“NO RELATIONSHIP IS SAFE”:
IN-DEPTH INTERVIEWS WITH HIV-POSITIVE BLACK WOMEN

by
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A thesis submitted to Johns Hopkins University
in conformity with the requirements for the degree of Master of Arts

COMMUNICATION
Baltimore, MD
January 2012

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Abstract

Through in-depth interviews with 12 HIV-positive African American women, this study explored the perceptions of HIV/AIDS prevention messages from the perspective of those for whom prevention efforts failed. Findings indicate that current HIV/AIDS prevention messages are neither informative nor prevalent enough to adequately connect with at-risk black women. Further, a surprising one-half of the women in the study revealed that they had been infected through unprotected intercourse with men they believed were long-term, monogamous partners. Results also suggest that the female condom could be a popular, empowering tool for increasing safe sex in black women. Future HIV/AIDS prevention campaigns should seek to increase condom use among women in relationships and promote the convenience and pleasure associated with the female condom.

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Preface

Acknowledgments

The author is deeply grateful to Erika Falk, Ph.D., for her guidance and unwavering encouragement throughout the thesis process. The author also thanks her husband, Geoffrey, for his advice and support, especially during the data collection phase. Finally, the author thanks Maranda Ward, Ph.D. candidate, for offering program contacts at multiple clinics, and Jylana Sheats, Ph.D., for helping the author determine whether any existing studies had used a similar research design.
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“No Relationship Is Safe”: In-Depth Interviews with HIV-Positive Black Women

African American women are nearly 15 times more likely to become infected with HIV than white women; an estimated 1 in 32 black women will diagnosed with HIV/AIDS in her lifetime (Centers for Disease Control and Prevention [CDC], 2010). Young women are particularly at risk, with nearly one-half of all new HIV diagnoses occurring in individuals who are not yet 25 years old (World Health Organization, 2009).

With current infection rates of more than 3%, Washington, D.C. has the highest HIV/AIDS case rate in the United States (District of Columbia HIV/AIDS, Hepatitis, STD, and TB Administration [HAHSTA], 2010; District of Columbia Department of Health, HIV/AIDS Administration, 2007). Further, an astounding 91.1% of the women living with HIV/AIDS in D.C. are black; comparatively, 3.0% are white, and 3.3% are Hispanic (HAHSTA, 2010). The majority (58.7%) of HIV-positive black women in D.C. became infected through heterosexual contact; 25.1% were infected through injection drug use (HAHSTA, 2010). Through in-depth interviews with Washington, D.C.-area black women who have HIV or AIDS, this study will explore what information participants wish they had known about the disease prior to diagnosis, and ask them to critique 1) the HIV/AIDS-related messages they have encountered and 2) specific HIV prevention materials created by the District's HIV/AIDS, Hepatitis, STD, and TB Administration.

Rates remain high even though researchers have explored the unique psychology of HIV/AIDS prevention among black women for more than two decades (Fullilove, Fullilove, Haynes, & Gross, 1990; Schinke, Botvin, Orlandi, Schilling, & Gordon, 1990). Most of the research has focused on one of three areas: (1) African American women’s
relatively low perceived HIV risk, (2) the effect of tailoring HIV prevention messages specifically to black female culture, or (3) the factors influencing condom use in black women. Some research has suggested that a concept called “the sex-ratio imbalance” may make African American women more susceptible to HIV infection. The concept posits that since women outnumber men in the black community, women may have less power in their sexual relationships (Adimora, Schoenbach, & Martinson, 2001; Albrecht, Fossett, Cready, & Kiecolt, 1997).

However, most of the research related to prevention messages has used surveys or interventions with post-questionnaires to test efficacy; few studies provided African American women the open-ended chance to detail the types of HIV/AIDS prevention messages that would resonate with them. Further, none of the research found during an extensive literature review encouraged HIV-positive African American women to critique prevention messages.

Through in-depth interviews with HIV-positive African American women in Washington, D.C., this study examined what kinds of HIV/AIDS prevention messages resonated with black women in the city. In the context of this research, HIV/AIDS prevention messages refer to any posters, billboards, flyers, radio and television advertisements, or social outreach providing health education about how to prevent HIV transmission. Health education “promote[s] health and prevent[s] disease, disability and premature death through education-driven voluntary behavior change activities” (Coalition of National Health Education Organizations, 2000, p.1).
The study concept is predicated on the idea that black women who have the disease possess a unique perspective about what might be missing from current prevention messages. The interviews documented the women’s thoughts and perceptions of prevention messages they have encountered, ask them to critique HIV/AIDS education materials produced or distributed by the D.C. Department of Health, and explore what information might have caused them to change their behavior before diagnosis.

