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Perceived Risks and Benefits in Intimate Partner Violence and HIV Research: Listening to the Voices of HIV-Positive African American Women

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Abstract

African American women living with HIV were asked to reflect on the perceived risks and benefits of research participation after completing a study examining socially sensitive issues in their lives, including intimate partner violence and HIV. Administration of standardized quantitative instruments yielded positive responses to the research experience. However, qualitative assessments of perceived risks and benefits revealed more nuanced responses. For example, confidentiality concerns were more prominent in open-ended responses as was participants' positive attitudes toward monetary compensation. In addition, some women reported that study participation provided them with new insights about their experiences with intimate partner violence. Findings suggest that empirical studies on research protections involving potentially distressing and socially sensitive experiences with vulnerable populations require both quantitative and qualitative assessments of perceived risks and benefits. We discuss implications of our findings for ethics practices in trauma-related research among populations with multiple social vulnerabilities.

Keywords

Intimate partner violence; HIV; research ethics; African American women

HIV/AIDS disproportionately affects African American women living in the United States (CDC, 2014). There is increasing evidence that HIV incidence in this population may reflect a larger syndemic in which HIV status intersects with experiences of intimate partner violence (IPV) (Maman, Campbell, Sweat, & Gielen, 2000). For example, research shows that IPV may heighten African American women's vulnerability to HIV and other sexually transmitted infections (STIs) (Morales-Alemán, Hageman, Gaul, Le, Paz-Bailey, & Sutton, 2014; Seth, Wingood, Robinson, Raiford, & DiClemente, 2015; Stockman, Lucea,

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Draughon, Sabri, et al., 2013; Willie, Kershaw, Campbell, & Alexander, 2017). Moreover, African American women's HIV-positive status may be a risk factor for their IPV victimization (i.e., physical, sexual, and/or psychological abuse perpetrated by a romantic or intimate partner) (Williams, Wyatt, Myers, Green, & Warda, 2008). There is an urgent need for population sensitive research that can help reduce the dual HIV and IPV burden among African American women. However, the personal distress and social stigma associated with these intersecting epidemics requires careful examination of ethical issues that may arise for African American women who participate in such research. To address this gap in the literature, the current study explores HIV-positive African American women's perceptions of risks and benefits after participating in a study on sensitive issues in their lives, including IPV and HIV.

Risks and Benefits of Participating in IPV and HIV Research

Institutional review boards (IRBs) often raise the issue of whether asking participants questions related to traumatic experiences, such as IPV, should be conceptualized as a research risk (Becker-Blease & Freyd, 2006; Griffin, Resick, Waldrop, & Mechanic, 2003; Newman & Kaloupek, 2009; Newman, Risch, & Kassam-Adams, 2006). In light of these concerns, scholars have stressed the importance of conducting empirical research to understand whether trauma-related questions put participants at greater risk (see Ellsberg & Heise, 2002, for review). The emerging research in this area suggests that answering questions related to IPV victimization may not elevate emotional distress for many participants (Johnson & Benight, 2003). For example, Walker and colleagues (1997) found that out of a sample of 330 women (race and ethnicity were not reported) who completed questions about sexual and physical victimization, approximately 13% reported feeling unexpectedly upset and only 1% indicated that they would not have completed the survey if they knew what they would experience in advance. They also found that more than 25% of the women in their sample gained something positive from completing the survey. Similarly, in a sample of 260 predominately White undergraduate students, Shorey and colleagues (2011) found that perpetrators and victims of dating aggression reported positive benefits of participating in IPV research, and some participants reported mild negative reactions to the research process and more perceived drawbacks. Despite this evidence, it is less clear whether questions related to multiple sensitive issues, such as IPV and disclosure of personal (and potentially stigmatizing) information (e.g., one's HIV status, sexual risk behavior, and substance use), elevate psychological distress. Given that IPV and HIV are overlapping public health epidemics that disproportionately impact African American women (Stockman et al., 2013), it is important for empirical ethics research to consider perceptions of risks and benefits that emerge when research examines the intersection of IPV and HIV.

Scholars have also begun to call attention to research biases that overestimate the vulnerability of trauma survivors and underestimate the benefits that participants may experience during the research process (Becker-Blease & Freyd, 2006). Given the public health urgency for understanding the HIV/IPV syndemic it is equally important to empirically examine African American women's perspectives on the potential benefits of participation. For example, in a sample of 260 participants who experienced IPV, a majority of participants reported that participation in survey research related to victimization was not

distressing and was an interesting and valuable experience (Griffin, Resick, Waldrop, & Mechanic, 2003). These findings are consistent with other studies that show that participants do not report greater emotional distress than that experienced in their everyday lives when asked to answer questions about traumatic experiences (see Becker-Blease & Freyd, 2006, for review). Moreover, evidence suggests that disclosing stigmatizing information in survey research may provide participants with an opportunity to process their past traumatic experiences and even seek help for these experiences (Becker-Blease & Freyd, 2006; Ellsberg & Heise, 2002). To date there is a paucity of empirical evidence on how African American women with histories of trauma perceive these types of potential benefits. Moreover, empirical ethics research is limited on reactions to participation in IPV *and* HIV research, particularly among African American women, who have a specific history with research ethics in the United States (Freimuth, Quinn, Thomas, et al., 2001; Washington, 2006).

