

Influence of Quality of Life and Reason for Non-disclosure on HIV Stress among Urban HIV-Infected African American Men

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Abstract

Background: Although antiretroviral medications are prolonging the lives of individuals with HIV/AIDS, many individuals still have to contend with the day-to-day stressors of living with the disease, which affects their quality of life. People living with HIV/AIDS also must contend with social stigma balancing who to tell and when to disclose their sero-positive status leading to greater burden of stress. Limited information exists on the path of disclosure, relationship to quality of life (QOL) and HIV stress among urban African American men. **Purpose:** The purpose of this study is to examine the influence of quality of life and reasons for nondisclosure on HIV stress among urban HIV-Infected African American men. **Methods:** A cross-sectional descriptive study consisting of a convenience sample (n = 117) urban African American men age ≥ 18 years who self-identified as living with HIV/AIDS were enrolled in the study. Participants' age ranged from 21-60 years (M= 43 years). A survey questionnaire consisting of 4 instruments was administered: (a) The World Health Organization Quality of Life Scale (WWHOQOL-BREF Scale), (b) Derlega Reasons for HIV Disclosure Scale, (c) HIV/AIDS Stress Scale and (d) Socio-demographic characteristics scale developed by the primary investigator. **Results:** As QOL increased HIV related stress decreased, while as reasons for non-disclosure increased, HIV stress increased. Multivariate hierarchical linear regression analysis showed QOL to mediate the influence of non-disclosure on HIV stress. Controlling for socio-demographic variables, non-disclosure factors significantly influence HIV related stress; however, when adding QOL to the equation, nondisclosure was no longer significant. **Conclusion:** Understanding factors associated with QOL, non-disclosure of HIV status, are important indicators to enhancing the well being of urban African American men living with HIV/AIDS. HIV/AIDS program should incorporate reasons for nondisclosure when addressing HIV stress.

Keywords: Urban African American Men, HIV Disclosure, HIV Related Stress, Quality of Life

1. Introduction

Today, a diagnosis of the Human Immunodeficiency Virus (HIV) or the Acquired Immunodeficiency Syndrome (AIDS) may no longer be considered a terminal diagnosis. With the advancement in antiretroviral therapy (ART), patients diagnosed with HIV/ AIDS are living longer healthier lives.¹ Although ART has transformed the HIV/AIDS epidemic to a level lower than in the 1980s and the 90s, many HIV-infected people living with the disease are facing new challenges—financial insecurity, relationship stress, societal discrimination and social stigma.¹ These issues add challenges for both the people living with HIV/AIDS and their healthcare providers. According to the Centers for Disease Control and Prevention, approximately 1.1 million Americans are living with HIV/AIDS; and over half of these individuals are African Americans.² The majority of new HIV diagnosis and existing HIV patients reside in urban areas. Health departments around the country are concerned about the increased rate of individuals living with HIV/AIDS. A report by the Wisconsin Department of Health suggest that with an increased segment of the population living with HIV/AIDS residing in urban settings, with limited economic opportunities and poorly developed health infrastructures, many individuals may be at increased risk for contracting HIV infection in these settings.³ Thus, there is a need to address HIV/AIDS related stress and quality of life issues of these urban HIV-

infected African American men. Although the use of ART has notably lowered the mortality rates of people living with HIV/AIDS, some are experiencing a greater burden of the disease.

Factors contributing to the disparities of health among HIV-infected urban African American men include poverty, low level of education and criminal conviction rates. In 2010, African American men accounted for 70% of the new HIV-infections, the rate of HIV infections among African American men was 7 times the rate of their White male counterparts; 2 times that of Latino men and 3 times that of African American Women.⁴ Reports also show that 1 in 16 African American men at some point in their lifetime will be diagnosed with HIV/AIDS.⁴ The increased risk of exposure to HIV/AIDS in urban America contributes to the HIV stress in the community. According to the Center of Disease Control and Prevention, in 2010, urban African American men had a HIV death rate of 11.6 per 100,000 compared to White male death rate of 2.8 per 100,000.⁴

