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Race-Based Medical Mistrust, Medication Beliefs and HIV Treatment Adherence: Test of a Mediation Model in People Living with HIV/AIDS

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Abstract

Race-based medical mistrust significantly predicts non-adherence to antiretroviral therapy (ART) in people living with HIV. The current study builds on previous research that shows beliefs about medication necessity (i.e., "My medicines protect me from becoming worse") and concerns (i.e., Having to take my medicines worries me) mediate the association between race-based medical mistrust and medication adherence. Racial and ethnic minority men and women living with HIV and receiving ART (N=178) in a southern US city completed computerized measures of demographic and health characteristics, telephone interviews of race-based medical mistrust and medication beliefs, and unannounced phone-based pill counts for ART adherence. Multiple mediation modeling showed that medical mistrust is related to medication necessity and concerns beliefs and ART adherence. Furthermore, medication necessity beliefs predicted ART adherence. The indirect effect of medical mistrust on adherence through medication necessity beliefs was also significant. Results confirm that medication necessity beliefs, although not concerns beliefs, mediate the association between medical mistrust and ART adherence. Medication necessity beliefs offer a viable target for interventions to improve ART adherence in the context of mistrust that patients may have for medical providers and health care systems.

Introduction

The majority of new HIV infections in the United States occur among African-Americans and Latinos and AIDS-related morbidity is greater for racial and ethnic minorities. Deathrates for blacks living with HIV are 13% higher than for whites (Siddiqi, Hu, & Hall, 2015). These health disparities are at least in part accounted for by late diagnosis of HIV infection and poor adherence to antiretroviral therapy (ART, McFall et al., 2013). While circumstances associated with poverty undermine ART adherence including lacking transportation, food insecurity, and substance abuse (Gaston & Alleyne-Green, 2013), social and economic constraints do not fully account for disparities in ART adherence (Maulsby et al., 2014).

Prejudice and discrimination experiences may lead to health care disengagement and may account for race and ethnic group disparities in HIV treatment and health outcomes. Of particular importance is trust in the health care system and how mistrust translates to poor retention in care and medication adherence (Casagrande, Gary, LaVeist, Gaskin, & Cooper, 2007; Earl et al., 2013). Histories of discrimination in the United States health care system and the legacy of institutional racism, including medical experimentation on African slaves, the Tuskegee Syphilis Study, and unequal access to quality health care have understandably earned a sense of mistrust in the public health system (Gaston & Alleyne-Green, 2013).

Several studies have demonstrated that medical mistrust is more common among minority groups than whites and mistrust reliably predicts ART non-adherence (Saha, Jacobs, Moore, & Beach, 2010). One in five African American men prescribed ART believe that people receiving HIV medications are treated as human guinea pigs and 17% believe that ART is a poison, with individuals who believe that HIV treatments cannot be trusted demonstrating the poorest adherence (Bogart, Wagner, Galvan, & Banks, 2010; Dale, Bogart, Wagner, Galvan, & Klein, 2014). Although medical mistrust is a reliable predictor of ART non-adherence among people of color living with HIV, the association is not well explained and there are few recommendations for how to remedy this problem.

Medical mistrust is theoretically grounded in the historical experiences of minorities by public health and health care systems. While medical mistrust can undermine engagement in health care, more specific attitudes and beliefs may be more closely aligned with particular health behaviors. For example, medication beliefs have been shown to adversely impact treatment adherence (Nozaki et al., 2013). Unlike medical mistrust, which depends more on structural changes, medication beliefs are amenable to patient education and counseling interventions. Taking a cost-benefit approach, Horne et al. (Horne, 1999; Jonsdottir et al., 2009) developed a commonsense approach to explaining non-adherence that emphasizes patient beliefs about the necessity of medications to directly improve health and beliefs regarding concerns over costs, inconveniences and adverse effects of medications (Gonzalez et al., 2007). The Necessity-Concerns Framework predicts medication adherence across chronic health conditions, including HIV infection (Horne et al., 2013). For example, Gonzalez et al. (2007) found that beliefs about medication necessity regarding ART predict better adherence, while medication concerns predict poorer adherence.