Ethical Considerations Beyond Psychological Distress

In the United States, African American women have been deceived, coerced, exploited, and mistreated in the name of science. For instance, Washington (2006) reviews evidence outlining centuries of medical abuse toward African American women via forced sterilization, exposure to disease, and even death. Given this history of past abuse, a number of studies have found that medical mistrust is a strong barrier to research participation among African Americans, particularly in HIV clinical trials and medical research (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Gamble, 1993; George, Duran, & Norris, 2014; Sengupta, Strauss, DeVellis, et al., 2000). Drawing attention to this particular historical context sheds light on why African American women may mistrust researchers and the research process, which in turn may raise the level of distress in reaction to study questions. Furthermore, when African American women agree to participate in research associated with medical centers at which they receive regular care, they may be concerned that refusal of participation will result in lack of access to services.

In addition to historical factors, it is possible that contextual factors, such as power dynamics within the research-participant relationship, may compromise participants' autonomy and voluntariness (Fontes, 1998, 2004). For instance, researchers and IRBs may assume that when participants sign a carefully crafted consent form, they are not only aware of these risks and benefits but also are exercising their right to refuse or agree to participation (Yick, 2007). However, rather than assume participants have understood the informed consent process, it is critical to understand how women with multiple social and health vulnerabilities perceive and understand the consent process, particularly as it relates to ethical issues such as coercion, voluntariness, and confidentiality protections. Despite the need for empirical ethics research with diverse populations (Lakes, Vaughan, Jones, Burke, Baker, & Swanson, 2012), research in this domain remains scarce. These ethical issues may be particularly critical for those who may have heightened mistrust because of a history of oppression, stigmatization, and trauma (Fisher, Oransky, Mahadevan, Singer et al., 2008; Yick, 2007). Researchers have argued that a limited focus on emotional reactions to the research process may overlook important ethical considerations that might emerge in IPV and HIV research, such as concerns over physical safety and confidentiality of one's

information (Ellsberg & Heise, 2002). In other words, while it is important to understand whether asking people about traumatic events heightens emotional distress, it is equally important to assess whether those who participate in IPV and HIV research may express concerns about their physical safety (e.g., risk of further violence from an intimate partner if they find out about their participation in violence research or if their HIV status is disclosed). Similarly, it is necessary to examine whether participants are concerned about breaches of confidentiality when disclosing sensitive health information to research staff (Reed, Khoshnood, Blankenship, & Fisher, 2014). The findings of this research have the potential to inform IRBs and researchers of the necessary measures need to prevent unintentional disclosure and community stigma related to participants' HIV and IPV status (Fisher, 2011; Jewkes et al., 2012; Logie, James, Tharao, & Loutfy, 2011; Overstreet & Quinn, 2013).

The Current Study

Empirical studies on risks and benefits of research participation, that require individuals to reflect on their experiences during the research process, has largely ignored the impact of research participation on African American women living with HIV and IPV. To date, research has explored ethical issues in IPV and HIV research separately with a focus on potential adverse effects of participation such as psychological distress. However, given evidence that African American women's HIV-positive status may be a risk factor for their IPV victimization (Williams, Wyatt, Myers, Green, & Warda, 2008), it is important for researchers to examine ethical issues in these areas simultaneously, in order to develop protections during recruitment and implementation. Moreover, the lack of empirical work on African American women's perceptions of the research process in these two intersecting domains undermines the ability of researchers and IRBs to develop ethical procedures sensitive to participant's needs.

In addition, the scarcity of empirical evidence in this research area may lead researchers and IRBs to rely on their own moral compasses and implicit biases in determining appropriate human subjects' protections for this population (Becker-Blease & Freyd, 2006; DePrince & Freyd, 2004; Ellsberg & Heise, 2002; Fisher, 1999, 2004; Kassam-Adams & Newman, 2002). The absence of participant perspectives may lead to over-or under-estimations of the benefits and burdens of participation in HIV/IPV that can limit African American women's involvement in research that is essential to the development of treatments and policies essential to their health and wellbeing (Fisher, 2008, 2011). Further, the extant literature on participant reactions to questions tapping HIV and IPV victimization has traditionally relied on quantitative analysis of responses to Likert-type survey items (e.g., whether participating in research is positive, beneficial, and personally meaningful). It is possible that nuances in perceived benefits may not be captured by these quantitative measures of the research process. We thus implemented a multi-method design to best capture African American women's attitudes toward their participation in a study focusing on their HIV status and IPV experiences. First, we examined women's reactions to their research experiences using the Reactions to Research Participation Questionnaire (RRPQ; Newman et al., 2001)—a quantitative measure previously used in empirical ethics research on trauma with other populations. We also explored whether women's open-ended qualitative responses provided

a more in-depth approach to understanding potential issues that can best inform the responsible conduct of research for this population.

Method

Participants and Procedure

The current study is part of a larger online investigation, the Women's Health Study (WHS), examining women's experiences with substance use, HIV, and IPV. Our study specifically focuses on African American women's retrospections on their experience participating in the Women's Health Study. Recruitment for the WHS and the current study took place at an HIV-related care clinic in Baltimore, MD. Women were recruited for the WHS if they were: 1) 18 years or older, 2) female, 3) HIV-positive, 4) receiving clinic care for at least 1-year prior to study enrollment, 5) in an intimate relationship during the year prior to the study, and 6) English speaking. The WHS is a cross-sectional survey that examined relationships between HIV treatment adherence, substance abuse, IPV, and mental health among 239 ethnically diverse women (Anderson, Campbell, Glass, Decker, Perrin, & Farley, 2018). The WHS included the use of technology 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 detailed description of safety protocol). Moreover, the survey questions assessed suicide and homicide risk to the participants. The research team provided additional resources and referrals that were tailored to participants' risk profile based on their responses during the survey.

