are least likely to be enrolled in continuous HIV care and treatment or to achieve viral suppression [1]. African American women, in particular, represent a higher proportion of persons living with HIV at all stages of the virus' progression from initial infection to death [2]. More specifically, 64% of women living with HIV are African American, and the majority of HIV-related deaths among women occur among African American

women [2,3]. African American women also experience poorer health outcomes compared to others living with HIV [1].

Caiola and associates [4] suggest that intersectionality is a fitting framework for analyzing the complex health inequalities that occur among various HIV-infected sub-populations. Empirical evidence suggests that barriers to HIV self-management and treatment among African American women hinge on something more than simple adherence to Antiretroviral Therapy (ART). Consider, for example, that the mortality of African American women living with HIV is greater than that of White men, after adjusting for the duration of ART [3,5]. The foundation for these health inequalities have, at times, been framed as something inherent about African American women themselves—due to misbehavior and/or lack of judgment [6]. However, others have attributed these inequalities to socioenvironmental factors including interpersonal stresses and differences in health care quality [7-9].

This article presents an empirically-based argument about stigma as a formidable obstacle to self-management, care and treatment. Intersectionality is presented as a framework for analyzing and understanding the multilayered stigmas [10,11] that face African American women who live with HIV. The multiplicative negative effects of these stigmas, especially in terms of impacts on health outcomes: diminished perceived quality of life, poorer rates of retention in HIV care and treatment, and suboptimal self-management of HIV are highlighted. In conclusion, it is asserted that clinical and research interventions designed to increase these women's engagement in HIV care and treatment must explicitly address the complexities of stigma.

Stigma

The term stigma refers to circumstances under which society views an individual as somehow tainted due to an attribute possessed by that particular individual [12]. Hence, stigma is a social process wherein those who are subjected to stigmatization have decreased power in the society. Stigma presents in several forms including enacted, perceived, internalized, and anticipated. Enacted stigma refers to sanctions applied individually or collectively, such as discrimination or bias. Perceived stigma results from negative social attitudes that affected persons experienced. Self or internalized stigma refers to accepting negative attitudes and beliefs, and applying these attitudes and beliefs to one's self. Internalized feelings of shame or guilt characterize this form of stigma. Anticipated stigma is an expectation of future stigmatizing experiences such as prejudice, discrimination, and stereotyping.

Socially endorsed stigmas often predetermine which social or cultural groups will be stigmatized. Consequently in many societies; women, those from ethnic minority backgrounds, and those with less economic power may experience multiple stigmas which are synergistic in nature, i.e., interacting together with each stigma contributing to the magnification of potential barriers to optimal health outcomes [13]. The theory of intersectionality assumes that socially constructed identities such as gender, race and class, interact in the context of social and power relations to create a unique health

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experience. Therefore, intersectionality is a useful framework for analyzing the syndemic impact of these stigmas on the HIV-infected African American woman's health care experience.

Intersectionality

The examination of power differentials; relationships between dominants and subordinates is at the core of the intersectional framework. Intersectionality was not developed to predict actions or cognitive processes; rather, it is a framework for analysis [14]. Intersectionality puts forth that HIV is often not the sole factor that precipitates the stigma experienced by these women; it posits that multiple factors precipitate stigmatizing experiences. An intersectional perspective acknowledges that these women's social identities experienced at the individual level (e.g., being female, an ethnic minority, and/or of low SES) interlock with oppressive forces at the macro-level of society (i.e., sexism, racism and classism) to create social injustices (e.g., health care inequalities). Intersectionality concedes that race and class are gendered thus producing compounded inequalities for marginalized groups, such as African American women. African American women were, in fact, the original focus of intersectionality theory [15].

The intersectional perspective recognizes that the socially constructed identities of these women both contribute to the woman's formative experiences and influence the sum total of these experiences. This framework acknowledges the African American woman's gender, race, class and disease conditions are not mutually exclusive. Instead, these attributes may be a collective catalyst for stigma-related experiences that are not generated by positive HIV serostatus alone; augmenting each other and contributing to stigmatizing health care encounters that further marginalize African American women living with HIV [6,16].

