Published in final edited form as:

Transl Issues Psychol Sci. 2020 September ; 6(3): 223–234. doi:10.1037/tps0000271.

Examining the Effect of Internalized HIV-Related Stigma on Perceptions of Research Participation among HIV-Positive African American Women

Nicole M. Overstreet, Thekia Cheeseborough

Department of Psychology, Clark University

Abstract

HIV-related stigma may influence ethical concerns in health disparity populations, particularly groups with histories of race, gender, and class oppression in medical research such as African American women. However, a dearth of research has examined how HIV-related stigma influences perceptions of the research process among African American women who participate in health research. The goal of the current study was to examine whether HIV-related stigma experienced on the micro-level, specifically internalized HIV-related stigma, is associated with reactions to research participation in 5 domains: attitudes toward participation, perceptions of research benefits, emotional reactions, perceived drawbacks of the research, and global evaluations of the research. We also examine whether internalized HIV-related stigma is associated with difficulty in answering questions related to sensitive topics. We found that women with higher levels of internalized HIV-related stigma reported more emotional reactions to research, perceived more drawbacks of the research, and expressed more difficulty in answering sensitive questions. Understanding how HIV-related stigma influences perceived risks and benefits of research participation may play an important role in guiding best practices for ethical engagement with HIV-positive African American women who participate in health research.

Keywords

African American women; HIV; intersectionality; stigma; research ethics

In the United States, HIV incidence rates have decreased by 27% among African American women (Centers for Disease Control [CDC], 2018). Despite this progress, HIV disproportionately affects African American women compared to women of other racial/ethnic groups. HIV incidence rates among African American women are 4 times higher than that of Latina women and 19 times higher than that of White women (CDC, 2018). The racial/ethnic disparities in HIV incidence and prevalence rates among women highlight a continued need for prevention and intervention research efforts to reduce the burden of HIV/

Correspondence concerning this article should be addressed to Nicole M. Overstreet, PhD, Clark University, 950 Main Street, Worcester, MA, 01610. noverstreet@clarku.edu.

Author Note

Nicole M. Overstreet, Department of Psychology, Clark University; Thekia Cheeseborough, Department of Psychology, Clark University.

We have no known conflict of interest to disclose.

AIDS on African American women. The participation of HIV-positive African American women in health research is vital to achieving this goal.

There is evidence to suggest that stigma, particularly stigma related to the topic of interest in health research (e.g., HIV), is a shared barrier to research participation among racially and ethnically minoritized populations such as African Americans, Latinos, Asian Americans, and Pacific Islanders (George et al., 2014). However, there is less empirical work on how stigma may influence ethical concerns *during* the research process for marginalized groups with histories of race, gender, and class oppression. African American women have a specific history of scientific gendered racism in medical research in the United States and their perspectives are often rendered invisible in the ethics literature. In the current work, we examine whether African American women's experiences of HIV-related stigma influences their perceptions of research participation. Specifically, we investigate the effect of internalized HIV-related stigma, that is acceptance of negative beliefs and feelings about the self because of one's HIV-positive status, on 5 domains of research participation: attitudes toward research participation, perceptions of research benefits, emotional reactions to the research, perceived drawbacks of the research, and global evaluations of the research. In addition, we explore associations between internalized HIV-related stigma and difficulty responding to questions about sensitive topics that have been shown to co-occur with HIV such as intimate partner violence, substance use, and mental health disorders (e.g., depression and posttraumatic stress) (Coker, 2007; Maman et al., 2000; Meyer et al., 2002; Gielen et al., 2007; Willie et al., 2016). Addressing these gaps in the ethics literature may play an important role in guiding best practices for ethical engagement with HIV-positive African American women who participate in health research.

Stigma as a Barrier to Research Participation

Stigma refers to societal devaluation of an attribute via social processes of labeling, stereotyping, and separation that results in status loss and discrimination (Goffman, 1963; Link & Phelan, 2001). There is a robust literature highlighting the detrimental impact of HIV-related stigma on psychological, physical, and behavioral health outcomes for people living with HIV and on their experiences of health inequities in several domains such as housing, employment, social relationships, and healthcare (Earnshaw & Chaudoir, 2009; Hatzenbuehler, Phelan, & Link, 2013). HIV-related stigma is theorized to constrain the well-being, resources, and opportunities of people living with HIV through various processes that operate on the micro- (e.g., individual beliefs and attitudes, interpersonal interactions), meso- (e.g., community/social norms), and macro- (e.g., policies and laws, health and social systems) level (Earnshaw & Chaudoir, 2009; Logie et al., 2011; Parker & Aggleton, 2003; Hatzenbuehler & Link, 2014). Given the material (e.g., loss of financial resources, criminalization of HIV) social (e.g., mistreatment from family and friends), and psychological consequences of HIV-related stigma, it is not surprising that stigma is often cited as a barrier to research participation among racially and ethnically minoritized populations, particularly among those with histories of race, gender, and class oppression in health research. Despite this risk, studies show that many African Americans do express willingness to participate in the research process if the appropriate ethical protections are in place, such as maintenance of privacy and confidentiality, if there is trust in the research

team, if there is financial compensation, and if they see the research as an opportunity to help themselves or a loved one (Freimuth et al., 2001; George et al., 2014).

