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Courtney R. Sholar Date

Internalized Stigma, Depressive Symptoms, and Disclosure as it relates to HIV Medication Adherence in HIV-Infected African American Adolescent and Young Adult (AYA) Females

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B.A., Spelman College, 2012

Thesis Committee Chair: Jessica Sales, Ph.D.

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Abstract

Internalized Stigma, Depressive Symptoms, and Disclosure as it relates to HIV Medication Adherence in HIV-Infected African American Adolescent and Young Adult (AYA) Females

By Courtney R. Sholar

Introduction: African American AYA females are disproportionately affected by HIV/AIDS (CDC, 2010a). Although antiretroviral treatment and adherence to treatment provide significant benefits to those infected, adherence is not common among this population (Flynn et al., 2007; Murphy, Wilson, Durako, Muenz & Belzer, 2001). In order to examine factors related to adherence and address a gap in current research, this study proposed to examine the relationship between internalized stigma, depressive symptoms, and disclosure of HIV status and medication adherence.

Theoretical Framework: Socio-Ecological Model

Methods: Survey responses from 34 participants in a larger, primary study were analyzed through bivariate analyses and a multiple linear regression model. Participants included HIV-infected African American AYAs between the ages of 14 and 24 who were recruited from the Grady Ponce Family and Youth Clinic (PFYC) and the Grady Women's Infectious Disease Clinic (WIDC) in Atlanta, Georgia.

Results: Results concluded that internalized stigma was significantly associated with medication adherence, suggesting that as feelings of internalized stigma increased, adherence to antiretroviral medication decreased.

Conclusion: Participants' reports of internalized stigma significantly affected their medication adherence. As for future studies, research has found that group cognitive behavioral therapy targeting internalized stigma has significantly increased rates of adherence (Roe et al., 2014; Shimotsu et al., in press; Safren et al., 2000; Tsang, Fung & Chung, 2010). This form of therapy would be beneficial to examine among HIV-infected African American AYA females. Additionally, since internalized stigma has origin in enacted stigma, interventions targeting HIV-related stigma in broader populations are necessary.

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Table of Contents

Introduction

HIV among African American Women

Over one million United States citizens are currently living with Human Immunodeficiency Virus (HIV) with around 50,000 new cases of HIV infection per year (U.S. Department of Health and Human Services, 2012). While the rate of new infections has decreased, the rate of those continuing to live with the disease has increased due to advances in HIV treatment (WHO, 2013). Furthermore, the rate of incident HIV infections has continued to remain high for specific groups throughout the country, including men who have sex with men, Hispanics, and African Americans (CDC, 2012a)

African Americans have remained the group most disproportionately affected by HIV in comparison to other races and ethnicities (CDC, 2012a). Although African Americans account for about 14% of the overall U.S. population (U.S. Census Bureau, 2010) it is estimated that African Americans accounted for around 44% of HIV cases in 2009 and 44% of new HIV infections in 2010 (CDC, 2012a; CDC, 2012b). African Americans have a new HIV infection rate that is eight times that of their Caucasian counterparts. (CDC, 2012a). HIV-related mortality likewise disproportionately affects African Americans (CDC, 2013b), with African American men being seven times more likely to die from HIV when compared to Caucasian men. Since the beginning of the HIV epidemic, African Americans have suffered from well over 200,000 deaths (CDC, 2013b).

In addition, according to CDC data from 2008-2011, the Southern region of the U.S. (AL, GA, FL, LA, MS, NC, SC, TN, TX) accounts for the largest proportion of African Americans with new HIV diagnoses and living with HIV (Reif, Safley, Wilson & Whetten, 2014). In 2010, 45% of those with new diagnoses in the United States were from the South, with 62% of

individuals being African American (CDC, 2012a). In Georgia specifically, there are currently over 30,000 people living with HIV, with majority being African American (CDC, 2010b).

In regards to gender, African American women accounted for almost 30% of new infections in 2010 (CDC, 2012a). Although rates of new infection for African American women have decreased between 2008 and 2010, African American women still account for 13% of all new infections and 64% of new infections among all women (CDC, 2012a). When compared to white women, African American women have an infection rate that is 20 times higher (CDC, 2012a).

HIV among African American Youth in the South

African American adolescents and young adults (AYAs) have a disproportionately high rate of infection. Approximately 12,200 young people between the ages of 13 and 24 were diagnosed with HIV in 2010, accounting for 25.7% of new cases that year (CDC, 2012c). The majority of those diagnosed (57.4%) were African American youth (CDC, 2012c). Among all female youth, 85.7% of infections were attributable to heterosexual contact. As expected, African American young women are most affected group among females when compared to all female youth (CDC, 2012c). Despite stable rates of infection among the general population, rates of infection among African American adolescents and young adults (AYAs) continue to increase (CDC, 2010a).

In regards to region, the highest rates of HIV diagnoses among AYAs, and specifically African American youth, are concentrated in the South (CDC, 2010a). In 2011, Georgia had the seventh highest rate of new HIV diagnoses of AYAs between the ages of 13 and 24 (CDC, 2013b). Although there is limited data regarding the specific percentage of how many of these

AYAs were female, it is expected that females made up a significant proportion based on trends in adult populations.