Given the focus of our research, we only recruited African American participants from the WHS for the current study. Of the 207 self-identified African American women in the WHS, we recruited 89 African American women. The first author approached members of the WHS via email about the retrospective ethics study a few months after the WHS began. Thus, recruitment for the current study took place with the remaining African American participants who completed the WHS. Participants were invited to participate in the current study immediately after participating in the WHS. We did not track the number of participants who declined to participate in the current study. After completing the WHS, members of the WHS research team informed participants that a secondary study was being conducted by researchers affiliated with another institution. Although the WHS research team administered the survey, they emphasized that they were not conducting the survey and would not be able to see participants' responses for the current study. Participants who expressed interest in participating were asked to read and sign the consent form for the current study on a tablet. In the consent form, we asked participants for their permission to link their responses in the current study to the information provided in the WHS using their randomly assigned study ID numbers. We informed participants that across both studies, their personal information such as their name, phone number, and address, would not be attached to their survey responses. Thus, the first author only had access to de-identified information from the WHS using the same assigned study IDs from the WHS. The WHS research team provided participants with the tablet to complete a series of questions about their experience during the WHS in a private setting at the clinic. The survey was created via

Qualtrics, a secure online research tool, and used the colors and logo of the researcher at the second institution. After the current study was completed, participants were remunerated a $50 gift card by the WHS team. The study was approved by both institutions' IRBs.

Measures

Open-ended questions.—The survey began with 2-open-ended questions in which participants were asked the following: "What was the greatest benefit of participating in the WHS?" and "What was your greatest concern about answering questions in the WHS?"

Reactions to study participation.—The Reactions to Research Participation Questionnaire (RRPQ; Newman et al., 2001) is a 23-item scale developed to assess participants' reactions to their study experience. We specifically asked participants 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. Participants were asked to rate the extent to which they disagree or agree with each item, with responses ranging from 1 (*Strongly disagree*) to 5 (*Strongly agree*) with a mid-score of *Neither disagree or agree*. Higher scores indicate more favorable reactions toward the research process for the following subscales: Attitudes toward Participation (Cronbach's alpha = .45), Personal Benefits (Cronbach's alpha = .76), and Global Evaluation (Cronbach's alpha = .52). Higher scores on the Perceived Drawbacks (Cronbach's alpha = .65) subscale reflect less favorable reactions toward the research process and higher scores on the Emotional Reactions (Cronbach's alpha = .80) subscale reflect more intense reactions during study participation. Reliabilities are based on the current sample.

Demographic information.—Using participants' study ID numbers, we obtained demographic information for age, racial/ethnic background, education, relationship status, health insurance information, and information about potential children from participants' responses in the WHS. The WHS did not ask information about participants' income. However, we did have information about participants' education level, which may serve as another indicator of socioeconomic status (Duncan, Daly, McDonough, & Williams, 2002).

Data Analytic Approach

Descriptive statistics were run for the five subscales of the RRPQ to examine participants' reactions to the WHS. In order to assess women's experiences beyond mean scores, we also examined percentage of agreement at the item-level for each subscale. We calculated percentages on the 5-point Likert scale into the following categories: *Strongly disagree* and *disagree somewhat* to indicate participants' disagreement, *Neither agree nor disagree* to indicate participants' indifference, and *Strongly agree* and *Agree somewhat* to indicate participants' agreement.

In addition to the quantitative responses to the RRPQ, we explored whether women expressed ethical concerns that were more descriptive than the broad items captured by the RRPQ. Specifically, we content coded participants' responses to the open-ended questions using the 5 RRPQ dimensions for the initial coding scheme (Schreier, 2012). Two research

assistants coded the responses into the 5 RRPQ categories, as they are defined by Newman and colleagues (2001) and based on the items' content. In total, 170 statements were coded by the research team over a series of meetings with iterative changes based on discussion of rater disagreements. Statements that were open to interpretation as to their meaning, or were incomprehensive were placed in an "other" category. Cohen's kappa was .80 (Altman, 1991).

Results

Of the 89 African American women who responded to our ethics-focused measures, 2 were not included in final data analysis because their quantitative responses were greater than two standard deviations from the sample mean on the RRPQ subscales—a decision based on previously established criteria to avoid violation of statistical assumptions (Warner, 2008). Table 1 illustrates the sample characteristics of the remaining 87 participants. All women identified as African American, 2 identified as multi-racial; and all were living with HIV. Based on their responses to violence questions in the WHS, 42 women reported experiencing IPV from a partner. Participants were classified as having experienced IPV in the past year if they answered 'yes' to an abuse assessment screen or if they reported moderate or severe physical or sexual violence from an intimate partner in the past year (see Anderson et al., 2018 for details on IPV measure).

Inter-Item Reliabilities and Correlations

Inter-item reliabilities were acceptable for all subscales (range: .52–.80) except for the Attitudes toward Participation subscale ($\alpha = .45$). Item-total statistics showed that Cronbach's alpha for this subscale increases to .79 when the item "I felt I could stop participating in the Women's Health Study at any time" was deleted. Relative to the other three items on this subscale, there was much more variability in the number of women who felt that they could stop participating in the WHS at any time. Excluding this item from the analyses did not change our results, therefore it was kept it in the analysis.