Research suggests the association between medical mistrust and medication adherence may to some degree be accounted for by medication beliefs (Altice, Mostashari, & Friedland, 2001; Kalichman, Eaton, Kalichman, & Cherry, 2015). In a cross-sectional study of African American men and women living with HIV and receiving ART, Kalichman et al. (2015) found that medical mistrust was significantly associated with ART adherence, as were beliefs about medication necessity and concerns. Mediation analysis showed that medication beliefs mediated the relationship between medical mistrust and ART adherence. These findings were the first to show that the associations between medical mistrust and medication adherence are partially accounted for by beliefs about medications. Conceptually, while medical mistrust may serve to keep some people out of care, it appears that medication beliefs may account for medication adherence. Beliefs about medications are proximal to pill taking when considered relative to more general experiences and

perceptions of the health care system. If beliefs about medications reliably mediate the relationship between medical mistrust and medication adherence, interventions may shift their focus on fostering beliefs that medications are necessary and addressing concerns about medications among patients who mistrust the health care system.

The current study was conducted to replicate and extend Kalichman et al.'s (2015) initial test of the Necessity-Concerns Framework as a mediator of the association between medical mistrust and ART adherence. In our previous research, ART adherence was measured using a single item self-report rating scale to assess ART adherence. Although the single item rating scale has shown evidence for reliability and validity in assessing medication adherence it remains dependent on self-report and is known to be biased toward overreporting adherence (Pellowski, Kalichman, & Finitsis, 2015). In addition, the study was cross-sectional in design, limiting the test of directional relationships. The current study was undertaken to address these limitations replicating the model where medication beliefs serve as mediators of the association between medical mistrust and ART adherence. We hypothesized that race-based medical mistrust and beliefs about medications would both predict ART adherence over a one-month prospective period using an objective measure of ART adherence. In addition, we hypothesized that beliefs about medication necessity and concerns would mediate the association between race-based medical mistrust and ART adherence after controlling for participant education, years since testing HIV positive, ART side-effects and HIV-related symptoms.

Methods

Participants

Participants were 145 men and 34 women of color living with HIV and receiving ART. Recruitment occurred between December 2013 and March 2014. The site of the study was Atlanta, Georgia, a major urban center with an annual HIV incidence of 30.3 per 100,000 population. Eligible participants were age 18 or older, HIV positive, self-identified as African-American or Hispanic, and currently receiving ART. The average age of the sample was 41.6 years (SD = 10.7), 168 identified as African-American, 5 Latino, and 6 as other non-White racial ethnic background (see Table 1 for sample characteristics).

Procedures

Participants were recruited through targeted community sampling with both venue and snowball techniques. Venue recruitment relied on the distribution of study brochures to waiting rooms of HIV service providers and infectious disease clinics throughout Atlanta, GA. At an initial office assessment session, participants provided informed consent and completed an audio-computer assisted self-interview (ACASI) to collect demographics and health information (Morrison-Beedy, Carey, & Tu, 2006). Participants were trained to conduct unannounced pill count assessments on the phone. We also asked participants to obtain their most recent HIV viral load and CD4 cell count results from their medical provider. Participants then completed three unannounced phone-based pill counts and phone assessments over the subsequent month. Participants were reimbursed \$145 for completing

all measures, pill counts, and providing medical chart information. The university Institutional Review Board approved all procedures.

Computerized Interviews: Demographic and Health Characteristics—

Participants were asked their gender, age, years of education, ethnicity, employment status, the year they first tested HIV positive, and whether they were currently taking ART. Participants also completed a 14-item scale to assess the number of HIV symptoms experienced from which we calculated a composite score, alpha = .70 (Kalichman, Rompa, & Cage, 2000). Medication side-effects were measured using 11 common side-effects attributable to current medications, (Carrieri, Villes, & 2007) responses made on 4-point scales 0 = Not experiencing, 3 = Severely experiencing, summed to a total score, alpha = .83.

