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Medical mistrust is related to lower longitudinal medication adherence among African-American males with HIV

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Abstract

African-Americans living with HIV show worse health behaviors (e.g. medication adherence) and outcomes (e.g. viral suppression) than do their White counterparts. In a 6-month longitudinal study, we investigated whether medical mistrust among African-American males with HIV (214 enrolled, 140 with longitudinal data) predicted lower electronically monitored antiretroviral medication adherence. General medical mistrust (e.g. suspicion towards providers), but not racism-related mistrust (e.g. belief that providers treat African-Americans poorly due to race), predicted lower continuous medication adherence over time (b=−.08, se=.04, p=.03). Medical mistrust may contribute to poor health outcomes. Intervention efforts that address mistrust may improve adherence among African-Americans with HIV.

Keywords

medical mistrust; medication adherence; African American Males; HIV

Introduction

In the United States, African-American men are disproportionately burdened by the HIV epidemic, representing 42% of males diagnosed with HIV (Centers for Disease Control and Prevention, 2013). As a group, African-American men have the highest rate of HIV diagnoses across all racial/ethnic groups and among both males and females (Centers for Disease Control and Prevention, 2013). Having sex with men is the major route of HIV infection and among African-American men who have sex with men (MSM) the risk of HIV infection more than doubles that of other racial/ethnic MSM (Centers for Disease Control and Prevention, 2013). Once infected with HIV, African-Americans also show worse

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medication adherence and experience worse health outcomes in terms of viral failure compared to Whites and Latinos (Simoni et al., 2012; Silverberg et al., 2009; Mugavero et al., 2009). Factors contributing to health disparities are not well understood, and thus further research is needed to identify and enhance our understanding of social factors that may contribute to medication nonadherence and may be targeted in intervention efforts to promote better health outcomes for African-American men with HIV and lessen health disparities.

Medical mistrust is distrust of the medical system, providers, and treatments (LaVeist et al., 2000). Among African-Americans, medical mistrust has been shown to be especially high (Armstrong et al., 2008) and may be linked to experiences with racism/discrimination in health care settings (Hausmann, 2013) and society in general as well as knowledge of historical examples of mistreatment of African-Americans in medical research such as the Tuskegee Syphilis Study (Gamble, 1997). Using the case of South Africa, Kagee and colleagues (2014) echoed that HIV medication adherence is better understood in the context of political and social developments. In diverse samples, medical mistrust has been associated with lower satisfaction with care (LaVeist et al., 2000) and underutilization of healthcare services including delay of routine check-ups and screenings for blood pressure and cholesterol (Hammond et al., 2010a; Hammond et al., 2010b). Similarly, medical mistrust has been related to unwillingness to participate in cancer screenings (Davis et al., 2012) less engagement in genetic counseling for cancer risk (Sheppard et al., 2013) and the decision not to receive adult vaccines (e.g. flu vaccines) (Burnett et al., 2005). Racism-related medical mistrust (e.g. beliefs that doctors do not treat African-Americans the same as White patients) has been significantly related to lower satisfaction with care and lower likelihood of receiving a referral for specialized cardiac x-ray among cardiac patients (LaVeist et al., 2000) as well as an increased likelihood of reporting a problem with care among diabetes patients (Hausmann et al., 2010).

Specific to individuals with HIV, medical mistrust may result in suspicions about physicians' recommendations regarding HIV medication, as well as the efficacy of the HIV medications, and consequently lead to lower medication adherence (Thrasher et al., 2008). Thrasher et al. (2008) reported that more discriminatory health care experiences were associated with higher health care provider distrust and both discrimination and distrust predicted lower medication adherence among HIV-infected patients. Similarly, Bogart and colleagues found that in a sample of African-American men with HIV, HIV-specific medical mistrust (i.e. HIV conspiracy beliefs such as the medicine that doctors prescribe to treat HIV is poison) was related to lower ART nonadherence over one month (2010b). Consistent with the negative association between medical mistrust and health behaviors/outcomes, Gaston (2013) found that the more African-American HIV-positive patients trusted their providers and believed that providers should integrate their culture in HIV care the more they engaged in medical self-care activities (e.g. exercise) and followed providers instructions. Similarly, among a general patient sample, Linn and colleagues (2014) found that receiving tailored information from providers was related to medication adherence. A systematic review of existing studies also concluded that among African-Americans with HIV conspiracy beliefs, racism, and patient-provider relationships impact engagement in care (Gaston and Alleyne-Green, 2013).

