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Contextual and Health Services Utilization Factors Associated with Perceptions of Social Stigma Among Urban HIV-infected African-American Men

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Abstract

Medical science has made progress in addressing the HIV/AIDS disease. New treatments have prolonged lives of many and HIV infection is no longer seen as a death sentence. Yet, ethnic minorities including African Americans males are purported to experience barriers in accessing healthcare. Many are purported to experience stigma within the health care system that affects their health-seeking behaviors. Thus, an initial step in providing optimal health care to African Americans living with HIV/AIDS is to understand the challenges experienced in utilizing healthcare. The purpose of this study was to describe and examine contextual and health care utilization factors associated with stigma among urban African American men living with HIV/AIDS. Methods: Using a quantitative mixed methods correlation study, a questionnaire was administered to (N = 117) African American men who self-identified as living with HIV/AIDS. Participants were 18 years and older (M = 42.6 years, SD = 8.25). Sowell et al (1997) HIV-related social stigma was the scale used to measure the outcome variable social stigma. Data were analyzed using the Statistical Package for the Social Sciences (SPSS-PC for Windows ®) version 20.0. [LL1] Findings: The patterns of utilizing healthcare varied with 28% reporting some difficulties in getting appointments; 27% reporting healthcare was costly, and 24% complained about inconvenient clinic hours. Stigma was a major factor with 67% feeling ashamed of their illness; 59% thought other people were uncomfortable being around them. Participants who perceived their providers as having positive attitudes perceived less stigma. Participants who felt that their healthcare providers spend adequate time with them during care, perceived less stigma. Participants who had multiple providers were more likely to miss their medical appointments. Hierarchical regression analysis revealed that the higher the income, the fewer stigma participants perceived. Finally, a participant's ability to receive health care and whether they could see a physician whenever needed was significant in explaining stigma. These findings provide important information for clinicians working with African American men living with HIV/AIDS.

Keywords: Access to healthcare, African American, HIV/AIDS

1. Introduction

In the US, roughly 1.2 million people over the age of 13 live with the Human Immunodeficiency Virus (HIV) (Centers for Diseases Control and Prevention (CDC), 2015). According to reports from the CDC, in 2013, approximately 47,352 people were reported to have been infected with HIV. The CDC further reports that an estimated 13,712 people died in 2012 and overall an estimated 658,507 people have died from AIDS in the US since the onset of the disease. Although the incidence of HIV infection in the US has consistently declined in the general population, the estimated number of people living with HIV has increased due to multiple factors that have led to certain subgroups being disproportionately affected (CDC, 2015).

Ethnic minorities are disproportionately affected by HIV/AIDS (Henry Kaiser Family Foundation, 2015). Of the racial and ethnic groups in the US, African Americans are the hardest hit by this epidemic. Although African Americans make up only 14 percent of the US population, they make up 44 percent of the population who are HIV-positive (Center of American Progress, 2012). Compared to their white counterparts, African Americans are 10 times more likely to contract HIV infection (National Minority AIDS Council, 2006). Important questions to ponder are: why has the HIV/AIDS disease been around for almost 4 decades, however, it is still adversely affecting ethnic minority groups? Also, although there has been some success in addressing HIV/AIDS in ethnic minority communities, can more be done, especially among vulnerable and high-risk populations? Finally, what can public health and policymakers do to help get people into early treatment and provide appropriate health and social services for those individuals who are already living with the disease?

Today, HIV/AIDS is regarded as a chronic disease; however, HIV/AIDS remains a complex disease and the reasons African Americans are greatly affected compared to other subgroups are complex and sometimes poorly understood (Buseh, Kelber, Stevens and Park, 2012). Although the US is advanced in healthcare delivery, millions of people do not have access to quality healthcare—thus, they face challenges in attaining basic healthcare. Statistically, one group that faces the greatest burden of poor health outcomes and low quality of life are African Americans—mainly urban African American males. The risks factors for contracting HIV infection are multiple. According to the CDC, gay, bisexual and men who have sex with men (MSM) are adversely affected by HIV/AIDS. As of 2010, MSM between the ages of 13-24 accounted for the highest rate of new HIV infections (4,800) (CDC, 2015). Compared to other racial groups, African American MSM was less likely to have access to screenings for HIV and was less likely to be aware of contracting HIV infection. African Americans are one of the racial groups that face structural inequalities on all major spectrums including health care access, education, housing segregation, employment and mass incarceration (National Minority AIDS Council, 2006). These structural inequalities are all reported to affect the health and wellbeing of urban minorities (National Minority AIDS Council, 2006).