Treatment for HIV

Comprehensive medical treatment for HIV-infected individuals is critical. The U.S. Department of Health and Human Services (2012) describes HIV as a virus that attacks the body's CD4 cells; these cells are vital to helping the body ward off disease and infection. Initial symptoms of HIV are similar to that of the flu or common cold, yet individuals can go years feeling healthy without any awareness of HIV infection (U.S. Department of Health and Human Services, 2012). AIDS supersedes HIV as the last stage of infection. In this stage, the immune system is severely damaged, and the development of other opportunistic diseases and infection is often imminent (U.S. Department of Health and Human Services, 2012). Currently, the gold standard in HIV treatment is Highly Active Antiretroviral Treatment (HAART), which helps to improve patient vitals and subsequently ward off opportunistic infections, reduce transmission, and avoid treatment-resistant HIV. HAART involves a combination of at least three different antiretroviral medications that are used to reduce replication of HIV within the body and to avoid treatment resistance to one, specific medication (WHO, 2013). Since the beginning of its use, HAART has shown great improvements in the morbidity and mortality of HIV-infected individuals (WHO, 2013).

HIV-Infection and Treatment in Adolescence

From a developmental perspective, sexual activity among adolescents is likely, with the average age of sexual debut being 17 years old (Guttmacher Institute, 2013). Although sexual activity among adolescents is common, condom use is not (Weller & Davis-Beaty, 2002). Broadly, it has been found that HIV-infected African American women have infrequent condom

use (Anderson, Santelli & Gilbert, 2003; Bedimo, Bennett, Kissinger & Clark, 1998; Kissinger, Clark, Dumestre & Bessinger, 1996; Massad et al., 2007; Raiford, Wingood & DiClemente, 2007; Sales, Latham, DiClemente & Rose, 2010). Currently, there is little research regarding condom use among HIV-infected female African American AYAs, but more broad data about African American female high school students concludes that there is a less than favorable percentage of condom use among this group (CDC, 2012c). Youth Risk Behavior Survey (YRBS) data between the years of 2009 and 2011 found that only 59% of African American female high school students used a condom during their most recent sexual intercourse (CDC, 2012c). Condom use during sexual activity is a particular concern for African American HIV-infected (AYA) females because of possible transmission to uninfected individuals, the acquisition of drug-resistant strains of HIV and co-occurring STIs among infected individuals (Bangsberg et al., 2001; Kalichman, Pellowski & Turner, 2011; Matchtinger & Bangsberg, 2005; Rabkin & Chesney, 1999).

Treatment adherence is important for HIV-infected female African American AYAs that may engage in risky sexual behavior (inconsistent condom use or lack of condom use) since adherence can help reduce transmission and disease progression for those engaging in such behavior (Weller & Davis-Beaty, 2002) HAART requires high levels of adherence, and complete adherence (100%) is not common among those infected (Matchtinger & Bangsberg, 2005).

Factors Affecting Adherence

Studies have examined the factors affecting HAART medication adherence. Specifically, depressive systems, disclosure of HIV status, and internalized stigma have been correlates to HAART medication adherence in prior research (Chaudoir, Fisher & Simoni, 2011; Ciesla & Roberts, 2001; Fields et al., 2012; Gonzalez, Batchhelder, Psaros & Safren, 2011; Kacanek et al.,

2011; Kourrouski & Lima, 2009; Magidson, Seitz-Brown, Safren, Daughters, in press; Murphy et al., 2001; NIMH, 2011; Pugatch, Bennett & Paterson, 2002; Rao et al., 2007; Rinatamki, Davis, Kripkaukas, Bennett & Wolf, 2006; Safren et al., 2000; Sankar et al., 2002; Stirratt et al., 2006). Research has shown that depressive symptoms and stigma decrease the likelihood of proper medication adherence among HIV-infected persons while disclosure has been shown to increase adherence (Chaudoir et al., 2011; Fields et al., 2012; Kacanek et al., 2011; Murphy et al., 2001, Stirrat et al., 2006). However, there is limited focus on the effect of these factors on medication adherence among HIV-infected African American AYA females. Other extraneous factors have been associated with non-adherence to HAART, including general barriers to medication (i.e. being away from home, forgetting medication, being to busy, etc.) and age, with younger age being associated with poorer adherence (Barclay et al., 2007; Catz, Kelly, Bogart, Benotsch & McAuliffe, 2000; MacDonell, Naar-King, Huszti & Belzer, 2013). The present study will not assess these factors but will control for them in data analyses.

Theoretical Background

As previously noted, medication adherence among HIV-infected AYAs has been shown to be influenced by several factors. Factors including depressive symptoms, disclosure of HIV status, and internalized stigma can be described by elements of the Socio-Ecological Model (SEM). Bronfenbrenner (1979) developed the SEM and described it as structure of different levels that affect and influence an individual's development. McLeroy and colleagues (1988) adapted this model and its systems to specifically apply to the ways in which these levels affect health-related behaviors. The systems within SEM include the intrapersonal, interpersonal, institutional factors, community factors, and public policy (McLeroy et al., 1988).

Although theoretical research in the area of medication adherence among HIV-infected populations is young and disjointed, the Socio-Ecological Model (SEM) is an approach that can clarify the behavior of adherence, specifically through its various components. The SEM is beneficial in that it allows the examination of different levels of behavioral influence in hopes of developing and promoting more healthful behaviors (McLeroy et al., 1988). The intrapersonal level of the SEM involves characteristics of an individual that can directly affect their behavior, including their knowledge, attitudes, skills, genetics, etc. (McLeroy et al., 1988). Depressive symptoms are a factor within the intrapersonal level because it fits the aforementioned criteria of being an individualized characteristic that has direct effect on a person and his/her behavior.