The results of this study provide health educators and communication professionals with rich, vivid insight into what types of campaigns and messages might inspire African American women to reduce risky behaviors. By asking women who have experienced an HIV diagnosis to reflect on what could have changed their behavior, the research had the potential to unearth myths, and expose holes in current HIV education materials, and help inspire HIV-negative women to take an active role in protecting themselves from the disease.
Literature Review

This literature review focuses on three findings that could be particularly beneficial for enhancing prevention messages. Studies have shown that African American women are less likely than women of other races to perceive that they are vulnerable to HIV infection, and that many black women feel disempowered when it comes to decisions about condom use. A series of experiments also found that cultural sensitivity increases the efficacy of HIV/AIDS messages targeted at black women.

Low Perceived Risk of HIV Infection

Although studies about racial differences in perceived vulnerability to HIV infection are limited, the existing research suggests that African American women are less likely than women of other races to think they are at risk of contracting HIV.

In a survey of adult women in Chicago, Kalichman, Hunter, and Kelley (1992) used a convenience sample of 272 women at three public-transit waiting areas (68% were African American; 26% were white). They asked participants to self-report sexual and drug-related histories and express their perceived risk of contracting HIV. The researchers found that the black women reported a lower sense of susceptibility to HIV infection than their white counterparts. Further, white women at high risk for contracting the disease were significantly more likely to perceive that risk than minority women who were also high risk.

Roberts and Kennedy’s (2006) study of female college students in southern California also supported this finding. They recruited a convenience sample of 100 women aged 18 to 24; 41 were white, 22 were black, and 30 were Hispanic. Participants
completed a pencil-and-paper questionnaire about their sexual and drug-related behavior, perceived risk of HIV infection, sexual assertiveness, and condom use. Researchers determined that white women had a significantly higher perceived risk of HIV infection than black women. Additionally, 24% of white women and 13% of Hispanic women surveyed rated their risk of HIV infection as “high,” compared with 0% of the African American women.

Finally, Nunn, Zaller, Cornwall, Mayer, Moore, Dickman, Beckwith, and Kwakwa’s (2011) study of men and women had similar results. Researchers surveyed 5,871 individuals at HIV testing centers throughout Philadelphia; 2,695 were black women, 153 were white women, 238 were Asian women, and 3 were women of other races. Analysis showed that having an ethnicity of white, Asian, or other was a significant positive predictor of perceived HIV risk across genders; being African American was not.

While further research is needed, the existing literature suggests that African American women have lower rates of perceived risk to HIV infection than other racial groups. This is particularly distressing since in reality, African American women have the highest risk for HIV infection of all women (Centers for Disease Control and Prevention, 2010).

**Cultural Relevance Increases Message Efficacy**

HIV prevention messages that are tailored to the culture of the target audience have generally proven more effective than messages created for the general public (Jemmott & Jones, 1993; Kalichman, 1996; Stevenson & Davis, 1994; Exner, Seal,
Ehrhardt, 1996). Resnicow, Soler, Braithwaite, Ahluwalia, and Butler (2000) define cultural sensitivity as “the extent to which ethnic/cultural characteristics, experiences, norms, values, behavioral patterns, and beliefs of a target population…are incorporated in the design, delivery, and evaluation of targeted health promotion materials” (p. 272). A number of studies have documented the importance of cultural sensitivity in prevention messages aimed specifically at black women.

Herek, Gillis, Glunt, Lewis, Welton and Capitianio (1998) explored the relationship between the culture of those presenting HIV/AIDS information and how well the audience responded to it. They recruited 174 African American adults (56% were female; the median age was 37) in Sacramento, who were randomly assigned to watch one of three videos at a local community center. Video 1 featured a white male speaker and a standard HIV prevention message; an African American male presented the same message in Video 2. In Video 3, the African American actor from Video 2 wore an Afrocentric necklace and hat and presented a message with more culturally specific language, using inclusive pronouns like “we” and “us” when discussing the black community. Participants completed a short survey immediately after watching the videos, rating Video 3 significantly higher than the other two for “technically quality” and “announcer attractiveness” (p. 724). Both of the videos with the black actor were deemed significantly more credible (in terms of content and speaker credibility) than Video 1.