Studies have shown that disclosure of HIV status benefits physical health, psychological health, and adherence to ART.^{5, 6} Many African American men live in inner-city urban areas where discussion of HIV/AIDS may still be a taboo and revelation that one is HIV infected may subject that individual to unnecessary gossips, discrimination and stigma all of which could impact the quality of life of those infected and living with HIV/AIDS. The stigma associated with HIV/AIDS deeply impacts the QOL of HIV-infected people.^{5,6} Because of the fear that people living with HIV/AIDS may be stigmatized, some individuals may become self-isolated and many may not feel comfortable disclosing their HIV status. To understand this problem, more information is needed about the patterns of disclosure including reasons for non-disclosure among urban African American men. A study among urban African American men found several factors attributing to the lack of disclosure among people living with HIV/AIDS including: fear of rejections, stigma, loneliness, not ready to disclosure, and not wanting to become a burden to others as reasons to withhold a positive HIV status(CITE). For some disclosing their status relieves stress, satisfy the need to be honest, help other HIV positive men, and to receive support. Gathering information holistically from HIV-infected African American men regarding disclosure of their HIV status may contribute to achieving positive health outcomes⁶.

The purpose of this study was to understand the relationship between QOL, reason for non-disclosure, and HIV stress among urban HIV-infected African American men. This study examines how these factors independently or jointly affects the stress of being HIV positive among urban African American men.

2. Literature Review

2.1 Previous Research

HIV-infected patients are a challenging group for healthcare providers (HCP) having multidimensional factors contributing to the stress of living with HIV/AIDS. Healthcare providers play a major role in the lives of their patients. For both chronic and acute care, providers set the tone for patients' clinical experience. Wei-Ti Chen et. al (2013)⁷ suggests that there is an important relationship between HCP and the QOL of their patients. Using a cross-sectional study method, a sample of 2,182 people living with HIV/AIDS from the United States, Canada, Puerto Rico, Namibia, and China were evaluated for QOL, antiretroviral therapy (ART) adherence, self-efficacy, self-esteem and symptom self-reporting. Results suggested that HCP engagement is fundamental for improving the lives of HIV-infected patients.⁷

Compared to twenty years ago, HIV/AIDS are no longer terminal diagnoses but now considered chronic diseases. People living with HIV (PLWH) may also suffer from such common chronic diseases as hypertension, chronic pain, hepatitis, arthritis, etc. Balderson et al⁸ assess the quality of life (QOL) of the ageing of HIV infected population compared with the burden of living with chronic illnesses. Over 450 PLWH beyond the age of 50 completed a telephone survey that included instruments measuring chronic health conditions, perceived stress, depression, and health related QOL. Results showed that nearly 95% of the participants were suffering from a chronic illness in addition to HIV. Although chronic diseases are common for people over the age of 50, multiple chronic illnesses contribute significantly to their QOL⁹. In another study, Bird et al (2013)¹⁰ explored how HIV-related stigma negatively affected sexual communication and HIV prevention. Participants in that study reported that HIV-related stigma is an issue in Black America because misinformation about HIV and homosexuality fuel discriminatory attitudes towards this population. Many participants also felt the need for methods that will make HIV visible in the community and to stop HIV infected individuals from living in isolation and in hiding.

Posttraumatic stress disorder (PTSD) is a mental diagnosis often given to people who are suffering from a tragic event and has also been used in the area of people receiving a positive HIV/AIDS diagnosis. According to Wagner,

G et al¹¹, PTSD is fairly common among HIV-infected individuals and is often associated with ART adherence. Because discriminatory behaviors often add to the stress of being HIV positive, this study evaluated how discrimination, ART adherence and PTSD affect PLWH. Wagner and colleagues found that discrimination played a significant role among HIV-infected African American men suffering from PTSD.¹¹

Other researchers have also examined the concept of HIV stress. Pakenham & Rinalds¹² developed a self-reported instrument to assess HIV stress.¹² Because of the harsh stigma and burden of living with HIV/AIDS, there is a need to understand the stress associated with this chronic illness. In the study, participants completed the HIV/AIDS Stress scale, which measures coping strategies, appraisal, and social support. Results showed that three factors were important for HIV stress analysis – social stress, instrumental stress, and emotional existential stress. This study extends HIV/AIDS research by allowing researchers to appropriately measure stress levels of infected individuals. In turn, these measurements will help HCP understand the stress associated HIV and enable them to personalize care plans.