HIV viral load and CD4 cell counts—We used a participant assisted method for collecting chart abstracted viral load and CD4 cell counts from participants' medical records. Participants were provided with a form to request their doctor's office to complete with results and dates of their most recent, and not older than 3-months, viral load and CD4 cell counts. These data were therefore obtained directly by the participant from their HIV care provider. The form included a place for the provider's office stamp or signature to assure data authenticity. HIV RNA below detection (i.e., viral suppression) was defined as less than 100 copies/mL for uniformity across providers.

Telephone Interviews: Medication beliefs and medical mistrust—During a brief telephone interview conducted after a pill count participants completed the Beliefs About Medicines Questionnaire to assess views of their beliefs about medication necessity and concerns (Horne, Cooper, Gellaitry, Date, & Fisher, 2007). The medication necessity scale consists of five items reflecting the perceived benefits of medications in direct relation to health; example items include "My health, at present, depends on my medicine" and "My medicines protect me from becoming worse", alpha = .80. The five item medication concerns scale reflects the potential adverse effects and costs of medications; example items include "Having to take my medicines worries me" and "I sometimes worry about the long-term effects of my medicines", alpha = .73. Items are responded to on a 5-point scale, 1 = *Strongly agree*, 5 = *Strongly disagree*.

Participants also completed the five-item Medical Suspicion sub-scale of the Group-Based Medical Mistrust Scale developed by Shelton et al. (2010). The items reflect a sense of mistrust in the medical system stemming from systemic racial prejudice. We modified the items from the original scale to indicate self-identified race rather than specifying 'Black' as race. Specifically, items in the original scale asked about perceptions of how 'Black people' are treated in health care settings. Because participants in the study may identify as Black or African American, and because we included Hispanics in the study, we changed the racial referent to "people of my race" to apply to all participants. The exact items are shown in the Results section. Items are responded to on a 4-point scale, $1 = Strongly \ agree$, $4 = Strongly \ disagree$. Scores were calculated by taking the mean response, alpha = .86.

Unannounced pill count medication adherence—Participants consented to three unannounced phone-based pill counts that occurred over a one-month prospective period. Unannounced pill counts are reliable and valid in assessing medication adherence (Fredericksen et al., 2014; Haberer et al., 2011; Kalichman et al., 2008; Kalichman et al., 2010). In this study we conducted unannounced phone based pill counts using studyprovided free cell phones. Following an office-based interview that included a full accounting of all prescription medications and training in the pill counting procedure, participants were called at three unscheduled times over 12 to 16 day intervals. The first of the three pill counts is used to establish the initial number of pills in possession with the subsequent two pill counts allowing for calculation of adherence, defined as the ratio of pills counted relative to pills prescribed, taking into account the number of pills dispensed. Adherence was calculated as the mean across antiretroviral medications and across pill counts. For descriptive analyses, suboptimal adherence was categorically defined by 80% of medications taken as prescribed, a level of adherence that places patients at risk for developing HIV treatment resistance (Bangsberg & Deeks, 2002; Lima et al., 2010; Parienti et al., 2013). Continuous adherence values were used as the dependent variable in regression models.

Data Analyses

Descriptive analyses first compared participants with less than or equal to 80% adherence to those with adherence greater than 80% (Parienti et al., 2013). Descriptive comparisons were performed for demographic and health characteristics, race-based medical mistrust, and medication beliefs. Statistical significance was tested using chi-square contingency tables for categorical variables and independent t-tests for continuous measures. We also examined the associations of continuous ART adherence with health markers, race-based medical mistrust, and medication beliefs. Bivariate correlations were calculated using Pearson correlation coefficients.

To test our main hypothesis that beliefs about medication necessity and concerns would mediate the association between race-based medical mistrust and ART adherence, we tested a multiple mediation model (Baron & Kenny, 1986) using SPSS mediation model macro designed by Preacher and Hayes (2008). This macro estimates paths for the effects of the predictor variable (medical mistrust) on the mediator variables (medication beliefs, the a paths), the effect of the mediators (medication beliefs) on the outcome (medication adherence, the b paths), and the effects of the predictor (medical mistrust) on the outcome (adherence, the c path). We computed 95% confidence intervals (CI) for the indirect effects of race-based medical mistrust on ART adherence through medication beliefs estimated from 5,000 bootstrap resamples. We included participant education, years since testing HIV positive HIV-related symptoms and medication side-effects as control variables in the model. There were no missing data for any variables included in the model. All analyses used p < . 05 to define statistical significance.