The interpersonal level involves an individual's formal and informal social networks (McLeroy et al., 1988). Therefore, interactions with family, peers, and others in a close, social network are placed within the interpersonal level because of their link with the individual (McLeroy et al., 1988). Based on the present study, disclosure of HIV serostatus falls within the interpersonal level because communicating one's status to individuals within his/her social network. Internalized stigma has been defined as "the product of the internalization of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV-positive" (Brouard &Wills, 2006). Because internal stigma is intrinsically connected to stigma that is outwardly expressed by those within a social environment, internalized stigma is also part of the interpersonal level.

In support of the focus on the intra- and interpersonal levels, a study of HIV medication adherence in Tanzania, which utilized the SEM as its driving theory, noted that individualized and social components, the intrapersonal and interpersonal levels respectively, have been found to be most relevant in this area of research (Watt, 2006). Although the other levels of the SEM

may be related to the outcome of interest (medication adherence), their influence was not be expounded upon due to limits in the current study's measurement tools.

Purpose/Objective

In order to fill a gap in the literature, the current study focuses on HIV-infected African American AYA females living in Atlanta, Georgia. The study will survey this population in order to determine the relationship between depressive symptoms, HIV serostatus disclosure, internalized stigma, and medication adherence. Given the negative consequences of non-adherence in the context of risky sexual behavior, it is important to examine the relationship between these factors in order to determine whether further research and treatment adherence intervention is necessary. In addition, there is a need to focus on this population because of high rates of HIV infection among African American AYA females and a lack of current literature for the population.

Research Questions

The current study seeks to answer the following question: What is the relationship between intra- and interpersonal level factors (depressive symptoms, disclosure of HIV serostatus, and internalized stigma) and medication adherence in HIV-infected African American AYA females living in Atlanta, Georgia?

Hypotheses

The study's hypotheses are as follows:

Depressive symptoms, disclosure of HIV status, and internalized stigma will be correlates of medication adherence within the given population.

(a) Depressive symptoms will be negatively correlated with medication adherence. As depressive symptoms increase, medication adherence will decrease.

(b) Disclosure of HIV status will be positively correlated with medication adherence. As disclosure to more people increases, medication adherence will increase.

(c) Internalized stigma will be negatively correlated with medication adherence. As internalized stigma increases, medication adherence will decrease.

In this study, depressive symptoms were defined as a participant's indication of feeling sad or blue within the past week and measured by the Center for Epidemiological Studies-Depression (CES-D) Scale (Radloff, 1977). Disclosure was defined as the declaration of positive HIV status to someone within an individual's social environment by the adolescent or young adult herself, which was measured by a scale developed from Vanable and colleagues (2006). Lastly, internalized stigma was defined as "the internalization of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV-positive" (Brouard &Wills, 2006). Specific items from a scale developed by Vanable et al. (2006) to measure participants' experiences with stigma-related experiences since diagnosis was used to measure internalized stigma. This measure utilized by Vanable et al. (2006) was informed by previous scales developed by Heckman and colleagues (1998) and Heckman (2003). These operational definitions were guided by the survey measures utilized to address each factor.

Internalized Stigma, Depressive Symptoms, and Disclosure as it relates to HIV Medication Adherence in HIV-Infected African American Adolescent and Young Adult (AYA) Females

HIV-Infected African American AYA Females

Although some studies focus on HIV-infected African American youth as a whole, research regarding African American HIV-infected AYA females is particularly important. African American women make up 30% of all new HIV infections among African Americans (CDC, 2012a). Although data on the current percentage of HIV-infected African American AYA females is limited, trends are expected to follow that of the larger African American female population. It has been noted that African American AYA females are the most impacted as compared to their white and Hispanic counterparts; African American AYA females have infection rates that are fivefold (CDC, 2013a). Furthermore, since new HIV infections among all African American AYAs are concentrated in the South, it is expected that infection rates among African American AYA females is similar to that of the average among all African American women in the South (CDC, 2013b).

Importance of HAART and Adherence

The World Health Organization (WHO) describes HAART as a combination of three antiretroviral medications that help to restrain replication of HIV and avoid HIV treatment resistance (WHO, 2013). The Department of Health and Human Services (2012) suggests that HIV-infected individuals should begin antiretroviral medication if they experience severe symptoms, acquire an opportunistic infection, have a CD4 count less than 350, become pregnant, or have kidney disease related to their HIV infection. Although HIV infection cannot be cured, the goal of treatment is to maintain a high CD4 count and low viral load (U.S. Department of Health and Human Services, 2012).

WHO notes that this form of HIV treatment can potentially reduce disease progression, death rates, and infectivity of other infections, while also providing an increasingly positive quality of life (WHO, 2013). The use of HAART is continuously proving to be advantageous in the reduction of HIV transmission (Dieffenbach, 2012, Cohen et al., 2011). One study discovered that, for HIV-infected spouses, starting HAART sooner rather than later could lower their risk of transmission to their partner by over 90% (Cohen et al., 2011). In addition, 2010 WHO guidelines for preventing HIV infections in infants suggests early and consistent use of HAART, potentially reducing transmission risk to 5% or lower (WHO, 2010).