Historical notions about the African American woman's place in US society have fueled the social construction of stereotypes. Frequently, for example, the media portrays African American women as being poor, downtrodden, hyper-sexed and as being drug users/abusers; in a word, they are depicted as dysfunctional [17,18].

Therefore, in reality, it is quite difficult to detangle the impact of one factor from another especially in the context of HIV frequently being sexually transmitted and/or due to illicit drug use. However, for purposes of clarity these factors will be presented separately to allow for a focused analysis of each factor and to illustrate how they may interact to further magnify the impact of HIV-related stigma on engagement in HIV care, treatment, and self-management.

Stigma and Gender

HIV-related stigma cannot be fully explored without taking gender into account. Gender is a social construct that does not refer to biological characteristics but rather to culturally determined role expectations for how men and women must act in society. In many societies, unequal power differentials continue to exist between men and women. Thus, gender must be considered when analyzing power structure and access to resources in the United States (US), where historically and socioculturally women have had lower social standing than men [19]. The challenges of power inequalities and group subordination within the social construction of gender have become increasingly important in the context of HIV transmission and engagement in HIV care, and treatment [20,21]. For women, HIV-related stigma is frequently layered on top of the stigma and

discrimination that sexism generates. Notably, gendered experiences of daily living and their impact on access to resources, power, and influence on risk behaviors have been associated with higher risk for HIV and less than optimal HIV-related health outcomes for some groups including African American women [22].

Women, experience HIV-related stigma differently and report higher levels of HIV-related stigma [23,24]. Women living with HIV and their families are more likely to experience discrimination and a loss of social support [25-27]. In a study exploring HIV-related stigma and discrimination conducted with 536 people living with HIV (67% female) across four sub-Saharan African countries women were significantly more likely to report interpersonal discrimination [27]. HIV-infected women are often hesitant to disclose their status for fear of being labeled promiscuous, a drug user, or simply dirty [20,28]. They know that disclosing their medical condition to others may jeopardize their personal relationships and economic status [21]. Lower rates of disclosure of positive serostatus among women have been associated with increased reports of mental health challenges [25]. In the case of African American women these challenges may be compounded because they may be subject to multiplicative stigmas; marginalized not only because they are women but because they are persons of color.

Stigma and Race

Socioenvironmental stresses have been associated with accelerated health deterioration among African American women when compared to US born Caucasian women. The social construction of race and race relations is prominent among the hypothesized etiologies for this phenomenon. Race has traditionally been drawn along the lines of "black and white" in the US [29,30] for purposes of establishing and maintaining power differentials. Racial discrimination has been associated with higher incidences of hypertension [31] and accelerated biological aging among African Americans [32] these processes have been conceptualized as "weathering" [9,33].

Many African American women experience pervasive racism throughout the life course [34]. For HIV-infected African American women gender-related stigma and the subsequent negative power differentials are often compounded by racial discrimination and/or racism. The subjective experience of racism includes subtle ideologies such as the concept of "free will," which implies that African American women's disadvantages are principally their own responsibility [35]. "Free will" can be the basis for assuming that African American women have contracted HIV due to their own risky behaviors [26]. Thus, all forms of racism, including the perpetuation of racially-based stereotypes, can contribute to the level of enacted, perceived, internalized and/or anticipated stigma that African American women living with HIV experience. Racialized stereotypes about African American women abound in pop culture: ranging from the bitchy person as depicted on "reality" TV shows to the titles of popular fiction that target African American readers [18,36]. Racialized framing can also prompt healthcare providers to assume that risks for medical conditions, such as hypertension-associated renal disease or HIV, are due to African Americans' biological characteristics, rather than due to socioeconomic and/or structural factors [8,31,37,38].