Results

Table 1 shows the characteristics of the sample partitioned by adherence less than or equal to 80% of ART taken in the previous month. Overall, one in three (n=61) participants were less than or equal to 80% adherent and 30% had detectable viral loads. As expected, participants who demonstrated greater adherence were significantly more likely to be aware of their viral load, of older age, and held greater medication necessity beliefs. Table 2 shows the distribution of responses to the specific medical mistrust items. Overall more than one third of participants held views that reflected race-based medical mistrust, with participants endorsing views that people of their race receive poorer health care and are more likely discriminated against, with relatively fewer participants endorsing items that reflect suspicion of providers intentionally harming persons of their race.

Bivariate correlations

Pearson correlation coefficients among measures of participant characteristics, medical mistrust, medication beliefs and ART adherence are shown in Table 3. Results indicated that ART adherence was significantly associated with medical mistrust, such that greater mistrust was related to poorer adherence. ART adherence was also significantly correlated with medication necessity beliefs, with greater necessity beliefs associated with greater adherence. However, medication concerns beliefs were not significantly correlated with adherence. Medical mistrust was associated with beliefs about medication necessity and concerns in the expected directions. In addition, greater HIV symptoms and ART side-effects were associated with greater beliefs about medication concerns but not beliefs about medication necessity. This pattern of associations supported moving forward with testing the proposed mediation model.

Medication beliefs as a mediator of the medical mistrust - adherence relationship

Results of the paths tested in the mediation regression model are shown in Figure 1. The full model accounted for 7.2% of the variance in ART adherence. Results showed medical mistrust significantly predicted medication necessity beliefs, $\beta = -0.21$, t = 2.3, p < .02 and medication concerns beliefs, $\beta = 0.52$, t = 5.5, p < .01, see Figure 1, a paths. In addition, the direct effect of medication necessity beliefs on ART adherence was significant, $\beta = .06$, t =2.17, p < .05, but medication concerns beliefs did not predict adherence, $\beta = -.01$, t = 0.39, n.s., see b paths. The total effect of medical mistrust on adherence was also significant, $\beta = 0$ -0.06, t = 1.98, p < .05, see c path. Accounting for medication beliefs resulted in a nonsignificant association between medical mistrust and medication adherence, $\beta = -0.04$, t =1.29, p > .1, see c' path. Based on 5,000 bootstrap resamples, the test of indirect effects of medical mistrust on adherence through medication beliefs was significant, unstandardized b =-0.01, 95% CI: -0.037 to -0.001. Medication concerns beliefs did not significantly contribute to the mediation, b = -0.01, 95%CI: -0.038 to 0.024. Education, years since testing HIV positive, medication side-effects, and HIV symptoms were included as control variables and did not significantly contribute to the model. Thus, results showed that medication necessity beliefs partially mediated the association between race based-medical mistrust and ART adherence.

Discussion

Using 80% of pills taken to descriptively define ART adherence, we found that one in three participants failed to meet this lower-bound threshold, placing individuals at considerable risk for developing drug resistant virus (Bangsberg & Deeks, 2002). Participants with poor adherence were somewhat younger and less likely to be aware of their most recent viral load test results. The less likely participants were to believe their medications were necessary the poorer their adherence. Medical mistrust was common in our sample, with between 15% and 30% of participants endorsing beliefs that people of their race are discriminated against and receive poorer care. Although individual race-based medical mistrust items did not differentiate participants with relatively poorer and better adherence, overall stronger medical mistrust was associated with poorer ART adherence.