Non-adherence to HAART can lead to significant problems for the individual's health and public health as a whole. Non-adherence is related to higher risk for infection transmission and delays in viral load suppression and CD4 count increase (Matchtinger & Bangsberg, 2005; Rabkin & Chesney, 1999). Non-adherence has also been associated with development of treatment resistant HIV and transmission of treatment resistant strains to partners (Matchtinger & Bangsberg, 2005; Rabkin & Chesney, 1999). Bangsberg et al. (2001) noted a risk of higher accounts of overall health complications and death. Non-adherence can be noted and tracked by healthcare providers, and research has suggested that continuous treatment monitoring could aid in adherence intervention (Bangsberg, 2008).

HIV Medication Adherence among AYAs

As described, treatment adherence is critical for HIV-infected individuals, yet non-adherence among African American AYA females is an issue. In a qualitative study examining HAART adherence among HIV-infected adult African American females, 76% of study participants reported being only partially successful in the recommended adherence to their HAART medication (Sankar et al., 2002). Although the majority of HAART adherence studies

focus on adults, the studies that have measured adherence among AYAs have found that adherence is low (Flynn et al., 2007; Murphy et al., 2001). For example, Murphy et al. (2001) found that among a sample of HIV-infected adolescents between the ages of 13 and 18, only 41% reported complete adherence to their medication. In addition, this study found a strong relationship between reduced viral load and a CD4 count equal or higher to 500 for those who reported full adherence (Murphy et al., 2001). In a three-year study on 120 HIV-infected adolescents and their adherence to HAART, only 37% remained on the treatment for the entire study (Flynn et al., 2007). Studies examining medication adherence among African American HIV-infected female AYA is limited, yet research in this area is important due to the overarching findings of poor adherence among HIV-infected AYA overall.

Risky Sex in the Context of Adherence

The importance of HAART adherence is underscored by inconsistent condom use. In addition to non-adherence to medication, inconsistent condom use is problematic for HIV-infected individuals because it further increases the likelihood of transmission, acquisition of drug-resistant strains of HIV and co-occurring STIs among infected individuals (Bangsberg et al., 2001; Kalichman, Pellowski & Turner, 2011; Matchtinger & Bangsberg, 2005; Rabkin & Chesney, 1999). Consistent condom use reduces transmission risk by about 80 percent, but consistent use is not expected among African American AYA females (Weller & Davis-Beaty, 2002). Studies have shown that seronegative adolescents and young adult females do not use condoms consistently (Anderson, Santelli & Gilbert, 2003).

Raiford et al. (2007) found that only half of HIV-infected African American women between the ages of 18 and 50 consistently used condoms when they had an HIV-infected male

partner. The rate of consistent condom use was higher when women had a negative partner, but there was still not 100% use.

A qualitative study about barriers to condom use among HIV-infected African American women between the ages of 18 and 45 found that condom use was infrequent and difficult due to lack of partner communication and condom negotiation skills (Bedimo et al., 1998). A more recent study among HIV-infected U.S. women found that over 30% did not use any form of contraceptive practice, including condoms (Massad et al., 2007). In studies that focused on the "dual method" among HIV-infected women, which involves the use of birth control and condom use as means for protection, reports of actual use of the method was shown to be as low as 5% (Anderson et al., 2003; Anderson et al., 1999; Crosby et al., 2001; Sales, et al., 2010).

Although studies specifically about condom use among HIV-infected African American AYA females is lacking, one study found that non-use of condoms among HIV-infected women is associated with being 22 years or younger (Kissinger et al., 1996). As for newly-positive African American AYA females in 2011, about 93% of those between the ages of 13 and 19 acquired the disease from heterosexual contact; 91% between the ages of 20 and 24 were infected through heterosexual contact, which speaks to the lack of condom use within this population.

Depressive Symptoms and Adherence

Various factors affect HIV medication adherence. The National Institute of Mental Health (2011) states that those diagnosed with HIV are more likely to experience depression than the general population. Through meta-analysis research, Ciesla and Roberts (2001) found that HIV-infected persons are twice as likely to develop major depressive disorder as compared to HIV-negative individuals. Clinical depression and sub-clinical depressive symptoms have

consistently correlated with non-adherence to HIV medication over time (Gonzalez et al., 2011). Research has shown that HIV-infected persons with depressive symptoms are twice as likely to be non-adherent (Kacanek et al., 2011). In regards to adolescents, Murphy et al. (2001) found that higher reports of depression were associated with a significant decrease in medication adherence among adolescents in 13 U.S. cities. Rao et al. (2007) discovered similar results through qualitative analysis of urban HIV-infected youth.

Interventions show further support for depression as a factor associated with medication adherence. Safren et al. (2000) studied strategies to increase HIV medication adherence among a small, clinical population. Following intervention, they found that lower depression scores were related to improvements in adherence (Safren et al., 2000). Magidson et al. (in press) implemented an evidence-based cognitive behavioral therapy intervention among a larger HIV-infected population in order to determine intervention effects on depression and adherence. Following the intervention, Magidson et al. (in press) found that there were slight increases in medication adherence after targeting mental health and depressive symptoms. In order to combat issues of non-adherence, depression is a potentially important factor that should further investigated.