Although researchers have identified several facilitators (e.g., altruism, financial compensation) and barriers (e.g., history of scientific racism, exploitative experimentation, distrust of the research process) to research participation among African Americans (Corbie-Smith et al., 1999; Floyd et al., 2010; Freimuth et al., 2001; Gamble, 1993; George et al., 2014), perceptions of the research process do not end with one's decision to participate in a research study. In other words, it is important to assess how participants perceive the benefits and risks of their participation throughout the research process and after study completion. This analysis may provide critical information for engaging in best ethical practices when working with marginalized groups. For instance, in our first paper with the sample in the current work, we found that quantitative assessments on perceptions of research participation yielded generally positive responses to the overall research process (e.g., the research is for a good cause) but the qualitative assessments showed more nuanced reactions to research participation in particular areas—some African American women reported confidentiality and privacy concerns about their research participation that was connected to disclosure of their HIV-positive status to others and the potential impact of this disclosure on their financial resources (Overstreet, Okuyan, & Fisher, 2018). Further, some women expressed greater emotional reactions when responding to sensitive questions during the research study. Thus, there is initial evidence of variability in responses to different aspects of the research process among African American women living with HIV. In the current work, we examine whether micro-level factors, such as individual attitudes and beliefs about one's HIV-positive status, predict some of the variability in reactions to research participation.

Internalized HIV-Related Stigma and Ethical Considerations in HIV Research

Earnshaw and Chaudoir (2009) proposed the HIV Stigma Framework as a conceptual model for understanding how stigma may manifest on the micro-level in people living with HIV. Their model highlights three HIV-related stigma mechanisms that are linked to poorer health outcomes: internalized stigma (i.e., acceptance of negative beliefs and feelings about the self because of one's HIV-positive status), anticipated stigma (i.e., expectations that one will experience bias because of one's HIV-positive status), and enacted stigma (i.e., one's experiences of discrimination because of one's HIV-positive status). There is some evidence that these HIV-related stigma mechanisms arise for people who participate in HIV research, and that these stigma mechanisms shape ethical concerns during the research process. For example, Reed and colleagues (2014) interviewed 30 female sex workers from Andhra Pradesh, India and found that participants reported fears about breaches in privacy and confidentiality that might lead to enacted stigma (e.g., incarceration, partner violence, stigma from community members). Moreover, some studies have found that concerns about breaches in privacy and confidentiality in HIV research may be linked to anticipated stigma from family members or others in participants' support networks (Floyd et al., 2010; George

et al., 2014). These findings provide initial support for the claim that stigmatizing processes on the micro-level may influence ethical concerns about participation in HIV research.

Despite this initial evidence, studies have yet to examine whether internalized HIV-related stigma influences ethical concerns during the research process. We suggest that internalized HIV-related stigma may have relevance for ethical concerns related to breaches in confidentiality and privacy, discomfort in answering sensitive research questions, and increased psychological distress. This hypothesis is based on the existing HIV literature which shows that internalized HIV-related stigma is a strong and consistent predictor of poorer psychological well-being and behavioral outcomes such as disclosure concerns about one's HIV-positive status (Earnshaw & Chaudoir, 2009; Kalichman et al., 2009; Overstreet et al., 2012). Moreover, it is possible that those with higher levels of internalized HIV-related stigma may have heightened concerns about breaches in confidentiality and privacy if their HIV-positive status is not known to others (Floyd et al., 2010; Overstreet et al., 2012). Thus, our work builds on the emerging HIV empirical ethics literature by examining whether internalized HIV-related stigma is another micro-level factor that is associated with African American women's ethical concerns about their participation in HIV research.

Centering African American Women in Empirical Ethics Research

Intersectionality theory is a multi-level, social justice framework focused on understanding how intersecting social identities (e.g., race, gender, class) are linked to interlocking systems of oppression (e.g., racism, sexism, classism) and shape people's lived experiences of disadvantage and privilege (Cole, 2009; Collins, 1990; Crenshaw, 1989; Rosenthal, 2016). There have been increased calls in psychology to deepen and enrich our scientific questions, methods, and understanding of diverse human experiences with intersectionality (Cole, 2009; Else-Quest & Hyde, 2016; Purdie-Vaughns & Eibach, 2008; Rosenthal, 2016; Warner, 2008). Recently, these calls have been extended to health research and shed light on the need for research that is ethical *and* socially just (Green et al., 2017; Paquin et al., 2019). Integrating intersectionality as a social justice framework into empirical ethics research requires critiquing the research enterprise and its role in perpetuating violence and oppression toward marginalized groups, engaging and collaborating with marginalized communities, centering their experiences and expertise, and committing to advance social justice inside and outside of the research process (Green et al., 2017; Paquin et al., 2019; Rosenthal, 2016). Thus, it is important to recognize that many of today's medical and scientific advancements often involved the exploitation of enslaved, poor, and working-class African American women without their consent, and despite these injustices, African Americans have contributed to scientific achievements and advancements utilizing their agency in these spaces (Gamble, 2014; Savitt, 1982; Washington, 2006). These institutionalized practices of gendered racism, or the unique oppression African American women face because of their gender and race (Essed, 1991) as well as class, violate fundamental ethical principles related to autonomy, beneficence, nonmaleficence, and justice.