Previous literature suggests that medical mistrust is a factor that may potentially contribute to our understanding of low HIV medication adherence among African-American men. Only a limited number of studies on mistrust have been conducted among people living with HIV, and even fewer studies have been conducted among Black MSM who are both racial and sexual minorities and bear the burden of the HIV epidemic. Moreover, prior studies have mostly been cross-sectional, thereby limiting our ability to draw conclusions about the direction of the relationship and our understanding of the relationships over-time. The aim of the present study was to investigate whether medical mistrust among African-American males predicts lower antiretroviral medication adherence over time.

Method

Participant recruitment

A sample of 214 African-American males infected with HIV participated. Recruitment strategies have been previously described (Bogart et al., 2010a, 2010b). From January 2007 through February 2009 participants were recruited at a HIV medical clinic and community social service agencies in Los Angeles, CA. Individuals who expressed interest were screened via phone to assess whether they met the following inclusion criteria: (1) Black/African-American racial/ethnic identity; (2) HIV-positive serostatus; (3) self-identification as male; (4) 18 years of age or above; and (5) on HIV antiretroviral medication. Institutional review board approvals were obtained from Boston Children's Hospital, RAND Corporation, and Charles Drew University of Medicine and Science (where the data were collected). A federal Certificate of Confidentiality was issued by the National Institutes of Health. All participants gave informed consent.

Procedure

At baseline and 3- and 6-month follow-up visits, participants provided data on socio-demographic and clinical variables as well as medical mistrust via an audio computer assisted interview (ACASI). Participants received a $30 financial honorarium for the baseline assessment and $20 for each follow-up assessment.

Measures

Socio-demographic characteristics—A self-report measure was used to gather information on participant's age (calculated from date of birth), education level (categorized into less than high school diploma versus high school diploma or greater), annual income (dichotomized into < $5,000 versus > $5,000), employment (divided into four categories of employed full/part-time versus unemployed, on disability, retired, or in school), sexual orientation (categorized into heterosexual versus other categories [i.e., gay/same-gender loving, bisexual, not sure or in transition, something else, or don't know]), and housing status (separated into stable [own or rent home or apartment; subsidized housing] versus unstable [homeless, residential treatment facility, living rent-free with friend/relative, temporary/transitional housing]).

Medical mistrust—At baseline and the 3-month follow-up visit, medical mistrust was assessed with two subscales by LaVeist and colleagues (LaVeist et al., 2000) to capture

general mistrust and racism-related mistrust. In the present study the alpha reliability coefficients were .70 (general mistrust subscale), and .64 (racism-related mistrust). The 4-item racism-related mistrust scale consisted of items such as “Racial discrimination in a doctor’s office is common” and “Doctors treat African American and White people the same”. The 5-item general medical mistrust scale included items aimed at general mistrust (e.g. “Patients have sometimes been deceived or misled at hospitals” and “Hospitals have sometimes done harmful experiments on patients without their knowledge”). For both subscales, response options were 1-strongly disagree, 2-disagree, 3-agree, and 4-strongly agree. Three of the 4 items on the racism-related mistrust scale were reversed scored (e.g. “Doctors treat African American and White people the same”). Possible average scores on both subscales ranged from 1 to 4.

Medication adherence—The Medication Event Monitoring System (MEMS; AARDEX, Inc., Zurich, Switzerland) was used to assess adherence continuously over the 6-month study period. When a medication bottle is opened the electronic Drug Exposure Monitor (eDEM) cap records the time and data are then uploaded to software that produces detailed reports of daily medication taking patterns, including the percentage of total prescribed doses taken. Since prior research has indicated that the rate of ART adherence does not differ across specific medications, only the ART medication with the most complex regimen was monitored (Arnsten et al., 2002). Participants were asked to refill the medication bottle after removing the last pill.