2.2. The Theory Of Self-Care Management

Chronic illnesses account for 60% of deaths worldwide making it the world's leading cause of death.³ In the United States, most causes of deaths are due to chronic-related diseases. Larsen (2013)¹³ suggests that overtime, chronic illnesses (e.g., hypertension, cancer, diabetes, arthritis,) lead to serious disabilities because they are not completely curable. For the purpose of this research on urban HIV-infected African American men, the Theory of Self-Care Management will be used as the foundation upon which the analysis is done and implications generated from the study are drawn. Multiple studies^{14,15} describes that theory of self-care and management of chronic illnesses as a framework that is designed to find approaches with which healthcare providers can improve the QOL of their patients diagnosed with chronic illnesses. Lorgi & Holman also suggest that with the use self-management and chronic illness theories in healthcare, patients with chronic illness can accrue benefits because overtime they become active participants in treatments and care.¹⁵

While maintaining patients' independence and self-respect, the theory of self care management attempts to improve the overall QOL (mental, physical, and emotional performance) of patients suffering from such chronic illness. Lorgi and Holman¹⁵ provides a history of the self-management theory and identifies three significant tasks for enhancing patient's self-care – medical management, role management, and emotional management. Within this conceptual framework, Lorgi and Holman discuss how self-care management programs can improve health behaviors, health status, health care utilizations; the role of self- efficacy; and how self-care management can be incorporated into medical practice¹⁵.

Medical management of HIV/AIDS involves adhering to special medical needs (e.g., special diets or faithfully taking medication). Dorsey and Murdaugh¹⁶ suggest that this is often difficult for vulnerable populations because socio-demographic factors (e.g, education, low income, poor living conditions) can contribute to individuals' ability to manage their illness. Patients diagnosed with a chronic illness often have to adjust to new life roles. Lorgi & Holman¹⁵ emphasizes that a limitation of self-care management is that it is based, on the patient's perceived problems. Larson stresses that although health care originally focused on curing patients for diseases and illnesses, healthcare is now shifting towards caring for people with disorders that are not curable.¹³ In efforts to care for patients, the self-care management theory gives patients the opportunity to control their illness under the influence of health care providers and related disciplines. Overall, the self-care management theory is a creditable nursing and health discipline theory that uses a holistic approach to care. The self-care management theory used in this study fits very well in understanding the challenges urban HIV-infected African American men faces in living with this HIV/AIDS.

3. Methods

3.1 Data Collection And Description Of Sample

Participants in this cross sectional, descriptive study were self-identified HIV-infected urban African American men (N=117), recruited by flyers at community based organizations and word of mouth notification. Participant's ages ranged from 21-60 years, resided in Milwaukee, Wisconsin and agreed to complete a 45-60 minute survey that included demographic information, instruments measuring their QOL, attitudes towards disclosure, and HIV stress. All research procedures were approved by the University of Wisconsin-Milwaukee Institutional Review Board

(IRB) for the protection of human subjects. Informed consent was obtained from all participants prior to administering the survey.

3.2 Variables/Measures

The dependent variable in this study was HIV stress. Using the *HIV/AIDS Stress Scale* developed by Pakenham and Rinaldis¹², a construct that measures the role stress plays in an individual adapting to various stressors in their life while living with their condition. The HIV stress scale was specifically designed to focus on issues of relevance to people living with HIV/AIDS and is comprised of 3 domains: emotional existential stress with the mean of 2.47 (SD = .976), social stress with the mean of 2.35 (SD = .858), instrumental stress with the mean of 2.27 (SD = .907). The higher the score the better the QOL.