Stigma is a prevalent factor that can compromise the health of a person living with HIV. Stigma is a social phenomenon that occurs when relatively powerful social groups devalue marginalized groups because of the perception that such groups may have social characteristics that are different from societal norms (Goffman, 1963). Stigma also entails discriminatory and prejudiced treatments that may lead to an HIV-infected person to socially isolate themselves and be ostracized. For many individuals who are living with HIV/AIDS, they also have to fight the feelings of shame and isolation and in many instances become marginalized out of the fears of being treated differently by others (Scrambler, 2009). Although stigma associated with HIV/AIDS is deplorable, it may be particularly evident for black MSM, for whom racial and sexual orientation stigma presents additive burdens (Bogart, Wagner, Galvan, & Klein, 2010).

Negative perceptions by HIV/AIDS clients have been shown to have adverse effects on their continual contact with the healthcare system and how well they follow treatment protocols (Bogart et al., 2010). To adequately work with urban African American men who are living with HIV/AIDS, it is important to put all of these factors in context by exploring and examining the men's experiences of social stigma and how the stigma they experienced impacts their abilities to seek healthcare.

Purpose of the study

The purpose of this research project is to describe and examine some contextual factors (socioeconomic status and health care utilization variables) associated with social stigma among urban American men living with HIV/AIDS. Research questions

To accomplish this task, the following research questions will be examined: (a) What are the patterns of access/utilization of health services among urban African American men living with HIV/AIDS? (b) What are the perceived stigmatizing experiences of urban African American men living with HIV/AIDS? (c) What are the relationships among selected socio-demographic variables and the variable of health services access/utilization relative to participants' perceived social stigma? and, (d) After controlling for selected socio-demographic variables, what is the contribution of access/utilization of health services on social stigma? [LL2]

2. Review of Literature

2.1. Ethnic Minorities and health disparities in the US

Minorities experience high disparity rates in diseases and health outcomes on multiple levels such as cancer, cardiovascular disease, chronic kidney disease, diabetes and HIV/AIDS (AHRQ National Health Disparities Report

2013). One health condition that continues to have an impact on the African American community is HIV/AIDS. Compared to other ethnic minorities and their white counterparts, African Americans are reported to experience higher HIV/AIDS rates. A study in 20 major U.S. cities found that 30% of Black gay and bisexual men in the study were infected with HIV, compared to 15% of Latino and 14% of white gay and bisexual men. Many of these men did not know they were infected (The Henry J. Kaiser Family Foundation, 2014). Efforts have been made in addressing the HIV/AIDS epidemic in the US and around the world. Due to the advances in early testing and treatment, more people are now living longer with HIV/AIDS (CDC, 2016).

2.2. HIV/AIDS Among African American and Black Males

Though there are more people living with HIV/AIDS, the impact of HIV/AIDS varies across the country and certain subpopulations continue to be disproportionately affected by the disease; specifically, ethnic minorities and gay and bisexual men (The Henry J. Kaiser Family Foundation 2014). Statistically, one group that faces the greatest burden of poor health outcomes and low quality of life associated with the disease are African Americans—mainly urban African American males. In 2010, male-to-male sexual contact accounted for half (51%) of new HIV infections among Blacks overall and a majority (72%) of new infections among Black men. In addition, newly infected Black men who have sex with men are younger than their white counterparts, with those ages 13-24 accounting for 45% of new HIV infections among Black men who have sex with men in 2010, compared to 16% among whites. (The Henry J. Kaiser Family Foundation, 2014).

2.3. Overview of HIV/AIDS in Wisconsin

Health disparities in relations to HIV/AIDS that are observed on a national level as well as locally are of concern. The annual Wisconsin HIV/AIDS surveillance review details the prevalence of HIV/AIDS annually. In 2015, 225 cases of HIV cases were discovered. Though ethnic minorities only make up 17% of Wisconsin's population, they account for 62% of new cases. Blacks compared to their white counterparts were 13 times higher to be diagnosed with HIV. Black MSM was identified as one in three (36%) living with HIV (Wisconsin Department of Health and Human Services 2015).