At 3- and 6-months follow-up visits, MEMS data for each participant were downloaded and participants completed a questionnaire asking whether and how often they (1) opened the bottle and did not remove a dose, (2) took a dose from another source besides the MEMS bottle, and (3) removed more than one dose at a time from the bottle (i.e., pocketed doses), over the past month. To more accurately reflect actual pill taking behavior data from this questionnaire was used to adjust electronic adherence scores based on a strategy that has been previously validated (Bangsberg et al., 2001). Thirteen percent of participants reported using such strategies and their data were adjusted. A continuous adherence measure (percentage of prescribed doses taken in past month) was derived for 3- and 6-month follow-ups. Additionally, a categorical variable was created with 1= adherence rate ≥ 80% and 0= < 80% adherence because research has indicated that moderate adherence to potent ART regimens is adequate to achieve HIV viral suppression (Bangsberg, 2006; Shuter et al., 2007; McNabb et al., 2001; Gulick, 2006; Muller et al., 2009; Kobin and Sheth, 2011). Electronic adherence was significantly related to undetectable viral load ($r = .20$, $p = .02$), providing support for the validity of our adherence measure. Viral load was obtained from medical records for the majority of participants (n=83); and in the event that medical records data were not available (n=57), we substituted self-reported viral load.

Medication side effects and health care barriers—At baseline and 3-month follow-up, participants were asked a single question “How much have side effects from your HIV antiretroviral medications interfered with your day-to-day activities?” with response options ranging from 1 (no interference) to 5 (a lot of interference). At each visit participants also endorsed applicable items on a 13-items checklist of tangible barriers to health care

access (e.g. didn't have a way to get there) (Bogart et al., 2010b). The mean of endorsed barriers was used in analyses.

Statistical analyses

SAS version 9.3 was used to conduct all analyses. A longitudinal dataset was created such that each participant contributed one set of observations (i.e. baseline mistrust and 3-month adherence) or two sets of observations (i.e. baseline mistrust and 3-month adherence as well as 3-month mistrust and 6-month adherence). Of the total 214 participants who completed baseline surveys, 74 were excluded from analyses due to missing data (70 missing 3 months adherence because they dropped out of the study or MEMS adherence data were not collected), 1 missing baseline medical mistrust, and 3 missing both baseline medical mistrust and 3 months adherence). Therefore 140 participants were included in the longitudinal analysis for the present manuscript who had survey data at baseline and electronic adherence data at 3-month follow-up. Of the 140 participants with both baseline survey data and 3-month adherence data, 78 also had both 3-month survey data and 6-month adherence data and therefore contributed a second set of observations to the analysis, and 62 were lost to follow-up at 6-month and did not contribute a second set of observations. T-tests and Fisher's Exact tests comparing participants included (I; n=140) in the analyses with participants excluded (E; n=74) showed that there were no significant differences on any socio-demographic or other study variables: racism-related mistrust (I [M(SD)= 2.59 (.62)], E [M(SD)= 2.60 (.58)], t= 0.11, p=.91), general mistrust (I [M(SD)= 2.66 (.58)], E [M(SD)= 2.59 (.50)], t= 0.87, p=.39), age (I [M(SD)= 44.8 (8.6)], E [M(SD)= 44.8 (8.6)], t=1.94, p<.06), medication side-effects (I [M(SD)= 1.97 (1.27)], E [M(SD)= 2.08 (1.31)], t= 0.60, p=.55), health care barriers (I [M(SD)= 0.46 (0.83)], E [M(SD)= 0.43 (1.03)], t= 0.20, p=.85), education (I=23.6%, E=16.2%, p=.22), and income (I=35.7%, E=41.9%, p=.38).

A multivariable repeated subjects regression predicted continuous adherence and a multivariable logistic repeated subjects regression predicted categorical adherence with an 80% cutoff, at 3- and 6-months follow-up with both mistrust subscales entered together. Data were structured so that adherence was measured 3 months after mistrust – that is, predicting 3-month adherence with baseline mistrust or 6-month adherence with 3-month mistrust. Analyses controlled for number of days between the baseline survey and adherence measurement, socio-demographic characteristics that were significantly associated with ART adherence (age, education, and income), medication side effect severity, and health care barriers (e.g. transportation to clinic).