There were two primary independent variables in this study. The first independent variable is quality of life. In this study, we used the *World Health Organization Quality of Life Scale (WWHOQOL-BREF Scale, WHOQOL GROUP, 1998)*. The WHOQOL-BREF Scale QOL Scale consisted of 26 items measuring participants' satisfaction of life with a total score and in 4 domains: physical health, psychological health, social relationships and environmental. Using a 5 point likert scale, 5 corresponding to very good and 1 corresponding to very poor, the overall total score for WHOQOL-BREF is calculated by multiplying the average of the 26 questions by 4. In this study, scores ranged from 4-20, and in the 4 domains were: physical health (M = 12.48, SD = 3.15); psychological health (M = 13.14, SD = 3.49); social relationships (M = 11.70, SD = 4.91); environment (M = 13.46, SD = 3.24).

The second independent variable was Reasons for HIV Disclosure. Derlega et. al (1997) developed the Reasons for HIV Disclosure scale to examine the impact of attitudes supporting disclosure as well as opposing disclosure (non-disclosure) of their HIV positive status.¹⁷ The questions identified 5 reason to disclose HIV status (catharsis, duty to inform/educate, to test other persons reactions, support and similarity), and 6 reasons not to disclose HIV status (privacy, self-blame/ self-concept difficulties, communication difficulties, fear of rejection, protecting others, superficial relationships). Scores for reasons to disclose and reasons not to disclose HIV status were on a Likert Scale ranging from 1-5 (1 being not at all a factor to 5 being very likely a factor). The non-disclosure score was used for analysis in this paper .The non-disclosure score ranged from 6-29 with a mean score of 18.08 (SD = 5.89).Reasons to not disclose subscales consisted of 6 domains: privacy (M = 3.65, SD = 1.36); self-blame/self-concept difficulties (M = 3.10; SD = 1.49); communication difficulties (M = 2.58, SD = 1.28) fear of rejection (M = 3.10, SD = 1.51); protecting others (M = 3.23, SD = 1.36); superficial relationships (M= 2.42, SD = 1.44).

To describe the sample, demographic questions were developed by the authors. Participants reported their age, income, education level, and employment, number of years since diagnosis, disease progression, and sexual orientation. All responses were self-identified and no further investigation was taken to validate information.

4. Analysis

Using the Statistical Package for the Social Science (SPSS-PC for Windows[®]) version 17.01, data were entered and coded for a statistical analysis. Descriptive statistics of frequencies, percentages, means, and standard deviations were computed to describe the sample. Pearson product-moment correlations were used to determine bivariate relationships of variables QOL, reasons for non-disclosure, and HIV-related stress. The mediating effect of QOL on the relationship of non-disclosure and HIV stress will be tested using multivariate hierarchical linear regression analysis while controlling for socio-demographic variables (age, income, education, employment, years since diagnosis, and clinical status). According to Baron and Kenny, for mediation to exist, three conditions must occur (1) The predictor variable (non-disclosure) must significantly correlated to the mediator (QOL) (2) The mediator must be significantly correlated to the criterion variable (HIV-stress) and (3) When the association from the first two conditions are controlled the direct relationship between the predictor and the criterion is substantially reduced or no longer significant.

5. Results

5.1 Socio-Demographic Characteristics Of Participants

The sample consisted of 117 urban African American men who self-identified as being HIV/AIDS infected. Participant's age ranged from 21-60 (M=43 SD=8.25). Most had an annual income of less than \$30,000 and were unemployed. Participants self-reported their sexual orientation with the almost half identified as homosexual and almost half self -identified their disease progression as symptomatic, their years since diagnosis ranged from 1 > years < 10 (M=13.17, SD=7.63). Summary information of these characteristics is displayed in Table 1.