Health inequalities dealing with HIV/AIDS is related to the lack of access or the ability to utilize health facilities and services (National Institute of Health, 2016). Socioeconomic status, structural inequalities, and geographical locations are contributing factors that play a role in the access and utilization of the health care system (Healthy People 2020, 2016). From a policy perspective, it matters for policymakers to pay attention to populations with high health disparities rate for any disease condition. Structural factors such as poverty are also a factor to consider in addressing health care disparities. Poor people are reported to receive worse care than high-income people (AHRQ, 2013).

2.4. Social stigma of HIV/AIDS

Another point of concern that should be addressed is social stigma. Social stigma is a major factor that must be considered in the organization and delivery of health care for individuals at risks for contracting the disease or may already be living with the disease. According to Aidsmap, social stigma is defined as a paradigm that is negatively viewed by society and regarded as unacceptable (Aidsmap 2012). Social stigma is one of the contextual factors that make the delivery of healthcare problematic. For urban, HIV-positive African American men, it is not only the hazards of decaying physical environments, violence, homelessness, unemployment, and crowding in their neighborhoods, with which they contend on a daily basis, but also the stigmatizing events related to their illness, and in other cases, related to their sexual orientation (Satcher, 2003; Treadwell and Ro, 2003).

Social stigma not only deteriorate one's environment but it also compromises one's health. Social stigma is an intrinsic factor in a society which influences how people perceive themselves and how others perceive them. For this instance, it serves as a contributing factor on whether or not HIV-infected African American men will seek treatment (Haile, Padilla & Parker, 2011).

Another contributing factor that may dictate the direction of self-perception of the stigmatized disease is the burden that is tied with being an HIV-positive male. The weight of carrying this information is so strenuous that an HIV-infected man's willingness to disclose their status is seen to them as a strain to their family and loved ones (Skinta, Brandrett, Schenk, Wells & Dilley, 2013). This, in turn, leads HIV-infected men to be forced to internalize the social stigma and burden of their status that they perceive and/or are experiencing. Over time this internalization becomes consequential.

2.5. Healthcare Access and Utilization Patterns

Barriers to access and utilization patterns are another contributing factor to the ability to seek treatment. Of those barriers amongst African Americans is their long-standing history of medical mistrust. One of the most devastating research studies was the Tuskegee Syphilis Study in which a sample of African American men was enrolled in a flaw research study and experimented on even though there was penicillin available to treat syphilis at the time of the study. Due to this study, many African Americans have been left feeling vulnerable and suspicious toward the health care system and their health care providers. The Tuskegee syphilis study, which was done between 1932 to 1972, experimented with medical research which resulted in human rights violation and ethical violation. The unethical conduct of the study has led to conspiracy theories related to accessing and utilizing health care within the African American community. Some African Americans have adopted a mistrust of the medical system and thus, the transmission and management of HIV/AIDS in African American communities are sometimes problematic. These conspiracy theories of the medical mistrust held amongst the African American community ironically contributes to the lack of medical utilization and the increase of HIV disparities (Ball, Lawson, Alim, 2013).

In addition to structural factors that prevent the delivery of healthcare in the US, many individuals living with HIV/AIDS are also faced with personal challenges that may make it difficult for them to access and use health care services in a timely manner. For example, the lack of transportation has been reported to serve as a barrier to the access and utilization of the health care system (The Henry J. Kaiser Family Foundation 2015). Transportation serves as a healthcare barrier as it limits a persons' ability to access and utilize the health care system. Studies have shown that the lack of transportation has increased the lack of health care utilization and medical treatment adherence specifically in the HIV-infected population (Sagrestano, Clay, Finerman, Gooch, & Rapino, 2013).

Overall, HIV patients amongst marginalized groups face discernable discrimination and prejudice in all aspects of society. Within these marginalized groups, African American encounter more health inequalities than any other race or ethnic group. Presently, stigma plays a pivotal role in this marginalized groups as to how HIV-infected urban African American men view themselves as well as how society views them. Gay men who are HIV-positive face stigma and discrimination from heterosexuals, HIV-negative men as well as the Lesbian, Gay, Bisexual and Transsexual community.