Such negative racial stereotypes and their deleterious effects on African American women's self-esteem and self-image have been associated with enhanced risks for engaging in risky sexual

behaviors, remaining in abusive relationships, and contracting HIV [39]. The intersectional perspective asserts that when an African American woman contracts HIV, negative historical stereotypes are augmented by additional stereotypes about promiscuity, drug use, lack of capacity for engaging in positive health behaviors (e.g., poor potential for adherence), and by the stigma associated with these stereotypes. Socially-constructed, negative images about race and HIV may color provider-patient interactions, ultimately limiting the potential for an effective therapeutic relationship.

Stigma and Class

Persons living with HIV, who also have lower incomes, have reported higher levels of stigma [40]. This is particularly disconcerting, because HIV has been termed a pandemic of the poor [41]. Similar to other health inequalities [42], risk and prevalence of HIV have also been associated with lower educational attainment and under- or unemployment-and are, thus, associated with lower Socioeconomic Status (SES), where SES is generally an aggregate measure of education, income, and occupational status. Nonetheless, SES is often conceptualized as class or social standing, when viewed through a social class lens, which emphasizes privilege, power, and control.

Notably, African American women are most often cared for by White health care providers of upper-middle class or upper-class standing [43]. In the context of these status inequalities, HIV-infected African American women are frequently assumed to be of a lower socioeconomic standing, until they prove otherwise [19,44,45]. If a provider possesses implicit biases about persons of lower socioeconomic status, African American women can be presumed to be noncompliant, “lost causes”. These presumptions may impact these women’s care and treatment [46-48]. In fact, compared to men, women are less likely to receive ART [49]. Hence, when one considers the contexts of race and class in addition to gender, African American women may be even less likely to receive ART in a timely fashion and may be more likely to experience the sequelae of inadequate viral suppression such as chronic inflammation [50]. Biased perspectives of socioeconomic status can combine with HIV-related stigma to create a less therapeutic provider to patient relationship. This was apparently the case for a group of HIV-infected African American women who participated in a qualitative study on stigma and HIV. At times these women reportedly felt socially shunned and disregarded when accessing healthcare services [26].

Intersectionality concedes that at the point of service, the African American woman often faces classism in addition to sexism and racism. The African American woman of lower socioeconomic means is frequently viewed as possessing little privilege or power. She must be directed as to how to care for herself and is expected to comply with instructions, rather than be free to participate in mutual goal-setting about her own health and self-management of HIV. Additionally, if public funds support her HIV care and treatment (i.e., Medicaid, Ryan White), she is often viewed as one of the collective “undeserving poor” [51]. At times her circumstances including that of being HIV-infected may be considered to be the result of her own individual failures, rather than of societal or systemic failures.

Stigma and HIV

Unfortunately, due to the nature of most HIV transmissions, HIV is often believed to be contracted as a penalty for misbehavior or lack

of judgment [52]. Thus, not unlike other stigmas, HIV-related stigma is also a sociocultural phenomenon. HIV-related stigma is a prejudice that discounts, devalues, and discriminates against persons believed to have HIV along with other individuals and/or communities with which these persons are presumed to be affiliated [53]. A 2015 synthesis of 55 qualitative studies revealed that people living with HIV commonly report that they have encountered stigma in healthcare settings [54]. Gagnon’s recent interviews of 21 HIV-infected persons exposed that stigmatizing interactions, though episodic in nature, continue to persist in health care settings in the form of individual interactions and institutional policy [55]. Notably, HIV-related stigma has been associated with less than optimal HIV-related health outcomes including decreased likelihood of initiating HIV care [56], ART non-adherence, CD4 counts less than 200 cells/mm and higher prevalence of co-morbidities [57,58].

Stigma takes several forms for persons living with HIV: enacted, perceived, internalized and/or anticipated [52,53,57]. All forms trigger anxiety or fear about other people’s reactions to one’s serostatus. Notably, stigmatizing experiences have been shown to be predictors of lack of engagement in HIV care and treatment as evidenced by missed health care appointments [40]. Different forms of stigma seemingly may have diverse influences on health status. Recently, Earnshaw and colleagues put forth that specific forms of HIV-related stigma were associated with different health behaviors and outcomes. For example, internalized stigma was specifically associated with ART non-adherence while enacted and anticipated stigma were linked to the presence of co-morbid conditions and lower CD4 counts [57]. Anticipated stigma has also been linked with patterns of HIV disclosure [21].