Although the current work does not directly assess the impact of this knowledge on African American women's reactions to research participation, we note that the interlocking systems

of oppression that contribute to ethical violations in research also shape women's lived experiences with HIV. For instance, Logie and colleagues (2011) found that women's experiences of HIV-related stigma in Ontario, Canada were linked to sexism, racism, homophobia, and transphobia, and occurred on the micro-, meso-, and macro-level. These findings highlight how micro-, meso-, and macro-levels of stigmatization intersect to influence the lives of HIV-positive marginalized women. Extending this work to empirical research ethics, we suggest that while African American women may express mistrust of the research process because of historically rooted oppression on the macro-level, their experiences of stigma on the micro-level (e.g., internalized HIV-related stigma) may contribute to heightened ethical concerns during the research process even if ethical guidelines are met. We also stress the importance of understanding how stigma operates during the research process, rather than as a barrier to research participation, given evidence that African Americans generally, and African American women more specifically, are willing to participate in research for altruistic and therapeutic reasons that are linked to helping themselves and others within their community (George et al., 2014; Gunn et al., in press; Overstreet et al., 2019). Therefore, the goal of the current study is to examine African American women's experiences of internalized HIV-related stigma and how these experiences shape their perceptions of research participation.

Method

Participants and Procedure

The current study is part of a larger cross-sectional investigation, the Women's Health Study (WHS), examining relationships between substance use, HIV, intimate partner violence, HIV treatment adherence, and mental health among 239 ethnically diverse women (Anderson et al., 2018). Recruitment for the WHS, and the current study, took place at an HIV-related care clinic in Baltimore, MD. Participants were eligible to participate in the WHS if they were (a) 18 years or above, (b) female, (c) HIV-positive, (d) receiving clinic care for at least 1 year prior to study enrollment, (e) in an intimate relationship during the year prior to the study, and (f) English speaking. The WHS included the use of technology (i.e., tablets) to ensure safe recruitment and contact strategies, verbal instead of written consent, and transparent disclosure of mandatory reporting responsibilities before research participation (see Anderson, Glass, & Campbell, 2017 for description of safety protocol). Moreover, the survey questions assessed suicide and homicide risk to the participants. The research team for the larger investigation provided additional resources and referrals that were tailored to participants' risk profile based on their responses during the survey.

Given the focus of the retrospective ethics study, we specifically recruited African American participants from the WHS study. Of the 207 self-identified African American women in the WHS, we recruited 89 women. The first author approached the WHS team about the ethics study shortly after data collection for the larger investigation began. Therefore, the current study recruited the remaining African American women who completed the WHS. Participants were invited to participate in the study immediately after participating in the WHS study. We did not track the number of participants who declined to participate in the current study. Participants were informed that the ethics study was being conducted

by the first author's research team and not the WHS research team. Although members of the WHS team administered the survey, participants were told that the WHS study team would not be able to see participants' responses for the ethics study. The retrospective ethics study was completed on a tablet. Prior to completing the ethics study, participants provided informed consent. After completing the study, participants were compensated \$50 for their study participation. Additional information on the method and procedure of the ethics study is outlined in Overstreet, Okuyan, and Fisher (2018). The study was approved by the IRBs at Johns Hopkins University (WHS) and Yale University (ethics study).

Measures

Internalized HIV-Related Stigma—Internalized HIV-related stigma was measured using the negative self-image scale of the HIV Stigma Scale (Berger, Ferrans, Lashley, 2001). The 9-item scale assesses negative attitudes, beliefs, and feelings about the self because of one's HIV-positive sero-status. An example item is "Having HIV makes me feel I'm a bad person." Items were rated on a scale from 1 (Strongly Disagree) to 7 (Strongly Agree). Items were averaged with higher scores indicate greater feelings of internalized HIV-related stigma. Cronbach's alpha for the current sample is .88. The HIV Stigma Scale was validated with a sample that included African American Participants (21%; Berger, Ferrans, Lashley, 2001).

Reactions to Study Participation—The Reactions to Research Participation Questionnaire (RRPQ) consists of 23 items that assess participants' reactions to their participation in a research study (Newman et al., 2001). Participants were asked to reflect on their research participation during the WHS. Items assessed research participation in 5 domains: attitudes toward participation, personal benefits, global evaluation, perceived drawbacks, and emotional reactions. Items were rated on a scale from 1 (Strongly Disagree) to 5 (Strongly Agree). Higher scores indicate more favorable reactions toward the research process for the following subscales: Attitudes toward Participation (e.g., "Participation in the WHS was a choice I freely made"; Cronbach's alpha = .45), Personal Benefits (e.g., "I gained insight about my experiences"; Cronbach's alpha = .76), and Global Evaluation (e.g., "I think the research in the WHS is for a good cause"; Cronbach's alpha = .52). Higher scores on the Perceived Drawbacks (e.g., "I found the questions in the WHS too personal"; Cronbach's alpha = .65) subscale reflect less favorable reactions toward the research process and higher scores on the Emotional Reactions (e.g., "The WHS raised emotional issues for me that I had not expected"; Cronbach's alpha = .80) subscale reflect more intense reactions during study participation. Reliabilities are based on the current sample. The Reactions to Research Participation Questionnaire (RRPQ) was validated with a sample that included African American Participants (Newman et al., 2001).