3. Conceptual Framework

3.1. Review of Frameworks and Models Associated with Access and Utilization of Healthcare

Access and utilization of healthcare services by persons living with HIV/AIDS is a complex process. The disease is a complex disease that involves encounters with varied healthcare providers within the healthcare system. In order to have an improved outcome, it is important that individuals who are living with HIV/AIDS have access to a primary healthcare provider as well as various forms of specialty care when needed. The US healthcare system is complex and fragmented making it difficult for many individuals to be able to appropriately navigate the healthcare system (Shi and Singh, 2013). The organization and delivery of healthcare impact life experiences on whether or not an HIV-positive client will enter and receive the best of care (Buseh, Kelber, Stevens, Poedel, Park, 2009). Living longer with the disease requires needing to enter the healthcare system earlier on in order to improve the quality of life (QOL). Stigma coincides with the lack of access as it prevents people from receiving early treatment as well as entering the healthcare system constantly.

A conceptual diagram was incorporated displaying the correlation of contextual factors to social stigma. Contextually, there are two categories, socio-demographic factors and access and utilization of health care services. From the conceptual diagram in Figure 2, socio-demographic factors will be measured as a means to examine how, in relation to stigma, does it enable or impede the access and utilization of the health care system. The factors being measured include age, length of time since HIV diagnosis, education, income, sexual orientation and HIV status. By controlling these variables, I will be able to conclude whether or not one's socio-demographics contributes to or hinders the access and utilization of health services.

Lastly, access and utilization of health care services will be measured. This factor includes variables such as the source of health care, perceived attitudes of medical doctors, access to health care when needed, missed appointments, insurance status and time spent with the healthcare provider. By analyzing these variables in accord with social stigma,

the information gathered may relay a relationship or no relationship to whether or not this factor impedes the access and utilization of the health care system.

4. Methods

4.1. Design

This study details the contextual factors and access and utilization patterns among participants in relation to the social stigma of living with HIV/AIDS. A quantitative mixed methods correlation study was used to survey a sample of (N = 117) HIV-positive urban African American men living with HIV/AIDS.

4.2. Participants & Setting

Participants in the study were recruited through a collaboration with a local community-based organization (CBO) that dedicates their resources to assist the African American community in addressing health and social services needs. The participants consisted of 117 HIV-positive urban African American men who self-reported as being diagnosed with HIV/AIDS. The ages ranged from 23-66 years with a mean of M=48.84 (SD=7.67). The average length of time since diagnosis measured was 10.79 years (SD=6.4).

4.3. Data collection procedures

Participants were informed about the student through the local CBO through the distribution of a flyer explaining the study and activities involved. Interested participants then contacted the study's principal investigator (PI). A mutually agreed upon date, time and place were then set up wherein the surveys were administered. Informed consent was obtained from each subject participating in the study prior to the survey administration. Administration of the survey questionnaire lasted for approximately 1 hour. Participants completing the survey received a gift card from a retail store of \$25 as a token of appreciation for their efforts.

4.4 Instrumentation and Measures

4.4.1. independent variables

Sociodemographic data were collected to describe the participants. These variables include the age of participants; length of times since diagnosed with HIV infection; self-rated clinical stage of the disease; income; years of education and sexual orientation.

4.4.2. access and utilization of healthcare indicators

These variables include items such as the usual source of primary care; perceived lack of medical doctor commitment; can access medical care whenever needed; can access care whenever needed; healthcare provider spends enough time with you; satisfaction with the healthcare provider; doctor's attitudes towards patient and type of insurance.

4.4.3. dependent/outcome variable

The dependent variable in this study was social stigma. Sowell et al (1997) HIV-related social stigma was the scale used to measure social stigma. This scale includes 13 items on a 4-point scale that asked participants to indicate how often they experienced thoughts or feelings of being stigmatized because of their HIV condition. On the scale, 1 being strongly disagree and 4 being strongly agree. Tallied scores could have a possible range between 40-160. A higher number on the scale entailed high stigma. In this study, social stigma ranged between 73-160 (M=110.36, SD=17.36). The Sowell HIV Stigma Scale in this study had a high coefficient reliability score with a Cronbach's alpha of .93.

4.5. Ethical Considerations

All study materials were approved by the University of Wisconsin-Milwaukee Institutional Review Board Committee (IRB). Participants were all given information about the study and consent obtained before any data were collected.