The current study results should be interpreted in light of their methodological limitations. The study was conducted in a large metropolitan area of the southeastern United States and may therefore not generalize to other cities or regions. This limitation is particularly important given the potential for medical mistrust to emerge differently among different cultural subgroups. Thus, while other studies conducted in other regions of the United States have found medical mistrust predicts medication adherence (Bogart et al., 2010), it should not be assumed that medication beliefs would mediate this relationship elsewhere. Our sample size was also relatively small, suggesting that the observed mediation model should be tested in a larger and more diverse sample. In addition, we included a small number of Hispanic and no other minorities in our sample, and the number was too small to allow us to examine differences among minority groups. Restricting our sample to racial and ethnic minorities was also a limitation. While African Americans are relevant to questions of medical mistrust and medication adherence, our study should not be interpreted as suggesting that mistrust of health care systems is unique to African Americans, Hispanics or any minority group. Our results are also limited by addressing medications and beliefs about medications in general rather than addressing a specific class of medications because greater specificity may increase the implications for interventions. Finally, our model accounted for a small amount of variance in medication adherence. While this finding replicates past research, and therefore appears reliable, the modest amount of variance accounted for suggests that the model may be of limited clinical utility in and of itself. Addressing medication beliefs to improve ART adherence in the context of medical mistrust should therefore occur within a broader approach to adherence improvement that addresses multiple factors known to impede adherence.

Another limitation of the study is that we measured medical mistrust at the same time point as medication beliefs, prohibiting us from drawing causal conclusions regarding the association between mistrust and medication beliefs. We also cannot rule out other (i.e., third) variables as explanations for our results. In addition to the possibility that medication beliefs may undermine medical trust, or vice versa, it is possible that other variables not measured in this study may account for the association. In addition, our measure of medical mistrust was not specific to participants' current providers and therefore reflects a more general perception of racism and discrimination in health care systems. With these

limitations in mind, the current study findings have implications for improving HIV treatment adherence in people who mistrust health care systems.

Medical mistrust is rooted in historical facts of abuse, neglect, and mistreatment of racial and ethnic minorities by public health services and health care more generally. Although no longer structurally sanctioned there remain health care disadvantages between racial, ethnic and economic subgroups, as reflected in widespread health disparities (Pellowski, Kalichman, Matthews, & Adler, 2013; Simoni et al., 2012). The degree to which racism and anti-immigration sentiments infiltrate health care will also have corrosive effects on patient trust. It is therefore not surprising that medical mistrust is associated with poor treatment retention, adherence and outcomes (Bogart et al., 2010).

Our findings suggest that there are intermediating variables that may serve as viable targets for interventions to improve adherence among mistrusting patients. We showed that beliefs about medication necessity at least in part account for the relationship between medical mistrust and medication adherence. Simply put, when patients perceived their medications as necessary they were more adherent even if they mistrusted the health care system in general. Medications beliefs stem from patient experiences with treatments or indirectly through social interactions. A commonsense approach to medication adherence posits that patients are motivated to take medications when the perceived necessity of treatment outweighs the perceived concerns (Horne, 1999). Patients are therefore motivated to adhere when they believe medications will effectively treat disease or ameliorate symptoms. Conversely, concerns over side-effects, long-term dependence, and costs associated with medications are demotivating. Medication beliefs are amenable to change through wellestablished educational and motivational interventions (Kalichman et al., 2011; Reynolds et al., 2008). Research is needed to determine whether addressing medication beliefs among patients who mistrust the medical care system can improve medication adherence and health outcomes.

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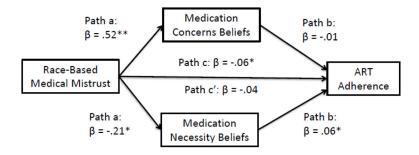


Figure 1. Medication beliefs mediate the association between medical mistrust and adherence to antiretroviral therapy.

Table 1

Demographic and health characteristics of people who had ART adherence below and above 80% of pills taken.