Difficulty Responding to Questions about Sensitive Topics—Participants were also asked to indicate how difficult it was to share their experiences with sensitive topics during the WHS. Participants were asked to answer 6-items about difficulty on a scale from 1 (*Not at all difficult*) to 5 (*Extremely difficult*). The items were as follows: How difficult was it for you to share your experiences openly and honestly?; How difficult was it for you to be open and honest about your relationship problems like fighting?; How difficult was it

for you to be open and honest about your alcohol and drug use?; How difficult was it for you to be open and honest about your experiences with HIV?; How difficult was it for you to be open and honest about your mental health?; Overall, how difficult was it to participate in the Women's Health Study? Items were averaged with higher scores reflect more difficulty in responding to sensitive questions. Cronbach's alpha was .82.

Demographic information—Participants reported their age, racial/ethnic background, education, relationship status, health insurance information, and whether they had children. We did not have information about participants' income. We did not ask participants about their age at diagnosis or length of diagnosis.

Statistical Analysis Plan

We examined the relationship between HIV stigma, reactions to research participation, and difficulty responding to sensitive topics. We conducted six hierarchical multiple regressions with HIV stigma as a predictor of the 5 RRPQ subscales (attitudes toward participation, personal benefits, perceived drawbacks, emotional reactions, global evaluations) and the difficulty responding to sensitive topics measure. We hypothesized that higher levels of internalized HIV-related stigma would be associated with less favorable attitudes toward research participation, less perceived benefits of the research process, more perceived drawbacks, greater emotional reactions to the research process, less favorable global evaluations of the research, and more difficulty answering questions about sensitive topics that have been shown to co-occur with HIV. A total of 89 African American women responded to our secondary ethics study. Of the 89 participants, two were not included in final data analysis because their quantitative responses were greater than two standard deviations from the sample mean on the reactions to research participation questionnaire (RRPQ). This decision was based on previously established criteria to avoid violation of statistical assumptions. None of the demographic variables correlated with any of the 5 subscales of the RRPQ and were not included in the regression analyses as covariates. Being employed and having health insurance were correlated with difficulty responding to questions about sensitive topics and were controlled for in the regression analysis for this outcome.

Results

Descriptive statistics for research participants are shown in Table 1. Correlations between study variables and demographics are shown in Table 2. Internalized HIV-related stigma was positively correlated with intense emotional reactions, greater perceived drawbacks, and more difficulty responding to sensitive questions. Participants reported moderate levels of internalized HIV-related stigma. Overall, participants evaluated participation in the WHS favorably. Participants scored above the mean for the attitudes toward participation, personal benefits, and global evaluations scales. In other words, participants evaluated their participation in the WHS positively, evaluated the WHS as personally beneficial to them, perceived the research as being for a good cause, and understood confidentiality and the informed consent. Participants expressed few drawbacks to participation in the WHS.

Main Analyses

Attitudes toward Participation, Personal Benefits, and Global Evaluation—

Internalized HIV-related stigma was not a statistically significant predictor of attitudes toward research participation, $F(1,84) = .01$, $p = .91$, perceived personal benefits, $F(1,84) = 3.63$, $p = .06$, and global evaluations of the research, $F(1,84) = 2.69$, $p = .11$.

Emotional Reactions—The four-item emotional reactions sub-scale taps into heightened emotional responses during the research process. The regression model was statistically significant, $F(1,84) = 16.98$, $p < .001$. The results of the regression analysis indicated that internalized HIV-related stigma was associated with more intense emotional reactions during the research process, $b = .17$, $t(86) = 4.12$, $p < .001$.

Perceived Drawbacks—The six-item perceived drawbacks subscale of the RRPQ assesses participants' willingness to participate in research again and perceptions of how burdensome the research process was (e.g., length of study). The regression model was statistically significant, $F(1,78) = 12.52$, $p < .001$. Results showed that internalized HIV-related stigma was positively associated with perceived drawbacks, $b = .20$, $t(86) = 11.18$, $p < .001$. Specifically, women with higher levels of internalized HIV-related stigma reported more perceived research drawbacks.

Difficulty Responding to Questions about HIV-Related Sensitive Topics—

Overall, participants expressed little difficulty responding to sensitive topics in the WHS, ($M = 1.34$, $SD = 0.54$). We found that internalized HIV-related stigma was significantly associated with greater difficulty in responding to sensitive questions and discussing experiences openly, $b = .39$, $t(85) = 4.02$, $p < .001$, after controlling for participants' employment status and health insurance coverage. This regression model was statistically significant, $F(3,85) = 10.41$, $p < .001$.