In a study of low-income African American women in Chicago, Kalichman, Kelly, Hunter, Murphy, and Tyler (1993) also found that culture-specific HIV/AIDS information materials were more effective than materials created for the general population. Researchers recruited a convenience sample of 106 women (average age =
32.1) through a local community center, and participants watched one of three videos in randomized small groups. Video 1 featured standard HIV information with former Surgeon General C. Everett Koop and two other white speakers; Video 2 used an identical script with African American female speakers. Researchers created Video 3 using themes (including pride in black culture, concern for community, and dedication to familial duties) deemed important to black women during a 1988 focus group; the speakers in the third video were also African American women. At a follow-up meeting two weeks later, more than half (18 out of 33) of those who had seen the culturally tailored Video 3 reported that they had gone to get tested for HIV, compared to 0 of the women who viewed the other videos. However, women who had viewed either of the videos with black female speakers were significantly more likely to request free condoms than those who saw the generic video.

Wechsberg, Lam, Zule, and Bobashev’s (2004) study of inner-city black female crack abusers demonstrated how culturally tailored HIV interventions can be successful with high-risk groups. Researchers conducted initial focus groups with African American women to develop a culturally targeted message grounded in female empowerment. Next, researchers divided 620 black women into three groups: One group received the culturally tailored, woman-focused intervention; a second heard a general HIV prevention intervention developed by the National Institutes of Health; and a third control group received no intervention. At both three- and six-month follow-up visits, women who had seen the tailored video were less likely to have had unprotected sex than the other two groups.
The importance of tailoring HIV prevention messages to fit the themes and culture of the intended audience has been well documented in existing literature. This is an important insight into the efficacy of HIV prevention messages for African American women.

**Black Women Think Their Partners Control Condom Use**

While consistent condom use significantly reduces HIV risk (UNAIDS, 2009), emerging qualitative research shows that African American women may feel disempowered when it comes to decisions about having protected or unprotected sex. Several studies suggest that many black women think their partners are ultimately in charge of whether to use condoms.

Bowleg, Lucas, and Tschann’s (2004) study of gender dynamics in heterosexual relationships found that black women felt their partners controlled condom use. They conducted in-depth interviews with 14 lower- and middle-class African American women aged 22 to 39 in Washington, D.C. All women had one primary sexual partner for at least six months; two were HIV-positive. Through a thorough coding process, the researchers narrowed responses into themes, focusing on those noted by at least half of the women. Of the 12 women who expressed a desire to use condoms during their first sexual encounter with current partners, more than half (n=7) reported that their partners had ultimately controlled the decision.

Wingood and DiClemente (1998) had similar findings when studying the effects of gender roles on condom use among young heterosexual African American women. Researchers recruited 128 women aged 18 to 29 from a low-income community in San
Francisco for interviews about interaction with their sexual partners, sexual assertiveness, familiarity with condoms, and perceived power over condom use. Forty-five percent of the women had not used condoms in the previous three months; factors such as lacking sexual assertiveness, believing that asking a boyfriend to use a condom implied infidelity, or being in a long-term relationship had significant associations with not using condoms. Further, respondents with partners who opposed condoms were three times more likely not to use them.

These results echoed the findings of a previous focus group study of young African American women in San Francisco (Wingood, Hunter-Gamble, and DiClemente, 1993). Eighteen women between ages 18 and 25 participated in two groups of nine; African American female moderators asked whether participants felt in charge of their relationships, were willing to talk about sex with their partners, or were comfortable starting a dialogue about condoms. The vast majority (13 of 18) of participants were comfortable bringing up conversations about safe sex with their partners, especially those who had just begun sexual contact with a partner. However, despite the comfort with initiating general safe sex discussions, 90% of the women (n=16) thought their male partners had more control over condom use, and only four of the women said that they had successfully convinced their partners to use condoms. Many reported that issues of trust and the desire to avoid conflict kept them from challenging what they perceived as their partners’ ultimate power over condom use.

Currently, most of the research exploring the influence of gender roles on condom use is qualitative. While these themes would need randomized quantitative testing to be
generalizable to a larger population, the striking similarities in the qualitative research appear to be worth noting.