Table 1. Socio-demographic characteristics of participants

Characteristics	N	Percent
Age groupings		
21-34	18	15.4
35-44	47	40.2
45-60	52	44.4
Sexual orientation		
Heterosexual	32	27.4
Homosexual	52	44.4
Bisexual	18	15.4
Don't know	7	6
Disease progression		
Asymptomatic	41	35
Symptomatic	51	43.6
Full blown AIDS		17.1
Education		
Primary or less		2.6%,
Some high school		20%,
High School graduate		27%,
Some college		38.3%,
College graduate and more		21.2
Employment		
	20	
Full time		13.9%,
Part time		17.6
Unemployed		68.50%
Income		
Less than \$5,000		38%
\$5,000-\$9,999		17%
\$10000-\$2999		37%
\$30,000 +		8%,

5.2 Bivariate Relationships With HIV-Related Stress:

Correlations between participant's scores for quality of life, HIV-related stress and reasons for non-disclosure score were calculated to test the first two conditions of mediation. (1) The predictor variable (non-disclosure) was significantly correlated to the mediator (QOL) and (2) The mediator (QOL) was significantly correlated to the criterion variable (HIV-stress) (Table 2)

Table 2. Correlations between participant's scores for quality of life domains, HIV-related stress and reasons for non-disclosure

	Quality of Life Total	Non-disclosure
HIV Stress	-.672**	.323**
Non-disclosure	-.316**	

*Correlation is significant at the 0.05 level (2-tailed). **Correlation is significant at the 0.01 level (2-tailed).

5.3 Multivariate Hierarchical Linear Regression Analysis

The third criterion for testing mediation was conducted by a Multivariate Hierarchical Linear Regression analysis (Table 3). The socio-demographic variables of age, clinical status, level of education and length of time since diagnosis were entered in the first step as control, explaining 4.9% of the variance in HIV related stress. In the second step non-disclosure was entered significantly explaining an additional 9.6% of the variance of HIV related stress. In the third step when QOL is added to the regression equation explaining an additional 33% of the variance in HIV related stress. Meeting the third criterion, with the addition of QOL the relation between non-disclosure and HIV related stress was no longer significant. QOL mediates the relationships between non-disclosure and HIV related stress. This information is displayed in Table 3.

Table 3. Hierarchical regression of non-disclosure and quality of life on HIV stress (n=117)

	Step 1 B	Step 2 β	Step 3 B
Age	-0.172	-0.131	-0.063
Clinical status	-0.008	0.01	-0.051
Level of education	-0.098	-0.099	-0.039
Length of time since diagnosis	-0.017	-0.013	-0.3067
Non-disclosure		.313**	0.11
Quality of Life			-.620**
R ² change	0.049	0.096	0.33

F = 6(103) = 15.50, p < 0.005 * p<.05 **p<.01

6. Discussion

6.1 Implications And Conclusions

African American men are at high risks for HIV related stress but programs focusing on strategies for disclosure can significantly increase their QOL. By increasing their quality of life they would decrease their HIV Stress. American men to address the stressors in their lives, assists them with appropriate strategies for disclosing their HIV status in an effort to enhance their quality of life.

6.2 Limitations Of This Study

Among the many limitations in this study, medical factors that may have been relevant were not evaluated; the survey did not include data on clinical health or biomarkers (e.g., CD4 cell count, HIV viral load) that may be useful in understanding the HIV/AIDS status of the participants. All of the data was self-reported. The participants were drawn primarily from a single community-based organization (CBO) that served predominantly African American patients. This CBO provide a non-random sample of participants and geographically limits the findings to a mid-size urban city. Because the current study uses a cross sectional survey design, it only provides a snapshot of the current population. Those individuals who are not a part of the partnering CBO may have a different perspective. The cross-sectional design does not capture life-long influences that can impact HIV-related stress among these men. A longitudinal design, with samples from diverse populations would capture findings that will allow for better evaluations on the influence of QOL, and reasons for non-disclosure among urban HIV-infected African American men.

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