Disclosure and Adherence

Chaudoir et al. (2011) have found that disclosure of one's positive HIV status is one of largest psychosocial challenges to HIV infection. They explicitly define disclosure as the event that occurs when an infected person communicates their positive status to a confidant (Chaudoir et al., 2011). Chaudoir et al. found that disclosure has the ability to promote HIV medication adherence because it gathers social support and diminishes an infected person's need to hide (and subsequently hinder) medication due to fear of unexpected disclosure. Stirrat et al. (2006) found

that greater reports of disclosure were associated with higher medication adherence among an HIV-infected population that had previously reported trouble with adherence. Research regarding the relationship between disclosure and adherence in adolescent populations is limited, yet one study found that lack of disclosure has been significantly associated with non-adherence among HIV-infected youth between the ages of 13 and 24 (Fields et al., 2012). Since there is limited research regarding serostatus disclosure, this factor should be examined in order to determine its impact on adherence.

Internalized Stigma and Adherence

HIV is a highly stigmatized disease (Alonzo & Reynolds, 1995). Goffman (1963) described health-related stigma as a societal norm that deems those with a given affliction as undesirably deviant in the context of his/her social environment. Link and Phelan (2001) have stated that stigma involves labeling, stereotyping, separation, and discrimination. An often forgotten dimension of stigma is internalization. Internalized stigma, which is also referred to as felt or self-stigma, has been defined as "the product of the internalization of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV-positive" (Brouard &Wills, 2006). Internalization of HIV-related stigma is impeding for health because of its association with increased risky behavior, including sexual risk taking and substance abuse as well as feelings of self-depreciation (Fife & Wright, 2000; Valdiserri, 2002) Further, although research is limited in this area, internalization of stigma has also been associated with decreased adherence to HIV medication (Lyimo et al., 2014; Martinez et al., 2012; Sayles, Wong, Kinsler, Martins & Cunningham, 2009).

In a study of a diverse HIV-infected population of almost 300 participants, most reported experiencing internalized stigma by either feeling embarrassment of their disease or finding it

difficult to disclose their serostatus to others (Lee, Kochman & Sikkema, 2002). A metasynthesis of qualitative data among HIV-infected women found that the majority of women experienced enacted stigma ("the real experience of prejudice, discrimination and disadvantage"; Adler, Abraham, van Teijlingen & Porter, 2009; Sandelowski, Lambe & Barroso, 2004), which was compounded by its internalization. Further, it was found that the internalization of stigma was worsened because they were women; participants often reported that they struggled with potentially being viewed negatively as women and/or mothers (Sandelowski, Lambe & Barroso, 2004). With regard to HIV-infected African American women, Vyavaharkar et al. (2010) found that most reported some form of internalized stigma among a sample living in the Southeastern region of the United States.

In terms of medication adherence, several studies have found an association between experiencing high levels of enacted stigma and low levels of medication adherence among HIV-infected women and AYAs (Fields et al., 2012; Kourrouski & Lima, 2009; Pugatch et al., 2002; Rao et al., 2007; Rintamaki et al., 2006; Sankar et al., 2002). With regard to internalized stigma, one study of Northern Tanzanian, HIV-infected men and women using antiretroviral therapy found that medication adherence was negatively correlated with internalized stigma (Lyimo et al., 2014). A study of 202 HIV-infected adults living in Los Angeles found similar results (Sayles et al., 2009). In a study of HIV-infected AYAs, an association between stigma (measured by outward and internalized stigma) and suboptimal medication adherence was found after moderation analysis (Martinez et al., 2012).

As previously noted stigma is a common and concerning aspect of HIV infection. Additionally, the CDC (2013a) notes that stigma is a significant problem within African American communities. In addition to HIV-related stigma, African Americans may face multiple

levels of stigma due to stigma against their HIV serostatus, their racial/ethnic background, and sex (if female) (Earnshaw, Bogart, Dovidio & Williams, 2013; Sandelowski et al., 2004). Research regarding internalized stigma in relation to HIV medication adherence among HIV-infected African American AYA females is lacking yet important for examination given previous findings.

Method

Participants

The present study is a secondary data analysis of a larger, exploratory cross-sectional study of HIV-infected AYAs. Participant recruitment followed that of the primary study. Participants in the primary study included150 female AYA between the ages of 14 and 24 years old. Due to the overlap in time of the primary and present study, the primary study was still in the recruitment phase during the development of the present study; therefore, only a subset of the projected population was measured.

Participants were recruited from the Grady Ponce Family and Youth Clinic (PFYC) and the Grady Women's Infectious Disease Clinic (WIDC) in downtown Atlanta, Georgia. The AYAs were recruited using a standardized recruitment script during one of their routine clinical care appointments. Eligibility criteria for the primary study required that all participants receive care at either clinic (which is an indicator of the positive HIV status), were between the specified age range (14-24), were female, not pregnant, spoke English, and willing to provide consent or assent. Eligibility criteria for the present study included all aforementioned factors in addition to being African American and having a current prescription for antiretroviral medication. Although being African American was not part of the eligibility criteria in the primary study, the present study focused only on those who are African American. Previous studies that involved recruitment within these clinics developed samples that were largely African American, thus the present study did not anticipate any difficulty in acquiring this specific sample.

Procedure

Participants were recruited during regular clinical care appointments. A research assistant explained the study using a standardized script, and consent was obtained prior to taking the

survey. All participants were given a participant ID prior to beginning the survey in order to ensure privacy of participant information. The survey, which took about 30 minutes to complete, was completed before or after the participant's appointment. Participants also had the choice to schedule their survey during their next regular clinical care appointment, if necessary. The surveys were administered on laptop computers using Audio Computer Assisted Self-Interview (ACASI) technology. The participants were compensated with a $25 grocery store gift card following completion of the survey. Following completion of the survey, a research assistant conducted a medical chart review for each participant in order to review their health records for information about their STD history, current HIV treatment, and treatment visits. This information was entered into a separate ACASI survey file.