This literature review has summarized the research on factors affecting the efficacy of HIV/AIDS prevention messages aimed at black women. Black women are less likely to perceive that they are at risk of contracting HIV than white women, which could make them less likely to pay attention to prevention messages. Numerous studies have also documented the importance of using African American female speakers and culture-specific themes in prevention messages aimed at black women. Finally, emerging qualitative research suggests that black women consider their partners more in control of condom use, which has the potential to reduce behavior change; even if a black woman wants to use protection, she may not feel empowered enough to make it happen.

Despite the plethora of research on specific facets of HIV/AIDS prevention strategy for black women, few studies have taken a holistic, open-ended approach that allowed black women to share their thoughts and feelings about what might best reach them. And none of the prevention literature reviewed for this study mined the insights of black women who had already been infected with the disease. To fill these gaps, the current study asks:

RQ1a: What messages have HIV-positive African American women living within 15 miles of Washington, D.C. been exposed to (either before or after diagnosis)?

RQ1b: What do they think could make any messages they have seen more effective?
RQ1c: How do women react to samples of the current messages produced or distributed by the D.C. Department of Health?

RQ2: What do African American women living with HIV/AIDS know now that would have changed their behavior before diagnosis?
Method

This study invited African American women living with HIV/AIDS in Washington, D.C. to critique current prevention messages and offer insight into the types of messages that might have changed their behavior before diagnosis. Because the research questions involved sensitive topics including sexual activity and other personal behaviors, this study employed the in-depth interview method. One-on-one interviews offered both the sense of privacy and the face-to-face opportunity to build the rapport that were necessary for participants to feel comfortable discussing extremely personal topics with a researcher they just met (Rubin & Rubin, 2005). Interviews also allowed for rich and vivid answers (Rubin & Rubin, 2005). Since limited studies have focused on the efficacy of messages according to individuals who already had HIV/AIDS, it was important to allow as many of the participants’ own words to come through in the data as possible. Therefore, the researcher ruled out quantitative methods like surveying, which would not have provided as much detail about the participants’ feelings and perceptions (Daymon & Holloway, 2002).

Participant Recruitment

The researcher aimed to recruit 10-12 women at HIV/AIDS counseling centers or other mutually agreeable locations such as community centers, in Washington, D.C. Before the recruitment phase, the Johns Hopkins University Homewood Institutional Review Board (HIRB) reviewed the research protocol to ensure ethical treatment of participants. Staff at multiple Washington, D.C. area HIV/AIDS counseling centers helped arrange the interviews. Two centers reported that female clients were less likely
than males to come in for regular treatment. Additionally, concerns about stigma, transportation constraints, and health challenges made recruitment difficult.

The researcher contacted the counselors by telephone (see Appendix A) and then followed up via email (see Appendix B) to explain the study. Of the half dozen centers contacted, the Women’s Collective, Metro Teen AIDS, and the Blair Underwood Clinic of the AIDS Healthcare Foundation agreed to participate. Metro Teen AIDS dropped out of the study shortly after the recruitment phase began because their few HIV-positive clients had only recently received their diagnoses and were therefore not comfortable discussing their status.

After the HIRB provided approval for recruitment to begin, the researcher asked clinic staff to pass one of the recruitment flyers (Appendix C and D) on to any clients who might have been willing to participate. The flyer encouraged participants to contact the researcher via telephone or email if they chose to participate. The researcher did not have access to any contact information unless the potential respondents chose to reach out and provide it. When potential participants called, the researcher thanked them for their interest, explained study procedures designed to protect their anonymity, and arranged a time to meet. (See Appendix E.) All interviews occurred in person, and respondents received $25 for their participation.

For this study, participants had to be black women living with a positive diagnosis for either HIV or AIDS within 15 miles of Washington, D.C. Participants self-reported their race, and time since diagnosis was not a part of the selection process. The women also had to be between ages 25 and 44, age groups that were chosen because of inflated
HIV risk. AIDS-related conditions were the leading cause of death for black women aged 25-34 in 2007, and HIV is currently the third leading cause of death in black women aged 35-44 (U.S. Department of Health and Human Services [DHHS], 2007; CDC, 2011).

The study’s two exclusion criteria were that individuals could not have been infected with HIV/AIDS through a blood transfusion or when they were born. Focusing on individuals who contracted HIV/AIDS through an active behavior of their own volition made participants more likely to imagine what messages could have kept them from contracting the disease.