Correlations between subscales and demographics are displayed in Table 2. The Attitudes toward Participation subscale was significantly and positively correlated with the Personal Benefits and Global Evaluation subscales. Thus, participants who had positive attitudes toward participation perceived the study to be more beneficial and personally meaningful. Moreover, having a positive attitude toward study participation was associated with more positive overall evaluations of the WHS. The Personal Benefits subscale was also significantly and positively correlated with the Global Evaluation subscale. Participants who indicated that their study participation was beneficial also evaluated the study positively. There was a significant and positive correlation between the Emotional Reactions and the Perceived Drawbacks subscale. Participants who experienced heightened emotional reactions during the WHS also perceived greater drawbacks related to the study. Emotional reactions were not significantly correlated with attitudes toward study participation, personal benefits, or global evaluations of the study. The Perceived Drawbacks subscale was significantly and negatively correlated with Attitudes toward Participation, Personal

Benefits, and Global Evaluation subscales. Women who were employed reported greater perceived drawbacks of the study than those who were not.

We further explored the relationship between the Emotional Reactions and Attitudes Toward Participation subscales to examine whether women who experienced emotional reactions to the WHS might regret their participation. To accomplish this, we assessed the correlation between the Emotional Reactions subscale and the average of the last two items of the Perceived Drawbacks subscale that tap into study participation regret. This analysis showed that emotional reactions were not correlated with regretting study participation (averaging the last two items of the Perceived Drawbacks scale, $r(83) = .06$, $p = .61$). However, emotional reactions were positively correlated with the remaining 4 items of the Perceived Drawbacks subscale, $r(83) = .47$, $p = .00$.

Analysis of Subscales and Open-Ended Responses

In this section, we present means and standard deviations for each subscale of the RRPQ, followed by mean scores, percentage agreement on individual subscale items (Table 3).

Attitudes toward participation.—The 4-item participation subscale of the RRPQ highlights participants' attitudes toward research participation and their perceptions of voluntariness. Overall, women reported a highly positive experience during the WHS ($M = 4.70$, $SD = 0.44$). The subscale mean was consistent with item-level responses on 3 of the 4 items in the subscale. More than 96% of participants agreed with the following items: *I like the idea that I contributed to science* and *I was glad to be asked to participate in the study*. Although 99% of the sample reported *freely choosing to participate in the WHS*, only 77% *felt that they could stop participating in the WHS at any time*. Thus, there was greater variability in women's perceptions that they could voluntarily terminate study participation at any time.

Open-ended responses.: Approximately 4% of the open-ended responses were coded in the participation category. These responses were consistent with the subscale mean and reflected participants' satisfaction with the WHS (e.g., "It was very interesting", "it was good, I enjoyed it").

Personal benefits.—Overall, women evaluated the WHS as personally beneficial and meaningful to them ($M = 4.77$, $SD = 0.40$). The item-level responses for the 4 items in this subscale were consistent with the subscale mean. Specifically, a majority of participants agreed that the WHS resulted in personal benefits such as "*gaining insight"* (95%), "*gaining something positive"* (94%), "*finding something positive from participating in the study"* (94%), and "*finding participation personally meaningful"* (95%).

Open-ended responses.: The RRPQ's personal benefit subscale taps into broad categories perceived benefits, yet the open-ended responses were more nuanced in what women considered beneficial and personally meaningful. Personal benefits were the most prevalent category in the open-ended responses, constituting 34% of the open-ended responses. Many women mentioned that the WHS provided them with an opportunity for insight in the areas of self-reflection (e.g. "Being real with self by answering honestly"; "learn a lot about

yourself"), emotional and experiential expression (e.g., "To express feelings"), and increased awareness about one's health (e.g., "learning more about the disease"). Participants also mentioned that another area of insight gained from their participation in the WHS was related to learning about the abusive parts of their relationship. Although 42 women indicated during the WHS that they experienced abusive behaviors (e.g., being physically threatened or having an object thrown at them) from an intimate partner in the past year, approximately 13% of these women stated that they were not emotionally, physically, or sexually abused by their partner (or felt unsafe in their relationship) in the past year. Some of the open-ended responses of the 11 women who answered "no" to being abused by a partner, yet screened for IPV during the WHS, suggest that one benefit of participation was realizing that their relationship was abusive. Comments included: "learning about my health and *being abused*; "I realize[d] I was in a[n] abusive relationship", "to help me understand the difference between violent parts of a relation[ship] that might require some help"; and "to know if my relationship was unhealthy/that my mate was violent". There were also some participants who, while they reported having experienced emotional and/or physical violence in the past year, indicated some additional insights about their relationships based on their WHS participation: Examples of such comments included: "recognizing some things that has occurred in my relationship"; "learning that I need help"; and "made me aware that there is a problem in my relationship".

The open-ended responses coded as personal benefit also provided insight into participant perceptions of monetary compensation. Fourteen percent of women responded to the open-ended benefit questions with comments indicating the monetary incentives for the study was motivating for them (e.g., "I get to go Walmart with a gift card something I rarely get", "Walmart gift card helps with monthly expenses!").

Emotional reactions.—The 4-item emotional reactions subscale taps into heightened emotional responses during the research process. In contrast to the predominantly positive reactions on the other subscales, on average, women's responses were at the mid-point of this scale ($M = 3.44$, $SD = 1.07$). The item-level responses support this finding. For instance, 78% of the participants endorsed the item indicating they *experienced emotional issues they had not expected* and 59% reported *feeling intense emotions during the study*. Similarly, 53% of the participants indicated that "*they thought about things they did not want to think about*". Approximately 40% of the sample reported *being emotional during the study*. We found a significant difference for emotional reactions between women screened for IPV during the WHS ($M = 3.76$, $SD = .76$) compared to those who did not ($M = 3.16$, $SD = 1.23$), $F(1,81) = 6.88$, $p = .01$), with participants who were screened for IPV indicating more heightened emotional reactions to the survey.