Results

Socio-demographic Characteristics

Among the 140 African-American HIV-infected males who were included in the analyses for this study, the average age was 44.8 (SD=8.6) and approximately 24% had less than a high school diploma. Eighty-six percent were unemployed and 36% earned an annual income below $5000. Although the majority (86%) were defined as MSM (i.e. ever having sex with men), 23% identified as heterosexual, and 54% identified as gay/same-gender loving. In terms of housing status, 63% of participants reported stable housing and 37%

reported unstable housing. Additional statistics on socio-demographic characteristics are provided in Table 1.

Levels of Medical Mistrust and Medication Adherence

Across the three study visits there were moderate levels of general mistrust (M [SD] = 2.66 [0.58]) and racism-related mistrust (M [SD] = 2.59 [0.62]). Ninety-two percent of males agreed with at least one item on the general mistrust subscale and 80% agreed with at least one item on the racism-related mistrust scale. Pearson's correlation indicated that the two scales were not significantly associated (r = .12, p = .18). On average, electronically monitored adherence (range 0–100%) was low among participants at 3-months (M [*SD*] = 60.8%, [33.5]) and 6-months (M [*SD*] = 60.1% [33.6]). Similarly, less than half of participants (40.7% at 3-months; 41.8% at 6-months) were adhering to ≥80% of doses.

Bivariate effects of independent variables on ART Adherence Over Time

To assess how each predictor variable and covariate was associated with ART adherence over time (continuous and categorical), multivariate analyses were run with each predictor entered separately, controlling for number of days since baseline. Results indicated that general mistrust (b= −.09, se= .04, p=.02), education (b= .13, se= .05, p=.02), health care barriers (b= −.08, se= .03, p=.01), and side effects (b= −.05, se= .02, p=.02) were significantly associated with continuous medication adherence at follow up, however racism-related mistrust (b= .05, se= .03, p= .14), days since baseline (b= −.001, se= .001, p= .14), age (b= .006, se= .003, p= .08), and income (b= −.07, se= .06, p= .19) were not significantly associated with adherence. Neither general mistrust (OR=.66, 95% CI: .39–1.12, p=.12), racism-related mistrust (OR=1.18, 95% CI: .77–1.80, p=.44), age (p=.28, OR=1.02, 95% CI: .98–1.07), education (OR=1.40, 95% CI: .68–2.90, p=.36), income (OR=.72, 95% CI: .37–1.41, p=.34), health care barriers (OR=.69, 95% CI: .46–1.05, p=.08), side effects (OR=.86, 95% CI: .66–1.13, p=.27), or days since baseline (OR=1.00, 95% CI: 1.00–1.01, p=.80) were significantly associated with categorical adherence (80% cutoff).

Multivariate Effects of Medical Mistrust on ART Adherence Over Time

Multivariate analyses were conducted to test how medical mistrust related to continuous and categorical ART adherence longitudinally, controlling for number of days since baseline, socio-demographic characteristics, medication side effect severity, and health care barriers. As displayed in Table 2, results indicated that general medical mistrust significantly predicted lower continuous medication adherence at follow-up, b=−.08, se=.04, p=.03. However, racism-related mistrust did not predict continuous medication adherence at follow-up, b=.05, se=.03, p=.12. Neither general medical mistrust (b=−.45, se=.28, p=.11, OR=.64, 95% CI: .37–1.10) nor racism-related mistrust (b=.18, se=.21, p=.40, OR=1.20, 95% CI: .79–1.82) significantly predicted categorical adherence (i.e., with an 80% cutoff).

Discussion

Among a sample of African-American males with HIV, we found that higher general medical mistrust significantly predicted lower continuous antiretroviral medication adherence over-time. This suggests that levels of medical mistrust may have negative

consequences for patients' medication adherence on a long-term basis. Our longitudinal findings are consistent with previous cross-sectional studies that noted that higher health care provider distrust (Thrasher et al., 2008) and higher HIV-specific medical mistrust were related to lower medication adherence (Bogart et al., 2010b). Medical mistrust among African-Americans living with HIV may partly explain the racial/ethnic disparity in medication adherence found in the literature (Simoni et al., 2012). Given that medication adherence is necessary to achieve viral suppression and improve immune response, medical mistrust may also contribute to other health disparities (e.g. viral failure) (Mugavero et al., 2009). General mistrust did not significantly predict adherence at a clinically significant rate of ≥80% (Bangsberg, 2006; Shuter et al., 2007; McNabb et al., 2001; Gulick, 2006; Muller et al., 2009; Kobin and Sheth, 2011) although our analyses may have been limited by our relatively small sample size.