Measures

There were four specific measures for depressive symptoms, disclosure of HIV status, internalized stigma, and medication adherence, respectively. In addition to these measures, relevant, descriptive information about participants was assessed. This information included socio-demographics such as age; sexual risk factors such as most recent condom use and time frame of most recent sex. Measures about condom use and sexual activity helped to determine the risky behavior among this population. All measures are described below.

Descriptive Information

Age. Age was assessed through an open-ended question. Participants were asked their ask age in years, and they typed their response to the question.

Lifetime Vaginal Sex. Lifetime vaginal sex was assessed by one dichotomous question that asked participants if they have ever engaged in vaginal sex.

Most Recent Condom Use. In order to assess condom use during their most recent vaginal intercourse, participants were asked to indicate ("yes" or "no") whether they used a condom during their most recent vaginal sex. Prior to this item, participants were asked when was the last time they had vaginal sex; only participants who had had sex within the past year were asked about most recent condom use due to a skip feature in the measurement.

Condom Use in Past 30 Days. Participants were asked to indicate "yes" or "no" to the following question in order to assess condom use in the past month: "During the past month, did your partner use a condom every time you had vaginal sex?"

Predictor Variables

Depressive Symptoms. Depressive symptoms were assessed using eight items from the Center for Epidemiological Studies-Depression (CES-D) Scale (Radloff, 1977). Participants used scaled responses from one to four to indicate how often they felt a particular way, with higher scores indicating greater frequency of depressive symptoms. Response choices ranged from (1) rarely or none of the time (less than once a day) to (4) most or all of the time (5-7 days). Scores could range from eight to 32, with higher scores indicating high levels of depressive symptoms. Sample items from this measure included "I thought my life had been a failure" and "I felt sad." A total score from this measure was calculated. Cronbach's alpha reliability for this scale was .87 suggesting high internal consistency of scale items.

Disclosure of HIV Serostatus. In order to assess disclosure of positive HIV status, a 12-item scale was used (Vanable et al., 2006). This scale included a list of potential members of an individual's social environment and asked the participant to indicate whether they have disclosed to the individual(s). Possible individuals to whom the participant may have disclosed their status included parents, siblings, sexual partners, etc. Response choices included (1) told none of them,

(2) told some of them, (3) told all of them, and (4) relationship does not apply. All items in the measure were recoded so that a score of zero would replace a response of "4," in order to avoid incorrect elevated scores. Scores could range from 12 to 36, with higher scores indicating more disclosure to individuals within the participants' social environments. All items in the scale were re-coded so that higher scores indicate higher disclosure rates. A total score across possible individuals was calculated. Cronbach's alpha reliability for this scale was .85 suggesting high internal consistency of scale items.

Internalized Stigma. Internalized stigma was assessed using five items from a 12-item stigma and discrimination scale (Heckman, 2003; Heckman et al., 1998; Vanable et al., 2006). Participants used the scale responses to indicate how many times in the past three months they felt stigmatized based on their experiences, feelings, and opinions of how they were treated by others. Response choices ranged from (1) never to (6) almost daily, with higher scores indicating higher internalized stigma. Scores could range from five to 30. Sample items form this measure included "I felt awkward or embarrassed because I am HIV+" and "I hid my illness out of fear that they would say or do something that could hurt me." A total score was calculated. Cronbach's alpha reliability for this scale was .83 suggesting high internal consistency of scale items.

Outcome Variable

Medication Adherence. Medication adherence was assessed with one item that asked participants to indicate the percentage of their HIV medication they have taken in the last month. Response choices ranged from (0) having taken no medication to (100) having taken every dose of medication, with lower responses indicating lower adherence. The response choices were spread by 10-point increments.

Control Variables

In prior research, specific perceived barriers (i.e. being away from home, forgetting medication, etc.) and age have been associated with non-adherence to HIV medication. (Barclay et al., 2007; Catz et al., 2000; MacDonell et al., 2013). The present study used two measures to control for perceived barriers to medication and age.

Barriers to Medication Adherence. Barriers to medication adherence were assessed by a 14-item scale. (Catz et al., 2000). The scale included a list of potential reasons why participants may have missed their medication in the past month. Response choices included: (1) never, (2), rarely, (3) sometimes an (4) often. The list of reasons included: being away from home, forgetting medication, being too busy, having too much medication, wanting to avoid side effects, not wanting others to notice, change in daily routine, feeling like the drug(s) was harmful, falling asleep, feeling ill, having problems taking medication at specific time, running out of pills, and feeling well. A total score was calculated from this measure.

Age. Age was assessed through one, open-ended question. Participants were asked their age in years, and they typed their response to the question.

Data Analysis

All results were analyzed using SPSS statistical software, version 21.

Demographics. In order to display participant characteristics, the means and frequencies of all descriptive and predictor variables were measured.

Predictor Assessment. Bivariate analyses (Pearson *r* correlations) were conducted in order to document the relationships between the predictors of interest (depressive symptoms, disclosure of HIV serostatus, internalized stigma) and the outcome variable (self-reported medication adherence). If the variables of interest were independently and significantly

associated with medication adherence at the $p<.05$ significance level, they were included in the subsequent linear regression model.