Open-ended responses.: The open-ended responses did not go into much depth about the nature of the emotional reactions participants experienced. Only 1.8% of the responses to either open-ended questions were coded in the emotional reactions category. In this small sample of answers given in response to the "greatest concern" question, participants referred to questions in the survey that asked about physical abuse (e.g., "about the abuse", "the abuse").

Perceived drawbacks.—The 6-item perceived drawbacks subscale of the RRPQ assesses willingness to participate in the research again and burden related to the research process (i.e., the length of the study, general inconvenience of participation, and discomfort responding to sensitive questions). Overall, participants endorsed few drawback items (M = 1.80, SD = 0.83). The item-level responses revealed variability in the aspects of the research process that participants perceived negatively. For instance, approximately 30% of the sample thought the study was "*inconvenient*" and approximately 20% felt that the questions in the WHS were "*too personal*." However, 16% of participants thought the study was "*too long*" and 14% found it "*boring*." Over 90% of the sample felt *positively about their research participation* and reported that *they would participate in the WHS again* (see Table 3).

Open-ended responses.: Only 1.8% of the total open-ended statements (e.g., "the time, how long would it be", "the personal questions") were coded in the perceived drawbacks category, which suggests that drawbacks were not a salient concern for the participants.

Global evaluation.—The 5-item global evaluation subscale of the RRPQ assesses participants' perception that the research will be helpful to people, that participants were treated respectfully by the research team, and measures participants' understanding of confidentiality and informed consent. Overall, women evaluated the WHS favorably (M = 4.77, SD = 0.41). Both the item-level responses and the open-ended responses indicated that women felt respected during the WHS, felt the research was for a good cause, and that the study procedure did not harm them. For instance, a majority endorsed the one item on the RRPQ that tapped into *being treated with respect and dignity by the research team* (90%). Ninety percent of the sample felt that the research they participated in was *for a good cause* and that the *results will be useful to others*. Finally, women highly endorsed items indicating their *data would be kept private* (87%) and that they *understood the study procedure outlined in the informed consent* (97%).

Open-ended responses.: In the open-ended responses, women mentioned that they appreciated the research team and "the concern that they show," and "being able to know you have great people who support you and are willing to help you." The open-ended responses also revealed participants believed that the study findings would be useful to other women who had similar experiences to their own. For instance, 11% of the open-ended responses reflected participants' belief that study results will be used to help other women experiencing violence and women living with HIV (e.g., "provide input to help HIV-positive people have better quality of life", "the possibility that it may help another"). Thirteen percent of open-ended responses to the "greatest concern" question mentioned confidentiality. For example, when asked about her greatest concern, one participant stated, "that you will tell and I don't want you to do that." Another participant mentioned that her greatest concern would be if her data would stay confidential "concerning the government programs that currently assist me with rent and income." Finally, 38% indicated that they had no concern about research participation in response to the "greatest concern" question. Responses that did not fit within the content covered by the RRPQ categories (13%) or did

not refer to clear meaningful patterns (7%, e.g., “letting off,” “being in a relationship,” “that people are losing control of themselves”) fell under the “other” category.

Discussion

African American women living with HIV and IPV have been largely overlooked in the ethics research literature. However, given the increasing research on the HIV/IPV syndemic among African American women (Morales-Alemán et al., 2014; Seth et al., 2015; Stockman et al., 2013), it is critical to understand how participation in HIV and IPV research impacts this population. In the absence of empirical evidence on how African American women living with HIV experience participation in trauma-related research, IRBs may under or over-estimate research benefits and harms. In the current study, we addressed this gap by examining HIV-positive African American women’s reactions to participation in a research study examining their lived experience with HIV, and with other trauma-related experiences such as IPV.

One of the most common ethical issues explored in trauma-related research is whether sensitive questions heighten psychological distress during the research process. In the current study, we used the RRPQ to assess whether women felt heightened emotional reactions during the WHS. These questions primarily focused on whether women experienced emotional responses they did not expect, if they experienced intense emotions or felt emotional during the study, and if they thought about things they did not want to think about during the study. We found that participants reported emotional reactions above the mid-point of the scale. Moreover, we found evidence that women who screened for IPV during the WHS reported greater emotional reactions to the research process compared to those who were not screened for IPV. However, it is less clear in our study whether these heightened emotional reactions equate to research risk and whether anticipation of such reactions would have led to participation refusal. For instance, previous studies have found that distress during the research process was not associated with regretting study participation (Kassam-Adams & Newman, 2005; Newman, Walker, & Gefland, 1999; Ruzek & Zatzick, 2000; Walker, Newman, Koss, Berstein, 1997). In addition, a recent retrospective study on perceived risks and benefits of participating in sexual victimization research found no association between levels of distress and personal benefit for participants with a history of sexual victimization (Wager, 2012), which suggests that for some participants processing emotional reactions to the research process may be personally beneficial (as some of our findings suggest) whereas for others, greater emotional reactions may not equate to personal gain. Our quantitative analysis is consistent with this finding: The Emotional Reactions scale was not correlated with regretting study participation. Moreover, our open-ended responses in this category suggest that although some women experienced emotional reactions related to questions about abuse, they responded fairly positively to the study overall, saw its benefit for themselves and others, and reported that they would be willing to participate in similar research again. Taken together, these findings suggest that more research is needed to understand whether emotional reactions function as a research risk, benefit, or both.