Racism-related mistrust did not significantly relate to continuous medication adherence or adherence with an 80% cutoff. This finding was also puzzling, given that related literature has noted significant associations between perceived racism (i.e., experiences with discrimination due to race) and medication nonadherence among African-American men with HIV (Bogart et al., 2010a). However, this inconsistency may exist because perceived discrimination captures personal experiences and thus maybe more likely to affect adherence behavior than racism-related mistrust, which are general beliefs about healthcare (not necessarily about personal experiences of what happened to them in healthcare). Further, prior research showing associations between perceived discrimination and nonadherence measured discrimination in terms of general everyday experiences, not just experiences with healthcare (which are less frequent) (Bogart et al., 2010a; Bogart et al., 2013). Additional research efforts are needed to better understand the concept of medical mistrust among African-American males with HIV as well as to explore why general mistrust but not racism-related mistrust may be more predictive of medication nonadherence.

Beyond our main outcomes of medical mistrust, covariates of education, health care barriers, and medication side effects that were entered in our multivariate analyses, were significantly associated with medication adherence. Specifically education was associated with higher medication adherence while health care barriers and medication side effects were associated with lower adherence. These results are consistent with existing literature noting that low education (Golin et al., 2002), low literacy (Kalichman et al., 2008), barriers such as transportation cost (Tuller et al., 2010), and medication side effects (Olem et al., 2014) are related to nonadherence of HIV medication.

Given that general medical mistrust predicted longitudinal continuous medication nonadherence, intervention efforts at the societal level, in the medical system, and at the individual level that target mistrust may improve adherence and health-related outcomes for African-American males living with HIV. African-Americans may be distrustful of medical providers, treatments and settings due to negative personal experiences as well as knowledge about historical examples of mistreatment of African-Americans in the medical community and society in general. Therefore policies, laws, and practices that create a more equitable and safe environment for African-Americans need to be enforced and developed. Interventions in the medical system may consist of cultural competency training for medical

providers and staff about the impact that medical mistrust has on patients' medication adherence as well as ways that medical providers may help to build and increase patient trust.

In addition to societal and system level interventions, interventions at the individual level are necessary to address medical mistrust among African-American males with HIV and empower them with tools that may result in better medication adherence. For instance, patients may be taught skills to navigate and advocate for their needs within the medical system (Madore et al., 2014)(e.g. how to change a provider with whom they are having negative experiences). For example, via role-plays patients can practice how to be assertive by both communicating their needs and validating the goals of the provider. Further, cognitive behavioral therapeutic skills (Safren et al., 2012) such as cognitive restructuring (a strategy patients can use to increase flexibility in their thoughts) may be beneficial for some patients with medical mistrust in helping them to develop greater flexibility in how much or how little they trust a provider or treatment. For instance, a patient who expresses high mistrust for a clinic or specific provider can be asked to brainstorm evidence for and against whether a provider is trustworthy and in doing so may become aware of reasons why they can trust the provider or how much they can trust the provider. Distress tolerance and emotional regulation skills (Neacsiu et al., 2014) may also provide patients with tools to effectively regulate their emotions and cope in situations when there are reasons to be distrustful. Distress tolerance skills include thinking of a nice scenery or an uplifting song and evaluating the pros and cons of engaging in a behavior and emotion regulation strategies range from observing and describing one's emotions to engaging in daily activities (e.g. exercise) that increase confidence. In addition, given that the present study and existing literature identifies other factors that are related to nonadherence (e.g. education, medication side effects, and health care barriers) interventions should also take these factors into consideration.