5. Data Analysis

Data were coded and entered into the Statistical Package for the Social Sciences (SPSS-PC for Windows ®) version 20.0 for statistical analysis. Statistical significance was set at p < 0.05 with a sample size of 117 and a power of 0.8 to detect a moderate effect size of 0.25. Descriptive statistics (frequencies, percentages, means, and standard deviations) were used to describe socio-demographic characteristics.

Descriptive statistics were conducted to answer research questions 1 and 2 proposed in the study as it relates to patterns of healthcare utilization. Statistics were also run to determine the stigmatizing perceptions among the participants. Correlation analysis was conducted to assess for relationships between selected contextual variables which included socio-demographic variables, health care utilization variables to determine if these factors were related to social stigma. Hierarchical multiple linear regression was performed to test the effects of selected socio-demographic variables and health utilization variables on social stigma.

6. Results

Findings from this research are arranged in the following order. The socio-demographic profile of the sample will be first presented to describe the participants. The findings will be arranged based on the research questions examined in the study.

6.1. Socio-demographic characteristics of participants

The sample in this study comprised (N = 117) urban African American men who self- reported to be diagnosed and living with HIV/AIDS. Participants ranged in age from 21 years to 60 years (M= 42.6, SD= 8.25). Annual income was variable; 38% had income of less than \$5,000; 46% had income between \$5,000-\$19,999. On the highest level of education completed, about half (50%) of the participants had less than a high school education or completed only high school. In this sample, 28% of the participants reported completing some college. Concerning the participants' sexual orientation, 85 participants (73%) identified as being homosexual or bisexual, and 32 participants (27%) identified as being heterosexual. The length of time since diagnosis of HIV infection was variable. The mean years since diagnosis of HIV was 13.17 (SD= 7.63). Forty-one participants (37%) reported as being asymptomatic; 51 participants (47%) indicated being symptomatic but not being diagnosed with AIDS and 20 participants (17%) reported that they had been given an AIDS diagnosis by their physician. Seventy participants (60%) were taking antiretroviral medications.

6.1.1 research question 1: what are the patterns of access/utilization of health services among urban African American men living with HIV/AIDS?

Participants were asked through which outlet they sought medical treatment. Participants sought healthcare through an array of healthcare settings. Forty-six percent received care at a doctor's office; 42% received care at a hospital; 32% sought health care through a free-standing clinic, and 36% sought health care through the emergency room. One-hundred and four (89%) of the participants reported that they had a specific site where they usually went to seek medical care. However, 55 (47%) sought healthcare from more than one healthcare provider. Only 50 (43) felt that they can always obtain healthcare when needed. Sixty (51%) reported that they had missed at least 1 medical appointment. Over three quarters, 98 (84%), felt that their healthcare provider devoted enough time for them when they sought healthcare.

6.1.2. research question 2: what are the relationships among selected socio-demographic variables and health services access/utilization relative to participants' perceived social stigma?

To address this question, a correlational analysis was conducted examining the relationships between several variables relative to social stigma perceived by the participants.

Age of participants were associated with: how long a participant had been HIV positive = .307, p=.001; annual income = .219 p=.010; and education = .234 p=.012. Income was correlated with education = .466 p<.0005. Attitudes towards the healthcare care provider were also correlated to whether provider devotes enough time =.502 p<.0005 and whether they were able to see a health care provider when needed .358 p<.0005. Whether the healthcare provider spends enough time with them during care was associated with whether they missed appointments =.241 p=.0005; whether they had one health care provider from which they sought healthcare =.189, p=.045 and whether they got healthcare when they needed such a care =.310 p=.001.

From the correlational analysis, results show that those who accessed healthcare in an outpatient clinic setting experienced a higher level of social stigma. Also, not being able to see a health care provider when needed increased perceived stigma. Participants were asked if they do miss or do not miss appointments. Those who missed appointments perceived higher social stigma than those that did not miss appointments.

7. Discussion

The purpose of this research project is to describe and examine the contextual factors and healthcare utilization variables associated with social stigma among urban African American men living with HIV/AIDS. Since HIV/AIDS is a chronic disease, it is imperative that a way is found to improve the quality of life of these individuals. African Americans specifically, are reported to have been disproportionately affected by HIV/AIDS which continues to increase over time (Henry J. Kaiser Family Foundation, HIV/AIDS fact sheet 2012; CDC Surveillance Report, 2012). In order to tackle the issues concerning disparities of the HIV/AIDS epidemic found among urban African American men, a look at their perceived social stigma must be taken into account. Negative perceptions of their disease and negative attitudes about the health care system held by HIV/AIDS clients have been shown to have adverse effects on their continual contact with the healthcare system and how well they follow treatment protocols (Bogart et al, 2010).