Outcome Assessment. To assess the overall relationship between significant predictor variables and adherence, a hierarchical multiple linear regression model was utilized. Because the present study sought to identify the overall relationship between all predictor variables and the outcome, the standard (enter) method was used. Due to the study's use of a holistically-driven theoretical approach (SEM) to guide the research, it was beneficial to utilize an analysis method that measured all predictors concurrently in regard to the outcome. Regressions controlled for potential covariates that have been related to medication adherence in previous research, including age and perceived barriers. Since a hierarchical multiple linear regression approach was used, the control variables were automatically entered in the first block of the regression and the predictors of interest were entered into block two.

Results

Descriptive Information

A total of 42 participants were eligible and recruited for the primary study by the time of data analysis for the present study. Three participants did not have a current antiretroviral prescription, four were not African American and one participant was in both of the aforementioned ineligible categories. Therefore, only 34 participants were eligible and included in the present study. The average age of participants was 19.88 (SD=2.51). When asked if they had ever had vaginal sex, 58.8% (n=20) reported they have had vaginal sex. Of those who had sex within the past year (n = 20), 14 participants (14.2%) reported that they used a condom during their most recent vaginal sex encounter. Of the 13 participants who had vaginal sex in the past 30 days, 32.4% (n=11) reported that their partner used a condom every time they had

vaginal sex. The average scores of all of the predictors of interest were calculated. The average stigma score was 10.18 (SD= 7.31). Disclosure of serostatus had an average score of 12.85 (SD= 7.38). The average score of depressive symptoms was 11.82 (SD= 4.26). Table 1 displays all descriptive statistics for all study variables.

Bivariate Analysis

Bivariate analyses (Pearson *r* correlations) were used to determine whether the control variables (age and barriers to medication) and predictor variables of interest (internalized stigma, disclosure of serostatus, and depressive symptoms) were significantly associated with medication adherence. Analyses determined that age (p=.026) and barriers to medication (p=.005) were significantly associated with adherence. Analyses further indicated that internalized stigma was the only predictor variable that was independently and significantly associated with medication adherence (p = .033). Depressive symptoms and disclosure of serostatus did not meet the significance level criteria ($p<.05$) for being independently and significantly associated with adherence. Results from the bivariate analyses are displayed in Table 2.

Regression Analysis

Based on the results of the bivariate analyses, only the internalized stigma variable was significant and therefore included in the linear regression model using the Enter method, using age and barriers to medication as controls. In order to control for age and barriers to medication, both variables were entered into the regression in Block 1, while internalized stigma was entered into Block 2. Results from this regression are displayed in Table 3.

Based upon the results of the regression, there was a statistically significant relationship between all of the independent variables (controls and the predictor of interest) and medication adherence (p = .001). Additionally, there was a significant increase (p=.034) in the variance

explained when stigma was added to the model, above and beyond the variance explained by the control variables alone. Specifically, there was a statistically significant relationship between internalized stigma and medication adherence. For each unit increase in stigma, medication adherence decreased by 1.1 points when controlling for age and barriers to medication (B= -1.09; 95% CI= -2.23, .034; p=.034), suggesting that as feelings of internalized stigma increased, adherence to medication decreased.

Discussion

The present study examined internalized stigma, disclosure of HIV serostatus and depressive symptoms in relation to medication adherence in HIV-infected African American AYA females. Although several studies have examined the aforementioned factors, this study advances the literature because of its focus on these factors together in an often-unstudied population of female HIV-infected African American AYAs. In addition, the results of the present study focused on a different dimension of stigma (internalized stigma) within this population.

Results concluded that internalized stigma was a predictor of medication adherence, while controlling for age and other extraneous barriers to medication adherence. These results indicated that as feelings of internalized stigma increased, adherence to antiretroviral medication decreased. Analyses did not support the role of HIV serostatus disclosure and depressive symptoms as predictors of medication adherence.

In the present study, depressive symptoms were not significant in relation to medication adherence. There are several potential explanations for this lack of significance. Specifically for African American adolescents, one study found that high home assets, including “caring adult relationships, high expectations, and opportunities for meaningful participation,” were protective

against depression (Tandon & Solomon, 2009). An older study by Zimmerman and colleagues (1999) found that the more sociopolitical control (control and self-efficacy throughout social and political systems) that African American adolescents felt, the lower their risk for depressive symptoms. Other protective factors against depression for adolescents overall include family cohesion, positive appraisal of one's self and positive relationships (Carbonell et al., 2002). Among HIV-infected children in China, trusting relationships, social support, and orientation for their future were protective against depressive symptoms (Wang et al., 2012). Additionally, social support proved to be protective against depression in HIV-endemic South Africa (Casale, Wild, Cluver & Kuo, 2014). Because participants were recruited from a comprehensive clinic solely serving those infected with HIV, they may have had an increased sense of social support from caring individuals, which could be protective against depressive symptoms.

Additionally, disclosure of HIV serostatus was not a significant factor related to medication adherence within the present study. A cross-sectional study of HIV-infected African American women found that 94% of participants disclosed to at least one of the following: children, father, mother, extended family or friends (Armistead, Morse, Forehand, Morse & Clark, 1999). Results indicated that participants were most likely to disclose to their mothers (66%) followed by their partners (56%). Since there are fairly high rates of disclosure among adult African American women, this trend could be similar among female African American AYAs. Furthermore, since the present study consisted of AYAs who were often accompanied by parents to their clinic appointments, there is a greater potential that participants had higher rates of serostatus disclosure, making it an insignificant factor as it relates to adherence.