Our study may have been limited by a few factors. Participants were not recruited randomly and instead were a convenient sample of African-American males with HIV who were recruited from community clinics and agencies serving predominately marginalized, low income, LGBTQ, and/or racial/ethnic minority clients. Levels of medical mistrust may vary based on geographic location in the US (Armstrong et al., 2007) and thus our findings may not adequately reflect the experiences of African-American males with HIV in the USA. The 74 enrolled participants who were excluded from analyses (due to drop-out or unavailable data) rendered our sample size to be smaller than anticipated and therefore we may have been inadequately powered to detect significant relationships between some variables. In addition, the alpha coefficient for racism-related mistrust (.64) was low. Though significant the ability to predict longitudinal medication adherence with general medical mistrust appears to be relatively small (b=.08) and this may be due to other factors (e.g. health care barriers) that are also related to medication adherence. The lack of significance between racism-related mistrust or general mistrust with the 80% adherence cutoff may suggest a loss in sensitivity from categorizing the continuous adherence variable into a categorical variable. Also, the electronic adherence assessment may not capture all pill-taking behaviors; thus, we collected additional self-reported data on pill-taking behaviors (e.g. opened the bottle and did not remove a dose) and used these data to adjust electronic adherence scores to improve

the accuracy (Bangsberg et al., 2001). Future studies with larger samples, other ethnic groups, and provider level information are needed to increase our understanding of the relationships between medical mistrust and adherence.

Despite these limitations, our findings highlight medical mistrust among African-American males with HIV as a variable that predicts lower medication adherence over time and may potentially help to explain disparities in medication adherence rates (as well as related HIV health outcomes) between African-Americans and other racial/ethnic groups. Intervention efforts at the societal, medical system, and individual levels targeting medical mistrust may help to reduce health disparities and improve medication adherence for African-Americans with HIV.

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Table 1

Sample Characteristics and Sociodemographic Statistics of 140 Participants

Characteristics	Mean (*SD*)
Age	44.8 (8.6)
General medical mistrust	2.66 (0.58)
Racism-related medical mistrust	2.59 (0.62)
Continuous ART adherence	
3 Months follow-up	60.8% (33.5)
6 Months follow-up	60.1% (33.6)
Days since baseline	102 (46)
3 Months follow-up	61 (7)
6 Months follow-up	153 (11)
Medication side effect severity	1.97 (1.27)
Health care barriers	0.46 (0.83)
	n (%)
ART adherence (≥80%)	
3 Months follow-up	57 (40.7%)
6 Months follow-up	46 (41.8%)
Men who have sex with men (MSM)	119 (86%)
Sexual orientation	
Heterosexual	32 (23%)
Gay/same-gender loving	75 (54%)
Bisexual	26 (19%)
Not sure or in transition, something else, or don't know	7 (5%)
Education	
Less than high school diploma	33 (24%)
Completed high school	78 (56%)
Some college	29 (20%)
Income	
Below $5,000	50 (36%)
$5,001-$11,999	55 (40%)
$12,001-$15,999	16 (12%)
$16,000 or more	17 (12%)
Unemployed	121(86%)
Housing status	
Own or rent home or apartment	75 (54%)
Subsidized housing	13 (9%)
Homeless	3 (2%)
Residential treatment facility	9 (6%)
Living rent-free with friend/relative	18 (13%)
Temporary/transitional housing	19 (14%)
Other	3 (2%)

Table 2

Multivariable Repeated Subjects Regression Analyses of the Effects of Medical Mistrust on ART Adherence Over Time

	Unstandardized Estimate	Error	Degrees of freedom	T value	P value	Standardized Estimate	Error
Mistrust							
General medical mistrust	−.08	.04	75	−2.25	.03*	−.13	.06
Racism-related medical mistrust	.05	.03	75	1.56	.12	.09	.06
Covariates							
Days since baseline	−.0004	.0003	75	−1.37	.17	−.06	.05
Age	.004	.003	134	1.13	.26	.10	.09
Low education	.12	.06	134	2.06	.04*	.35	.17
Low income	−.07	.05	134	−1.36	.18	−.22	.16
Health care barriers	−.05	.03	134	−1.77	.08	−.12	.07
Medication side effect severity	−.04	.02	134	1.72	.09	−.14	.08

Note. Estimated R-square = .08