Discussion

The current study examines the effect of internalized HIV-related stigma on African American women's reactions to research participation. In partial support of our hypothesis, we found that internalization of negative beliefs and feelings about one's HIV-positive status was associated with more intense emotional reactions to research participation, more perceived research drawbacks, and more difficulty when responding to questions about HIV-related sensitive topics. We did not find evidence that internalized HIV-related stigma was associated with attitudes toward research participation, perceived personal benefits of research, or overall evaluations of the research process. These findings suggest that there may be some aspects of research participation that are influenced by micro-level factors such as internalized HIV-related stigma. This information points to potential areas for researchers and institutional review boards (IRBs) to enhance ethical and socially just protections in HIV research with African American women.

One common ethical concern mentioned by researchers and IRBs is whether participants experience greater risk for psychological harm or distress when they answer questions about trauma-related or stigmatizing experiences. Researchers have cautioned that IRBs may

incorrectly assume that research with health disparity populations equate to higher risks, and that IRBs may rely on their own biases to identify human subjects' protections that are deemed appropriate for these groups rather than drawing on empirical evidence to guide this determination (Fisher, 2004; Mustanski, 2011). These ongoing challenges highlight a need for empirical approaches to research ethics that minimize overestimation of risk and perceived vulnerability (i.e., diminished autonomy) in health disparity populations. Our research takes one step in this direction by identifying internalized HIV-related stigma as a factor that may heighten particular ethical concerns during the research process. For instance, we found that internalized HIV-related stigma is associated with more intense emotional reactions to research participation, including experiences of unexpected emotional issues and having unwanted thoughts during the research process. In addition, internalized HIV-stigma was associated with more perceived research drawbacks, and more difficulty when responding to questions about HIV-related sensitive topics. These findings may provide insight on individual-level factors that contribute to more discomfort during the research process and tailored debriefing processes for those who have these reactions to research participation.

Moreover, our findings support the idea that empirical approaches are needed to avoid overestimation of risks and perceived vulnerability in health disparity populations (Mustanski, 2011). We found no evidence that internalized HIV-related stigma was related to diminished autonomy (e.g., feeling like they could not stop participating in the study, not understanding the consent form) or personal benefits of research (e.g., gaining insight from study participation) for the women in our study. Thus, our findings show that overestimation of risks and perceived vulnerability may underestimate the potential benefits that African American women experience through their research participation such as the opportunity to share their stories and help others who are experiencing similar issues (Gunn et al., in press; Overstreet et al., 2019). Given that many marginalized groups consider their research participation an opportunity to benefit their communities directly, we echo calls for research that not only meets ethical guidelines but also advances social justice goals (Paquin et al., 2019; Rosenthal, 2016). There are several avenues researchers can take toward reaching these goals including macro-level changes that dismantle stigmatizing processes shown to heighten internalized HIV-related stigma in African American women (e.g., gendered and racialized stereotypes that African American women are promiscuous, Davtyan et al., 2016) and critiques of systems/institutions that perpetuate HIV stigma for women at various social locations (e.g., religion, homophobia, laws that criminalize HIV) (Logie et al., 2011; Rosenthal, 2016). In line with feminist and anti-oppression researchers (Fontes, 2004; Paquin et al., 2019; Rosenthal, 2016), we also believe that ethical and socially just approaches to research centers the experiences and expertise of marginalized communities, accounts for how historical context shapes power dynamics during the research process, and moves toward community-engaged practices where marginalized communities directly benefit from the research process (e.g., ownership of their narratives, material benefits of research).

Recommendations and Best Practices

First, it is important for researchers and IRBs to accurately assess and communicate risk in research involving HIV-positive African American women in order for them to make informed decisions about their research participation. When research involves information that is not only sensitive but also elevates social, economic, and physical risks (Fontes, 2004), there is a greater need to strengthen protections for research participants (e.g., describing safety protocols in the consent form, enhancing confidentiality protections in the research protocol). This process requires an understanding of how societal stigmatization informs ethical concerns and potential risks that marginalized groups may face when they participate in research and providing adequate protections to address these risks.

Second, our findings underscore the importance for researchers to address the negative emotional reactions and responses that participants may feel due to sensitive questions. A common way that researchers address the issue of sensitive topics in research is by including a statement about distress being a potential risk of research in the informed consent (Fendrich et al., 2007; Mustanski, 2011). Although this is one solution for addressing this concern, our findings suggest that extra protections may be necessary around this issue for those who report higher levels of internalized HIV-related stigma. For instance, in addition to stating that distress may be a potential risk in the informed consent form, researchers may also consider tailoring their debriefing process to specifically address these concerns for participants who report higher levels of internalized HIV-related stigma during the research study. This tailored approach was used in the WHS to provide specific resources to participants based on their study responses (see Anderson et al., 2017, for details).

Third, we recommend that researchers clearly communicate the drawbacks of research participation that were highlighted in the current study (e.g., being long, personal, or inconvenient), and remind participants of their right to leave the study at any time without consequence if these drawbacks become too strong for some participants. This will ensure that research is aligned with meeting the standard of minimal risk in that the research does not increase the magnitude of harm or distress that participants encounter in their daily lives.