	Less than or equal to	Less than or equal to 80% Adherence N = 61	Greater than 80% Adherence $N = 117$	Adherence N = 117	
Characteristics	Z	%	Z	%	\mathbf{X}^2
Male	49	80	95	81	
Female	12	20	22	19	0.02
African-American	56	92	112	95	0.80
Latino	2	3	3	2	
Other non-white	3	'n	3	2	
Unemployed	44	74	06	76	0.1
Aware of most recent viral load	25	41	89	28	* 4.5
Viral load detectable	22	36	33	28	1.2
CD4 < 200 cell/mL	∞	13	21	18	9.0
	M	SD	M	SD	t
Age	38.4	11.5	43.3	6.6	2.9 **
Years of education	13.2	1.7	12.9	1.7	1.1
Years since HIV diagnosis	6.6	7.4	11.1	8.2	6.0
CD4 cell count	467.9	253.5	476.2	291.3	0.2
ART side effects	0.5	0.4	0.4	0.4	1.8^+
HIV symptoms	41	3.2	3.6	3.3	6.0
Race-based medical mistrust	2.0	9.0	1.9	9.0	1.4
Necessity beliefs	3.9	0.7	4.2	0.7	2.3 **
Concerns beliefs	2.6	6.0	2.5	0.8	6.0

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Table 2

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	Less than or equal to 80% Adherence $N=61$		Greater than 80% Adherence N	Adherence N = 117	
Medical Mistrust Belief	N	%	Z	%	X ₂
People of my race cannot trust doctors and health care workers					
Strongly Agree	4	7	9	5	4.4
Agree	15	25	15	14	
Disagree	24	40	48	41	
Strongly Disagree	17	28	46	40	
People of my race should be suspicious of information from doctors and health care workers	health care workers				
Strongly Agree	2	8	9	5	5.0
Agree	12	20	24	20	
Disagree	31	52	41	35	
Strongly Disagree	15	25	45	38	
People of my race should not confide in doctors and health care workers because it will be used against them	because it will be used against them				
Strongly Agree	0	0	1	1	1.50
Agree	S	∞	∞	7	
Disagree	31	52	52	45	
Strongly Disagree	24	40	55	47	
People of my race should be suspicious of medicine					
Strongly Agree	3	S	∞	7	3.2
Agree	13	22	20	17	
Disagree	27	45	41	35	
Strongly Disagree	17	28	47	40	
Doctors and health care workers do not take the medical complaints of people of my race seriously	eople of my race seriously				
Strongly Agree	3	\$	9	S	3.0
Agree	7	12	21	18	
Disagree	30	51	44	38	
Strongly Disagree	19	32	46	39	
People of my race are treated the same as people of other groups by doctors and health care workers	ors and health care workers				
Strongly Agree	10	17	10	6	3.0

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	Less than or equal to 80% Adherence $N=61$		Greater than 80% Adherence $N = 117$	Adherence N = 11'	
Medical Mistrust Belief	z	%	Z	%	X ₂
Agree	01	17	23	20	
Disagree	22	37	46	39	
Strongly Disagree	16	27	38	33	
People of my race receive the same medical care fro	People of my race receive the same medical care from doctors and health care workers as people from other groups				
Strongly Agree	7	12	∞	7	2.0
Agree	12	21	21	18	
Disagree	23	40	48	41	
Strongly Disagree	16	28	41	35	
In most hospitals, people of my race don't receive as good of care as people of other races.	s good of care as people of other races.				
Strongly Agree	7	12	10	6	3.6
Agree	21	36	37	32	
Disagree	21	36	36	31	
Strongly Disagree	6	15	33	28	

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Table 3

Correlations among measures of health characteristics, medical mistrust, medication beliefs, and ART adherence.

	Race-Based Medical Mistrust	Race-Based Medical Mistrust Medication Necessity Beliefs Medication Concerns Beliefs ART Adherence Years Education	Medication Concerns Beliefs	ART Adherence	Years Education	Years Since Testing HIV ⁺	Medication Side-Effects
Medication Necessity Beliefs	14+						
Medication Concerns Beliefs	.40 ***	03					
ART Adherence	15*	.19**	10				
Years Education	.01	02	90.	90-			
Years Since Testing HIV $^+$	60	02	01	.05	02		
Medication Side-Effects	.12	03	.21 **	13	04	08	
HIV Symptoms	.04	02	.19	08	.05	90	.45 **

 $\it J\,Behav\,Med.$ Author manuscript; available in PMC 2017 December 01.