Researchers have also called for studies on participant reactions to involvement in trauma research that move beyond psychological distress (Becker-Blease & Freyd 2006; Ellsberg &

Heise, 2002; Fontes, 2004). The findings of the current study support this call, particularly as it relates to ethical issues such as autonomy, voluntariness, consent, and confidentiality protections. For instance, we found that 99% of respondents reported that they freely chose to be a part of the WHS, yet only 77% felt that they could stop participating in the WHS at any time. The WHS consent form included the withdrawal option and in the current study 97% of women in the sample indicated that they understood the consent form. These findings suggest that informed consent procedures at the start of the study may be insufficient in assuring individuals that they have a right to withdraw from a study at any time, even after they have signed a consent form. However, it may also indicate that women who value their own experience in the research and the value to others in the future, may be referring to their own attitudes toward continuing to contribute to the study, despite discomfort. Future studies will need to tease apart these motivations.

Our findings are also consistent with previous research on vulnerable population's attitudes toward participation withdrawal. For example, Fisher, Arbeit, Dumont, Macapagal, and Mustanski (2016) reported that 13% of sexual and gender minority youth surveyed would find it difficult to refuse participation in an HIV medication prevention study, even when informed consent materials indicated they had the right to do so. Other studies have reported that a percentage of individuals involved in sex work or illegal drug use believe that the informed consent represents a "contract" that cannot be broken (Fisher, 2011; Reed, Fisher, Blakenship, Brook, & Khoshnood, 2017). Our open-ended responses do not provide insight into why some women felt that they could not stop participating in the study, yet scholars have discussed power differences between researchers and participants as one potential explanation for our findings. For instance, Yick (2007) suggests that for participants who experience IPV, the power dynamics between the researcher and the participants in the research settings, where researchers have seemingly more control over the conditions and outcomes, might trigger emotions and behavior similar to the ones these individuals have in their abusive relationships. Thus, it is possible that participants in the current study felt that they were not be able to voice their desire to end the study once the process starts due to power differences between researchers and participants. However, continued participation may not always reflect a lack of autonomy. A qualitative study based on interviews with Peruvian female sex workers about a Human Papillomavirus (HPV) vaccine trial revealed that some participants while they knew they could, and wanted to withdraw from the study at any time, continued participating as they valued the outcomes of the study, and how it might be beneficial for their community in terms of access to medical care (Brown, Davtyan, & Fisher, 2015). These ethical considerations should be probed further, particularly among those living with various marginalized identities.

Another finding that has relevance for autonomy is participants' frequent mention of compensation as a benefit of the study. Federal regulations do not permit IRBs to evaluate monetary or other forms of participation incentives or compensation as "research benefits." Moreover, there is a general belief that monetary incentives are neither a risk or significant benefit in research involving non-vulnerable populations. For example, Newman and Kaloupek (2009) stated that in the literature on research experiences, participants do not usually cite the payment they received from participation as a benefit in their answers to open-ended questions. Thus, the RRPQ does not include an item about material incentives in

the personal benefit subscale. Others, have incorporated monetary compensation in scales reflecting motivation to participate (Appelbaum, Lidz & Klitzman, 2009). There are divergent opinions in the literature related to monetary incentives. Some researchers consider material incentives as potentially diminishing the autonomy of participants coming from lower SES backgrounds, while some point to participants' agency (Fine, Weis, Wessen, & Wong, 2000; Fontes 1998, 2004; Oransky, Fisher, Mahadevan, & Singer, 2009; Yick, 2007). Moreover, there is evidence to suggest that compensation for study participation may be perceived as the investigators' appreciation and respect for participants' efforts during the research process. The extent to which the amount of monetary incentive (e.g. $50 in the parent study) influences these perceptions is an important avenue for future research. In the current study, we found that participants talked about material incentives in conjunction with other benefits such as indicating that the study is for a good cause (therefore, *they* are part of that good cause), and helping other women living with HIV who might experience IPV. Through a sense of helping a cause, and helping others, participants might have found a sense of personal agency in the research context, which could be considered an additional incentive for participation (Taylor, 2002).

Scholars have noted that research involving socially marginalized populations can serve as an intervention in participants' lives (Ellsberg & Heise, 2002; Fisher, Fried, Desmond, Macapagal & Mustanski, 2017) particularly for African American women who are survivors of IPV (Taylor, 2002). For instance, our findings revealed that taking part in the WHS helped some women become aware of and re-conceptualize parts of their relationships that were abusive. For instance, responding to specific and concrete depictions of violence items ranging from mild to severe forms of abuse (e.g., "How often in the past year has your partner threw, smashed or broke an object? Drove dangerously with you in the car? Hit you with an object?") might have facilitated the labeling of abuse in their own relationship. Another way in which the WHS could have accomplished this educational function is by the study's inclusion of scales that encouraged participants to reflect on their experiences and future risks, such as a security check about (re)assault, and a scale which asked women with male partners a list of questions exemplifying coercive sexual conduct (see Anderson, Glass, & Campbell, 2017). Our data suggest that exposure to such scales have the potential to lead women to reevaluate risks for their individual past/present relationships and seek needed support (Fontes, 1998).