Given the present study's definition of internalized stigma, participants felt a significant sense of shame regarding their disease, which subsequently affected their adherence behavior.

Items in the internalized stigma measure focused on how participants felt about their disease and interacted with others based upon their disease status. This study's results follow that of previous research (Lyimo et al., 2014; Martinez et al., 2012; Sayles et al., 2009), which demonstrates an association between increased internalized stigma and poor medication adherence, highlighting its importance in the area of HIV treatment.

Implications for Intervention

Although research is limited, a few studies have examined the association between internalized stigma and HIV medication adherence. For example, one study focused on several factors and their association to medication adherence in an adult HIV-infected population and the usefulness of medication monitoring and cognitive behavioral therapy on adherence (Safren et al., 2000). One of the factors examined within the study was punishment beliefs (Safren et al., 2000). Punishment beliefs were measured by items such as "I have HIV because I am being punished for the things I have done." These beliefs are similar to internalized stigma as they are defined in the present study because they promote some sense of internal shame. Although the study by Safren et al. (2000) did not yield significant results, it proposed the use of cognitive-behavioral techniques in order to increase medication adherence when punishment beliefs and other factors were involved.

Mental illness is another area of health in which internal stigma is common (Corrigan & Watson, 2002). A study by Tsang and colleagues (2010) found that medication adherence was better when mental illness patients had lower reports of internalized stigma. In a recent study focusing on group cognitive behavioral therapy (CBT) among Japanese patients suffering from various mental illnesses, group CBT was significantly associated with a decrease in internalized stigma (Shimotsu et al., in press). Similarly, Roe et al. (2014) found that group cognitive therapy

paired with narrative enhancement, which involves the development of a positive life story, found a significant reduction in internalized stigma among adult patients with severe mental illness.

Because internalized stigma is connected to enacted stigma, interventions targeting enacted stigma are also important. In a mass media stigma intervention in Malawi, a reduction in fear of potential casual contact with an HIV-infected person and shame if one were to become HIV-infected were significantly reduced in the study's intervention group (Creel, Rimal, Mkandawire, Bose & Brown, 2010). Another study focused stigma reduction on a university campus in the Southeastern United States (Millimet, Miller, Ross, Samson & Churi, 2013). The intervention involved using lectures, slogans, t-shirts and other promotional materials to decrease HIV stigma across the campus. Results indicated that this form of intervention leads to significant short-term reduction in stigma, specifically social distancing from HIV-infected individuals (Millimet et al., 2013). Enacted stigma is also common among mental illnesses, and interventions for this dimension of stigma have also involved large-scale media and educational campaigns (Pinto-Foltz & Logsdon, 2009).

Directions for Future Research

Given this study's findings and the lack of research and interventions focusing on internalized stigma and medication adherence among specialized HIV-infected populations (such as female African American AYAs), it is important for further research in the field. Following prior success of cognitive-behavioral techniques to reduce internalized stigma and improve medication adherence, it is also important to test these intervention techniques among the present study's population. Overall, there is also urgency for large-scale anti-stigma campaigns, which could potentially reduce the internalization of stigma among HIV-infected persons. A systematic

review of electronic media-based health interventions targeting youth found that almost all studies in the review found at least one statistically significant outcome in the proposed behavior change, which denotes the relevancy and appropriateness of such interventions for youth (Hieftje, Edelman, Camenga & Fiellin, 2013). In further support of media-based interventions, studies have found that youth consistently view technology as empowering and positive (Cohall, Nshom & Nye, 2007; Valaitis, 2007). Based on the present study's theoretical framework, it is important to target several layers of an individual's life (specifically, the personal and social context in this study) in order to enhance the behavior of adherence.

Limitations

Despite its strengths, this study had several limitations. First, the study had a very small sample size, which potentially affected its results. Although depressive symptoms and disclosure of serostatus were not associated with medication adherence, these results may have been due to the study's small sample size, and it is important not to discredit those factors as predictors in future studies with similar populations. Further related to the sample size, normality of the data was not assessed. Since the present study was a secondary analysis of a primary study, the measures utilized were only those found in the primary study; therefore, these measures were not directly informed by the theory utilized in this study. Furthermore, participants in the study were recruited from comprehensive HIV clinics where only HIV patients are served; therefore, their experiences may not be generalizable to other HIV-infected individuals. Lastly, all responses were provided via self-report; therefore, there was a potential for social desirability bias.

Public Health Significance

This study and its findings are important for public health. Although internalized stigma is a personal level factor, internalized stigma is important to the larger public since it is a product

of enacted stigma, which is outwardly expressed by those not infected. Given the findings, internalized stigma is important in the context of medication adherence. Overall, examining and enhancing medication adherence among HIV-infected individuals is critical for reducing HIV transmission and reducing the acquisition and spread of treatment-resistant strains of HIV throughout the larger public. As for HIV-infected individuals, adherence is necessary to ward off opportunistic infections and the possibility of acquiring co-occurring STIs and improve overall quality of life. By aiming to reduce internalized stigma and subsequently increasing medication adherence, a healthier environment could be ensured for all.

Conclusion

Overall, this study was innovative in its population focus and use of a theoretical framework. Additionally, it contributed to the body of stigma research by focusing on an underrepresented dimension. The study provided a baseline for further research. With continued research, the effects of several factors on adherence behavior can be examined in order to better the lives of those infected.

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