Limitations and Future Directions

There are several limitations of this study that may be addressed with future research. First, despite being a previously validated measure in the literature, reliabilities on the RRPQ were not as high for the following subscales: attitudes toward participation, global evaluation, and perceived drawbacks suggesting that this measure may not adequately capture HIV-positive African American women's perceptions of research. Although we attempted to provide a more contextualized perspective on research ethics that attends to power and social location, it is possible that this contextualization may also be needed for future ethics measures. Specifically, future work is needed to develop ethics measures that tap into population-specific concerns. Given the history of past abuses in science and medicine, we recommend developing measures that specifically address concerns around violations of autonomy, privacy, confidentiality, and consequences of involuntary disclosure of stigmatizing information.

Second, the current study did not examine stigma related to multiple aspects of participants' identities (Logie et al., 2011), and these experiences of stigmatization may also shape reactions to the research process. Research is needed to assess how micro-, meso-, and macro-level factors influence African American women's experiences during the research process. We investigated one aspect of individual level factors but there is evidence that anticipated stigma and enacted stigma are micro-level processes that influence psychological and behavioral outcomes of people living with HIV. Further, meso-level factors may have ethical implications for HIV research that involves family members or one's social network (Floyd et al., 2010). Further, macro-level factors, such as HIV criminalization, may also influence participants' ethical concerns during the research process. Taken together, future research should examine how stigmatizing processes that elevate psychological, social, and material risks affect perceptions of research participation among marginalized groups.

Third, our analyses excluded several potential covariates that were not measured in the study. For example, we did not ask additional information about participants' diagnosis (e.g., age at diagnosis). It is possible that factors related to participants' diagnosis, such as length of time living with HIV, may differentially impact their internalized HIV-related stigma because of engagement in coping, resilience, and resistance strategies to challenge HIV stigmatization (Logie et al., 2011). Likewise, we did not examine additional factors that may impact internalized HIV-related stigma, such as religiosity or notions of promiscuity. Subsequent research could benefit from measuring and examining these factors to provide a more nuanced understanding for how internalized HIV-related stigma impacts the research process.

Despite these limitations, the current research expands our knowledge of the far-reaching negative effects of internalized HIV-related stigma. In particular, our findings provide evidence that internalized HIV-related stigma may be one factor that influences reactions to research participation, particularly around increased distress and difficulty answering sensitive questions. These findings underscore the importance of examining how stigma related to participants' identities shape their experiences during the research process. In sum, our findings highlight the importance of empirical approaches to ethics research in guiding best practices for ethical and socially just engagement with HIV-positive African American women who participate in health research.

Acknowledgments

This research was funded by Fordham University's HIV Prevention Research Ethics Training Institute (National Institute on Drug Abuse Training Grant #R25-DA031608, Principal Investigator, Celia B. Fisher). We would like to acknowledge Jocelyn C. Anderson and Nancy E. Glass for their contributions and support with this study.

References

- Anderson JC, Campbell JC, Glass NE, Decker MR, Perrin N, & Farley J (2018). Impact of intimate partner violence on clinic attendance, viral suppression and CD4 cell count of women living with HIV in an urban clinic setting. *AIDS Care*, 30, 399–408. 10.1080/09540121.2018.1428725 [PubMed: 29397777]
- Anderson JC, Glass NE, & Campbell JC (2017). Conducting clinically based intimate partner violence research: Safety protocol recommendations. *Nursing Research Month*, 66, 405–409. 10.1097/NNR.0000000000000235