Research Agenda

During informed consent, the WHS described detailed procedures that would be used to protect participant confidentiality. However, a minority of women in our study continued to express confidentiality concerns. For women living at the intersection of HIV and IPV, confidentiality may be a major concern because of potential consequences of HIV stigma (Maman et al., 2000). For instance, women involved in sex work in India expressed confidentiality concerns related to HIV stigma, intimate partner violence, and institutional punishment (Reed et al., 2014). Participants in our study also indicated government access to their study information was a confidentiality concern. Such responses may reflect the research distrust documented among other groups of African American participants based on a history of research exploitation (Fisher, 2010; Fisher et al., 2008; Freimuth et al., 2001;

Gamble, 1993; Sengupta et al., 2000; Washington, 2006). These findings should challenge investigators and IRBs to think more carefully about confidentiality vulnerabilities of African American women living with HIV and IPV (Fontes, 2004).

Best Practices

In light of our findings, we point to several considerations for researchers who conduct IPV and HIV research with African American women and others who come from multiply disadvantaged positions. First, we recommend that investigators place additional emphasis in the informed consent on the right to stop participation at any time before and *during* the study. Additionally, during the study researchers should remind participants of this right without expecting them to bring it up themselves (Newman & Kaloupek, 2009). These measures may mitigate participants' hesitation about study withdrawal and also provide opportunity for them to ask additional questions that may arise during the course of their research experience. Second, although our findings suggest the effect of the amount and type of compensation on participants' autonomy is an important point of discussion and further empirical investigation (Singer & Bossarte, 2006), we favor the view that material incentives are appropriate compensation for participants who experience multiple levels of disadvantage (Oransky et al, 2009; Brown et al., 2015).

Some women noted that their experience in the WHS allowed them to understand unhealthy and potentially abusive behaviors in their relationships. For example, approximately 48% of the women in our sample were screened for IPV in the Women's Health Study. If our assessment of ethical considerations only involved HIV-related concerns and benefits, we would have overlooked an informational benefit reported by women who identified for the first time through research participation that violence within their own relationships were unhealthy behaviors. Thus, our research underscores the suggestion that participation in non-intervention research can provide an educational function that may serve as an intervention (Ellsberg & Heise, 2002; Fisher et al., 2017). However, this influence needs to be considered with caution. For example, Fontes (2004) has expressed ambivalence about the risks and potential benefits of participation in research on IPV interventions. She questions what one does with more awareness of her condition when she does not have enough power to change it. In this regard, our findings do not give us much information about whether increased awareness about interpersonal violence would lead to more positive outcomes for the women in our sample or jeopardize their safety within social and institutional systems in which they have little power. Researchers should be cognizant of such structural constraints on women's agency and autonomy, including honest recognition of the barriers to escaping such victimization and provide realistic and available referrals for community support to their participants.

Confidentiality concerns also underscored safety issues unique to this population where HIV infection is associated with increased risk of IPV. We recommend extra measures are taken to reassure the safety of participants with experiences of IPV, particularly for research that contains sensitive information about the abuse/the perpetrator (Becker-Blease & Freyd, 2006; Btoush & Campbell, 2009; Ellsberg & Heise, 2002; Newman & Kaloupek, 2009). For instance, Ellsberg and Heise (2002) recommend affording total privacy to participants even

outside conventional research environments, and prioritizing safety in providing information about resources and services in the community. Participants should be given an explanation about these additional safety measures, and reassured that their information is being protected (Reed et al., 2014). Furthermore, marginalized group members' confidentiality concerns deserve more critical consideration from researchers as these groups face varied forms of structural disadvantage. For example, in cases in which some aspects of IPV may require mandated reporting, researchers should educate themselves about what (not) to report, and be transparent with their participants about these regulations because participants may not be aware that such regulations exist (Fisher & Goodman, 2009; Yick, 2007).

Limitations

We did not explicitly ask about the impact of race on the research experiences of participants with HIV, yet some of our findings suggest potential relevance. For instance, distrust with formal procedures of research might point to a systemic issue—i.e., socio-historical conditions of the African American community in the US—rather than a technical one (Gamble, 1993). Indeed, while results did not explicate the influence of race on the experience of participants, the collective memory of the Tuskegee Study, and other ethical violations in medicine (Washington, 2006), could have led to concerns about autonomy and confidentiality, critically heightened due to disclosing sensitive personal information. In addition, Fontes (2004) underscored structural factors that might put participants who rely on third party aid such as the police, state organizations, or women's shelters, in a particularly vulnerable position. Additional empirical research is needed to understand further the effects of race, class and gender in participants' experience in HIV and IPV-related research.

Another limitation may be around the different wording of our open-ended questions on perceived benefits and risks of the research process. For instance, our open-ended question on research benefit ("What was the greatest benefit of participating in the WHS?") was framed in a way that may elicit broader ethical considerations among participants whereas the wording of our research risks question ("What was your greatest concern about answering questions in the WHS?") may have elicited ethical concerns specifically around the research questions. Thus, future research may benefit from asking open-ended responses that capture broader reactions to the research process or develop open-ended questions that tap into specific aspects of the research process such as recruitment, informed consent, or confidentiality concerns.

Educational Implications

African American women living with HIV and IPV remain relatively invisible in empirical studies on research ethics. Many of these women are subject to multiple forms of personal, economic, social, and institutional marginalization that requires a very specific research lens. The present study underscores the need for a more contextualized perspective in research ethics in order to understand connections between participants' identities and their research experience. This study also illuminates the value of a multi-method approach to address these gaps in the literature. Quantitative assessments of women's research experience yielded positive responses to the research experience. However, qualitative assessments of

perceived risks and benefits revealed more nuanced responses as it relates to ethical issues such as voluntariness, confidentiality, and research benefits. Thus, we echo previous calls to include open-ended questions alongside quantitative assessments of empirical research ethics (Wager, 2012). We hope that future studies in research ethics begin to recognize the importance of using both quantitative and qualitative approaches to yield valuable insight into best ethical practices in multiply marginalized populations.