7.1 Access and Utilization of Health Care Services

In this study, participants were asked to report their patterns of health care utilization. Over half of the participants reported having missed an appointment with their healthcare provider. The most common reasons for missing their appointments were: forgetting about appointments, not having the mode of transportation, they were too busy to attend the appointments, not being sick enough to bother to go in, they could not afford the care and being too embarrassed to go to an HIV clinic. The two common sentiments were not having the mode of transportation and forgetting about the appointment.

A study examining barriers in transportation with HIV/AIDS participants was conducted. The study surveyed participants and asked them questions pertaining to the five A's of access to frame transportation vulnerability. They are availability, accessibility, accommodation, affordability, and acceptability. These questions yield important information detailing reasons for lack of adherence of the healthcare system. The research concluded that transportation vulnerability is an impending issue that serves as a barrier to the utilization of the healthcare system amongst HIV-infected individuals (Sagrestano, Clay, Finerman, Gooch, and Rapino, 2013). Since transportation is an issue with this population, policymakers should aim to address these transportation issues as it could help improve adherence to treatment protocols for people living with HIV/AIDS. Furthermore, better modes of the public transportation system must be invested and flexible scheduling of appointments that are in line with modes of transportation should be implemented. In a study that examined attitudes towards health care providers relative to appointment attendance, investigators found that tangible support transportation facilitated appointment attendance (Bodenlos, et al., 2007).

7.2 Social Stigma

The perception of social stigma associated with living with HIV/AIDS rated by the participants was examined. In the study, stigma was the outcome variable where participants indicated how often they experienced thoughts or feelings

of being stigmatized because of their HIV condition. Participants noted that they sensed stigma within the health care system as they felt they would not get as good of health care if people knew about their illness. They felt stigma on a personal level as well. Participants reported that they avoided receiving treatment because there was a chance someone could find out about their illness. They also reported that they felt compelled to change their residence due to their illness. A 12-month longitudinal survey that was conducted in Cambodia with HIV positive participants showed that there is a significant issue in the percentage of individuals who experienced stigma and housing discrimination due to their illness. Over the 12-month study, participants reported having to change residence and/or were unable to rent accommodation (Yi, Chhoun, Suong, Thin, Brody, Tuot, 2015). Policymakers have an obligation to endorse policies that refute discrimination amongst the HIV-positive population and address the inhibiting issue that is housing inequality.

8. Limitations

Though this study sheds light on the contextual factors related to social stigma and access/utilization of health services with HIV-positive urban African American men, a more diverse sample would have been beneficial to represent and describe these phenomena and this racial group. Future researchers are recommended to collect a large and diverse sample that is representative of the urban African American community. Methodologically, the data collected was non-random, geographically limited through a cross-sectional design. The participants were attained through a CBO that served the African American community. Thus generalizing these results to within this racial group would be inconclusive. The survey instrument did not include data on clinical health (e.g., CD4 cell count, HIV viral load) that may be useful. In future studies, socio-demographic along with clinical indicators could be used to observe how utilization of health services can influence the clinical outcome.

9. Conclusion

Today, HIV is no longer a death sentence. People are now living longer because of new medications discovered, However, the disease still affects ethnic minority communities and especially among African American males. As people live longer with the disease the healthcare community must find ways to make sure that they are able to access and utilize the healthcare services needed without fear of being stigmatized by their families, communities and the within the healthcare system. Findings from this study show that social stigma had a strong association with access/utilization. In relations to perceived health, stigma was robust in explaining the patterns of access/utilization of health services. Social stigma was a consistent outcome between access/health services utilization when sociodemographic characteristics were controlled. The conclusion in this study suggests that the level of stigma that an HIV-positive urban African American man experiences impact their ability to access and use health care services. Thus, policymakers and healthcare providers must find ways to address the factors of social stigma surrounding the disease in an effort to increase adherence and quality of life of urban African American men living with HIV/AIDS.

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