- Berger BE, Ferrans CE, & Lashley FR (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health*, 24(6), 518–529. 10.1002/nur.10011 [PubMed: 11746080]
- Centers for Disease Control and Prevention. HIV Surveillance Report, 2018 (Preliminary); vol. 30. <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published November 2019. Accessed May 26, 2020.
- Coker AL Does physical intimate partner violence affect sexual health? A systematic review. *Trauma, Violence, & Abuse*. 2007, 8(2):149–177. 10.1177/1524838007301162.
- Cole ER (2009). Intersectionality and research in psychology. *American Psychologist*, 64(3), 170–180. 10.1037/a0014564
- Collins PH (1990). *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. New York, NY: Routledge.
- Corbie-Smith G, Thomas SB, Williams MV, & Moody- Ayers S (1999). Attitudes and beliefs of African Americans toward participation in medical research. *Journal of General Internal Medicine*, 14, 537–546. [PubMed: 10491242]
- Crenshaw K (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum*, 139–167.
- Davtyan M, Farmer S, Brown B, Sami M, & Frederick T (2016). Women of color reflect on HIV-related stigma through PhotoVoice. *Journal of the Association of Nurses in AIDS Care*, 27(4), 404–418. 10.1016/j.jana.2016.03.003
- Earnshaw VA, & Chaudoir SR (2009). From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures. *AIDS and Behavior*, 13, 1160–1177. 10.1007/s10461-009-9593-3 [PubMed: 19636699]
- Else-Quest NM & Hyde JS (2016). Intersectionality in Quantitative Psychological Research: II. Methods and Techniques. *Psychology of Women Quarterly*, 40, 319–336. 10.1177/0361684316647953
- Essed P (1991). *Understanding everyday racism: An interdisciplinary theory* (Vol. 2). Sage.
- Fendrich M, Lippert AM, & Johnson TP (2007). Respondent reactions to sensitive questions. *Journal of Empirical Research on Human Research Ethics*, 2(3), 31–37. 10.1525/jer.2007.2.3.31
- Fisher CB (2004). Ethics in drug abuse and related HIV risk research. *Applied Developmental Science*, 8, 90–102. 10.1207/s1532480xads0802_3
- Floyd T, Patel S, Weiss E, Zaid-Muhammad S, Lounsbury D, & Rapkin B (2010). Beliefs about participating in research among a sample of minority persons living with HIV/AIDS in New York City. *AIDS patient care and STDs*, 24(6), 373–380. 10.1089/apc.2009.0306 [PubMed: 20515415]
- Fontes LA (2004). Ethics in violence against women research: The sensitive, the dangerous, and the overlooked. *Ethics & Behavior*, 14(2), 141–174. 10.1207/s15327019eb1402_4 [PubMed: 15835038]
- Freimuth VS, Quinn SC, Thomas SB, Cole G, Zook E, & Duncan T (2001). African Americans' views on research and the Tuskegee Syphilis Study. *Social Science & Medicine*, 52, 797–808. 10.1016/S0277-9536(00)00178-7 [PubMed: 11218181]
- Gamble VN (1993). A legacy of distrust: African Americans and medical research. *American Journal of Preventive Medicine*, 9, 35–38. [PubMed: 8123285]
- Gamble VN (2014). The immortal life of Henrietta Lacks reconsidered. *Hastings Center Report*, 44(1), 1. 10.1002/hast.239
- George S, Duran N, & Norris K (2014). A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American Journal of Public Health*, 104(2), e16–e31. 10.2105/AJPH.2013.301706
- Gielen AC, Ghandour RM, Burke JG, Mahoney P, McDonnell KA, & O'Campo P (2007). HIV/AIDS and intimate partner violence: Intersecting women's health issues in the United States. *Trauma, Violence, & Abuse*, 8(2), 178–198. 10.1177/1524838007301476
- Goffman E (1963). *Stigma: notes on the management of spoiled identity*. New York: Simon & Schuster Inc.

- Green MA, Evans CR, & Subramanian SV (2017). Can intersectionality theory enrich population health research? *Social Science & Medicine*, 178, 214–216. 10.1016/j.socscimed.2017.02.029 [PubMed: 28238539]
- Gunn A, Hardesty M, Overstreet NM, & Wallace S (in press). “Every time I tell my story I learn something new:” Voice and inclusion in research with Black women with histories of substance use and incarceration. *Crime and Criminology*.
- Hatzenbuehler ML, Phelan JC, & Link BG (2013). Stigma as a fundamental cause of population health inequalities. *American journal of public health*, 103(5), 813–821. 10.2105/AJPH.2012.301069 [PubMed: 23488505]
- Hatzenbuehler ML, & Link BG (2014). Introduction to the special issue on structural stigma and health. *Social Science & Medicine*. 10.1016/j.socscimed.2013.12.017
- Kalichman SC, Simbayi LC, Cloete A, Mthembu PP, Mkhonta RN, & Ginindza T (2009). Measuring AIDS stigmas in people living with HIV/AIDS: the internalized AIDS-related stigma scale. *AIDS care*, 21(1), 87–93. 10.1080/09540120802032627 [PubMed: 19085224]
- Link BG, & Phelan JC (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27(1), 363–385. 10.1146/annurev.soc.27.1.363
- Logie CH, James L, Tharao W, & Loutfy MR (2011). HIV, gender, race, sexual orientation, and sex work: A qualitative study of intersectional stigma experienced by HIV-Positive women in Ontario, Canada. *PLoS Med*, 8 (11). 10.1371/journal.pmed.1001124
- Maman S, Campbell J, Sweat MD, & Gielen AC (2000). The intersections of HIV and violence: directions for future research and interventions. *Social Science & Medicine*, 50(4), 459–478. 10.1016/S0277-9536(99)00270-1 [PubMed: 10641800]
- Meyer JP, Springer SA, Altice FL (2011). Substance abuse, violence, and HIV in women: A literature review of the syndemic. *Journal of Women’s Health*, 20(7), 991–1006. 10.1089/jwh.2010.2328
- Mustanski B, Newcomb ME, & Clerkin EM (2011). Relationship characteristics and sexual risk-taking in young men who have sex with men. *Health Psychology*, 30(5), 597. 10.1037/a0023858 [PubMed: 21604883]
- Newman E, & Kaloupek DG (2004). The risks and benefits of participating in trauma-focused research studies. *Journal of Traumatic Stress*, 17(5), 383–394. 10.1023/B:JOTS.0000048951.02568.3a [PubMed: 15633917]
- Overstreet NM, Earnshaw VA, Kalichman SC, & Quinn DM (2013). Internalized stigma and HIV status disclosure among HIV-positive black men who have sex with men. *AIDS care*, 25(4), 466–471. 10.1080/09540121.2012.720362 [PubMed: 23006008]
- Overstreet NM, Okuyan M, & Fisher CB (2018). Perceived risks and benefits in IPV and HIV Research: listening to the voices of HIV-positive African American women. *Journal of Empirical Research on Human Research Ethics*, 13(5), 511–524. 10.1080/01973533.2012.746599 [PubMed: 30183457]
- Paquin JD, Tao KW, & Budge SL (2019). Toward a psychotherapy science for all: Conducting ethical and socially just research. *Psychotherapy*, 56(4), 491–502. 10.1037/pst0000271 [PubMed: 31815508]
- Parker R, & Aggleton P (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social science & medicine*, 57(1), 13–24. 10.1016/S0277-9536(02)00304-0 [PubMed: 12753813]
- Purdie-Vaughns V, & Eibach RP (2008). Intersectional invisibility: The distinctive advantages and disadvantages of multiple subordinate-group identities. *Sex Roles*, 59, 377–391. 10.1007/s11199-008-9424-4
- Reed E, Khoshnood K, Blankenship KM, & Fisher CB (2014). Confidentiality, privacy, and respect: Experiences of female sex workers participating in HIV research in Andhra Pradesh, India. *Journal of Empirical Research on Human Research*, 9, 19–28. 10.1525/jer.2014.9.1.19
- Rosenthal L (2016). Incorporating intersectionality into psychology: An opportunity to promote social justice and equity. *American Psychologist*, 71(6), 474–485. 10.1037/a0040323
- Savitt TL (1982) The use of Blacks for medical experimentation and demonstration in the Old South. *The Journal of Southern History*, 48(3), 331–348.