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Table 1

Demographic Variables for HIV-positive African American Women Participating in the study (N = 87)

Demographic Variables	***N (%)***
Age mean (*SD*)	47.7 (9.21)
Education	
No high school diploma	12 (13.8)
High school graduate	17 (19.5)
Some college	31 (35.6)
Associate's degree or vocational graduate	20 (23)
Bachelor's degree/postgraduate	7 (8)
Married or with 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 under 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 Subscales of the RRPQ and Demographic Variables

Subscale	1	2	3	4	5	6	7	8	9	10
1. Attitudes Participation	-									
2. Personal Benefit	.52**	-								
3. Emotional Reactions	.02	.11	-							
4. Perceived Drawbacks	−.24*	−.26*	.43**	-						
5. Global Evaluation	.55**	.66**	−.06	−.33**	-					
6. Age	−.09	−.05	−.10	−.14	.08	-				
7. Education	−.09	−.10	−.20	−.11	.08	.18	-			
8. Children under 18	−.13	.06	−.10	−.20	.01	.52**	−.09	-		
9. Health Insurance	.08	−.01	.11	.03	.07	.03	.20	.06	-	
10. Employment	.04	.14	−.02	−.26*	−.12	.08	−.21*	.10	−.22*	-

Note. The employment, child under 18, and insurance variables were re-coded such that 0 represents participants who reported being employed, having children under 18, and having some type of insurance.

* p < .05:

** p < .001

Table 3

Subscales means and standard deviation, item-level percentages, example items from open-ended responses

Subscale	*Disagree (n)*	*Neither Agree nor Disagree (n)*	*Agree (n)*	
	M	***SD***	***N***	Qualitative Examples
Attitudes toward Participation	4.70	0.44	84	
I like the idea that I contributed to science.	-	1.1% (1)	96.6% (84)	
I was glad to be asked to participate in the Women's Health Study.	-	2.3% (2)	96.6% (84)	
I felt I could stop participating in the Women's Health Study at any time.	12.6% (11)	8% (7)	77% (67)	• It was very interesting • It was great • It was good, I enjoyed it
Participation in the Women's Health Study was a choice I freely made.	-	1.1% (1)	98.9% (86)	
	M	***SD***	***N***	
Personal benefits	4.77	0.40	83	
I gained insight about my experiences through research participation in the Women's Health Study.	-	3.4% (3)	95.4% (83)	
I gained something positive from participating in the Women's Health Study.	1.1% (1)	2.3% (2)	94.3% (82)	• I get to go Walmart with a gift card something I rarely get • Learning that I need help
I found participating in the Women's Health Study beneficial to me.	1.1% (1)	-	94.5% (83)	• Learning about different things and about myself so I can improve things I didn't know about
I found participating in the Women's Health Study personally meaningful.	2.3% (2)	1.1% (1)	95.4% (83)	
	M	***SD***	***N***	
Emotional reactions	3.44	1.07	83	
The research in the Women's Health Study raised emotional issues for me that I had not expected.	12.6% (11)	8% (7)	78.2% (68)	
I experienced intense emotions during the Women's Health Study.	23% (20)	16.1% (14)	58.6% (51)	• The abusive part • The abuse
I was emotional during the Women's Health Study.	42.5% (37)	14.9% (13)	40.2% (35)	• about the abuse
The Women's Health Study made me think about things I didn't want to think about.	26.4% (23)	18.4% (16)	52.9% (46)	
	Disagree (n)	*Neither Agree nor Disagree (n)*	*Agree (n)*	

	M	*SD*	*N*	Qualitative Examples
Perceived Drawbacks	1.80	0.83	80	
The Women's Health Study took too long.	64.4% (56)	14.9% (13)	16.1% (14)	
Participating in the Women's Health Study was inconvenient for me.	60.9% (53)	5.7% (5)	29.9% (26)	
I found participating in the Women's Health Study boring.	71.3% (62)	12.6% (11)	13.8% (12)	
I found the questions in the Women's Health Study too personal.	64.4% (56)	14.9% (13)	19.5% (17)	▪ the time, how long would it be ▪ The personal questions
Knowing what I know now, I would participate in the Women's Health Study again if given the opportunity. (reverse)	1.1% (1)	3.4% (3)	94.3% (82)	
Had I known in advance what participating in the Women's Health Study would be like, I still would have agreed to participate. (reverse)	-	4.6% (4)	94.3% (82)	
	M	***SD***	***N***	
Global Evaluation	4.77	0.41	80	
I think the research in the Women's Health Study is for a good cause.	4.6% (4)	3.4% (3)	90.8% (79)	
I believe the results from the Women's Health Study will be useful to others.	2.3% (2)	2.3% (2)	90.8% (79)	▪ Being able help someone else ▪ Would my answers be held against me ▪ Being able to know you have great people who support you and are willing to help you
I was treated with respect and dignity in the Women's Health Study.	4.6% (4)	1.1% (1)	89.7% (78)	
I trust that my replies from the Women's Health Study will be kept private.	3.4% (3)	8% (7)	87.4% (76)	
I understood the consent form.	-	1.1% (1)	96.6% (84)	