**Procedure**

The interviews took place between September 23, 2011, and December 1, 2011. Two of the interviews occurred in a private room at the AIDS Healthcare Foundation office, eight happened in a confidential room at the Women’s Collective, and two were in a closed room at a public library near the Women’s Collective. Each audio-recorded interview lasted for approximately 30 to 60 minutes. The study followed HIRB procedures designed to ensure anonymity of all participants and informed consent for all research.

The researcher began each interview by informing participants of the audio recording and that their responses would become data. Participants also received assurances that their names would not be associated with their responses, but their ages would be. Next, the researcher informed participants they could stop the conversation if ever they felt uncomfortable or unwell. Finally, the researcher informed the women that they did not have to answer any questions that made them feel uncomfortable. Participants provided verbal confirmation that they agreed with the study conditions.
before the interview began. Next, the researcher read an oral informed consent script (see Appendix I) to each participant and provided her with a copy of the research statement (see Appendix J). The interviews only began after the women read the research statement and verbally affirmed that they understood and choose to participate in the research.

An interview guide (see Appendix G) helped lead the discussion, using the tree and branch method. In this method, the interviewer keeps the discussion going by sticking to several specific main questions and then using follow-up questions to elicit vivid, detailed responses to more specific questions (Rubin & Rubin, 2005). The tree and branch method is more effective when studying how an interviewee relates to a specific subject rather than a general life history because the method relies on the interviewer’s ability to keep the conversation from veering too far off-course (Rubin & Rubin, 2005). Since an HIV/AIDS diagnosis is an all-consuming event, the tree and branch method helped participants focus on critiquing current HIV/AIDS messages rather than digressing into the general devastation of the disease.

For RQ1, participants answered questions about whether they remembered any specific messages that they encountered related to HIV/AIDS (on Metro ads, billboards, from education in schools, or other sources) and whether those messages resonated with them. The researcher asked if the messages they encountered had been clear, relatable, or sufficient, and then asked what, if anything, could have made the messages better. Finally, participants looked at three HIV prevention ads created or distributed by the D.C. Department of Health and discussed how those messages made them feel.

To answer RQ2, the researcher asked participants what information or messages they wish they had received about HIV/AIDS before diagnosis. From there, participants
answered questions about what they did know about the disease prior to diagnosis, what they have since learned, and what messages would have resonated enough to have changed their behavior prior to infection.

**Data Analysis**

Following each interview, the researcher transcribed the data into a complete text document and assigned each participant a pseudonym to help protect anonymity. Because of the confidentiality risk present in this study, only the researcher listened to the recordings. Further, because audio recordings are considered identifiable, all recordings were deleted from the audio recorder following careful transcription. The researcher reread each transcript multiple times, allowing several days to absorb the data before beginning to analyze it.

After studying the data as a whole, the researcher used highlighters to identify similar language and ideas that emerged and clarified those data blocks into themes. According to Rubin and Rubin (2005), themes are high-level concepts – and participants’ feelings about those concepts – that recur in qualitative data. This study further defined themes as concepts that came up in at least three interviews. Participants did not have to use identical language, but if their main ideas were the same, the idea became a theme. Responses received light editing for clarity and length as necessary, and particularly resonant excerpts from the data became evidence of each theme. The researcher organized the themes according to which of the two research questions they answered.
Results

A total of 12 women participated in this study, with ages ranging from 30 to 44. Among participants, education ranged from some high school to some graduate school, and annual income ranged from $8,000 to $36,000. Seven did not have regular access to the Internet, but all 12 had personal mobile phones. While there were no specific questions about how infection occurred, participants often introduced the topic while discussing what they wished they had known before diagnosis. Eleven of the women reported that they became infected through consensual heterosexual contact, and one did not raise the topic. The amount of time since participants learned their HIV status ranged from 1 year to 27 years. Below, data appears as it relates to each research question, with particularly illustrative quotations demonstrating each theme. Each participant received a pseudonym to protect her anonymity.

RQ1a: What Messages Have HIV-positive African American Women Living Within 15 Miles of Washington, D.C. Been Exposed To (Either Before or After Diagnosis)?

This research question aimed to test whether the HIV prevention materials that numerous government agencies and medical organizations produce have actually connected with the public. The messages participants reported seeing varied; however, a pattern related to the women’s opinions of the messages did emerge.