Hence, HIV-infected African American women who perceive HIV-related stigma in addition to other interlocking forms of stigma, may then experience shame, guilt, and depression, and conclude they are unworthy of self-care and good health, resulting less than optimal engagement in HIV self-management, care and treatment [10,11,23,59,60]. Intersectionality allows that their trepidation about the possibility of being discounted, devalued, and discriminated against due to being HIV-infected in the context their gender, race and class may multiply to present a nearly insurmountable barrier to effective HIV self-management and active engagement in treatment [27].

Engagement in HIV Care, Treatment and Self-management

There is a preponderance of evidence that active self-management positively impacts outcomes for persons living with chronic diseases. Adherence to prescribed medical regimens and engaging in active self-management of HIV are essential to living well with HIV. Whatever the source, stigma affects disclosure patterns, health outcomes, and quality of life for those living with HIV [43,60-62]. Social support has been identified as a facilitator of self-management of HIV and significantly associated with positive coping for women living with HIV [16,63]. African American women who encounter and/or anticipate stigma related to HIV, may infer that engaging in HIV self-management might disclose their serostatus directly or indirectly-thus, jeopardizing their actual or potential social support networks.

This perspective is not without justification, given what is known about gender differences and HIV-related stigma. Compared to men,

being a woman has been associated with higher levels of stigmatized attitudes toward persons living with HIV [64,65] and women most often look to other women for social support. It is, therefore, hardly surprising that African American women might not present readily for HIV care or take ART; they may anticipate that such services will impact confidentiality within their communities, resulting in a loss of social support from other women. As emphasized earlier, loss of social support due to stigma also compromises health outcomes as a result of enhanced risk for non-adherence to ART [58] and less than optimal self-management [16]. Accordingly, preserving confidentiality and neutralizing potentially stigmatizing interactions are foundational to HIV care and treatment services and when designing programmatic and investigational interventions.

Conclusion

African American women constitute a specific population who carry distinct sociocultural luggage into the realm of HIV care and treatment. They have often experienced structural inequalities related to gender, race and class. Alas, in the case of the African American woman the presence of HIV infection may be spur additional stigma that further compounds the stigmas generated by these pre-existing factors. Conversely stigma related to HIV infection may be magnified in the presence of female gender, black race and lower socioeconomic status [10,20].

Intersectionality helps us to recognize and begin to understand the social constructs and power relationships that precipitate stigmas and the multiplicative effects of various forms of stigma on these women's view of themselves, their material resources, propensity for engaging in HIV self-management, and their perceived access to health care services. Yet, HIV-infected African American women do not have to be victims of stigma; they can be resilient and resourceful even in the face of this virus [26,57]. Health care providers and researchers have a responsibility to employ stigma neutral gender-specific and culturally relevant interventions that promote resiliency in these women.

Evidence-based stigma reduction interventions are limited. Most interventions teach clinicians about stigma and its affect instead of helping them to effectively address the various underlying sources of their own stigmas and enabling them to build capacity for assisting persons living with HIV to successfully cope with stigmatization [10,66,67]. Interventions designed to assist HIV-infected African American women live well with HIV and to enhance their health outcomes must strategically minimize the impact of stigma, while incorporating methods for facilitating strong social support networks and adaptive coping. Specifically, these interventions must take into account the intersectional perspective; accounting for the negative racialized and class-based ideologies, images, narratives, and implicit bias [47,48] that color health care interactions for African American women living with HIV. Such initiatives must recognize that, when these women perceive that stigma is at work, they will not be likely to engage fully in their own care or be skilled at self-managing their illness. Therefore, it is imperative that the design and development of culturally relevant gender-specific stigma reduction strategies be at the forefront of any public health efforts to decrease community-specific levels of HIV incidence and prevalence not relegated to the bottom of budgetary priorities.

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