- Warner LR (2008). A best practices guide to intersectional approaches in psychological research. *Sex Roles*, 59, 454–463. 10.1007/s11199-008-9504-5
- Washington HA (2006). *Medical apartheid: The dark history of medical experimentation on Black Americans from colonial times to the present*. New York, NY: Anchor Books.
- Willie TC, Overstreet NM, Peasant C, Kershaw T, Sikkema KJ, & Hansen NB (2016). Anxiety and depressive symptoms among people living with HIV and childhood sexual abuse: the role of shame and posttraumatic growth. *AIDS and Behavior*, 20(8), 1609–1620. 10.1007/s10461-016-1298-9 [PubMed: 26837633]

Impact Statement:

This study draws on intersectionality theory as a multi-level, social justice framework to advance research on how HIV-related stigma influences reactions to research participation among historically marginalized groups in medical research. Our findings highlight the importance of developing best practices in health research that are empirically informed, ethical, and socially just.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 1

Demographic Variables for HIV-Positive African American Women Participating in the Study (n = 87).

Demographic variables	<i>n</i> (%)
Age mean (<i>SD</i>)	47.7 (9.21)
Education	
No high school diploma	12 (13.8)
High school graduate	17 (19.5)
Associates Degree or vocational graduate	20(23)
Bachelor's degree/postgraduate	7 (8)
Married or with a partner	75 (86.2)
Partner	
Male	69 (79.3)
Female	6 (6.9)
Intimate partner violence	
No	45 (51.7)
Yes	42 (48.3)
Have children below age 18 years	22 (25.3)
1–2	20 (23)
More than 2	2 (2.2)
Health insurance	85 (97.7)
Private	7 (8)
Public	77 (88.5)
Currently unemployed	69 (79.3)

Table 2

Correlations between Study Variables

Subscale	1	2	3	4	5	6	7	8	9	10	11	12
1. HIV Stigma	-											
2. Participation attitudes	-.01	-										
3. Personal benefits	-.24 [*]	.58 [*]	-									
4. Global evaluation	.15	.52 [*]	.64 [*]	-								
5. Emotional reactions	.33 [*]	.02	.06	-.07	-							
6. Perceived drawbacks	.36 [*]	-.21	-.34 [*]	-.25 [*]	.44 [*]	-						
7. Difficulty responding	.38 [*]	-.26 [*]	-.48 [*]	-.37 [*]	.41 [*]	.32	-					
8. Age	-.27 [*]	-.08	-.04	-.03	-.08	-.11	-.21	-				
9. Education	.05	-.09	-.03	.03	-.12	-.10	.08	.17	-			
10. Children below 18	-.29 [*]	-.14	.10	.01	-.05	-.15	-.13	.52 [*]	-.09	-		
11. Health insurance	.12	.07	-.01	.06	.11	.03	.32 [*]	.03	.18	.06	-	
12. Employment	-.21	.03	.19	-.08	-.03	-.26	-.29 [*]	.08	-.21	.10	-.22 [*]	-
Mean	3.44	4.70	4.77	4.77	3.44	1.80	1.34	47.7	-	-	-	-
SD	1.44	.44	.40	.41	1.07	.83	.54	9.21	-	-	-	-

Note. The employment, child below 18 years, and insurance variables were recoded such that 0 represents participants who reported being employed, having children below 18 years, and having some type of insurance. RRPQ = Reactions to Research Participation Questionnaire.

*
 $p < .05$