Current messages are not strong enough. All but one of the women reported having seen a prevention message at some point, with individual women mentioning the television-based “Wrap It Up” campaign, large ads on buses promoting the female condom and HIV testing, and “Get Tested” flyers in clinics.
However, four of the women said that what they encountered related to prevention did not make a strong impression. Dorothy, 40, who was diagnosed with HIV in 2005, had never heard of the disease until her mother contracted it in 2001:

I’m not gonna say [prevention efforts] weren’t out there because the message was out there. I just never heard of it. I probably was just thinking about one thing: Getting my drugs. I never noticed anything or I never looked around for anything because I wasn’t expecting it.

Karen, 44, had similar fears that prevention messages went unnoticed. “I don’t think ‘Get tested’ is enough. I see a lot of those signs… People don’t pay anything any attention anymore. The thought is gone just as quick as you glance at it.” Anna, 35, concurred: “You can read about it and forget about it and just keep living your life.”

While the vast majority of participants were indeed encountering prevention efforts, one-third of them thought the messages did not have an impact.

**RQ1b: What Do They Think Could Make Any Messages They Have Seen More Effective?**

**More messages are needed.** Five women said that additional prevention messages were necessary, suggesting both increased frequency and more diverse efforts. Individual women suggested family reunion-style gatherings in their neighborhoods to discuss HIV and condom use, church-based education efforts, and more ads on public buses.

Karen, 44, said that while prevention efforts had improved greatly since she was
first diagnosed in the 1990s, “Even now, it’s not as many as it should be I don’t think. I’ve seen some, but not very many.” Carrie, 44, said that prevention efforts needed to be more constant in order to reach the individuals at higher risk. “Everybody knows this virus is out here, but the people that’s druggin’ don’t give a damn… You just got to say it enough so that they understand.”

Anna, 35, expressed frustration that while she constantly heard about walks or fundraisers for other diseases, she only saw messages about HIV on World AIDS Day:

I don’t think there is enough message. It makes me mad. Because I wouldn’t want whatever happened to me to happen to someone who is still healthy now. I am sure there are people who are diagnosed every single day who would have been saved if there was a better message.

As this final quotation demonstrates, almost half of the women felt prevention messages were not prevalent enough, and many were quite frustrated by that realization.

**AIDS education should happen in schools.** The second theme under this question related to HIV education in schools. Five women argued that organized HIV prevention education should be mandated in the public school system, though there was some disagreement about what age was appropriate.

Charlene, 40, thought that education should start around age 12. “I made it my business to make sure my daughter took a sex ed class where you can learn about it. When we was in school, we had sex ed. [Now] they don’t -- it’s optional.” Karen, 44, suggested education during high school. She recalled that her 20-something son and his friends were unable to answer a basic question about HIV transmission. “These young people, they don’t know things. And they don’t have anyone to tell them, so they assume
things that are not right. They’re putting themselves at risk just because of a lack of knowledge.”

Dorothy, 40, suggested that HIV education happen as early as elementary school. “They start having sex in the fifth and fourth grade… There are some parents who don’t want them to know that. But your child is learning about sex, why not want them to learn about prevention of HIV?”

The women who suggested teaching HIV prevention in schools were adamant that the education system should be more involved because of its authority and ubiquity. Overall, responses related to RQ1a and RQ1b suggested a need for more attention, more information, and more open discussion about HIV.

RQ1c: How Do the Women React to Samples of Current Messages Produced or Distributed by the D.C. Department of Health?

For this research question, women reviewed samples of three print advertisements (see Appendix H) created or distributed by the D.C. Department of Health. Participants then articulated what they found effective about the message and what could be improved. Themes related to each message are below.

Reactions to Ad #1. The first ad, which featured an African American man and woman hugging with the tagline “Get Wrapped Up in the Moment,” received mixed reviews. Some women had positive reactions; however, those who did not like this ad felt very strongly.
The image is relatable. Charlene, 40, thought the image depicted a realistic situation. “It’s kinda like when you being in the moment, and you be like, ‘Baby you got a condom?’ So I mean, that’s pretty good – let’s get wrapped up.” Carrie, 44, concurred: “There you go! You know the guys get in the heat of the moment. You get to kissing and all that. Well, put the condom on first. Put the condom on, then do your thing.” Dorothy, 40, also related to the ad. “Us grown-ups, we will [understand]. I like it the way it is. It’s simple, it’s noticeable, and it’s understandable.”

The text needs improvement. Gladys, 42, thought the tagline did not fit the image: “Get wrapped up for what? To hug? That don’t say they’re going to have sex just because they’re hugging.” Karen, 44, suggested adding “You could save your own life” under the tagline. “This is not a good catch phrase. It’s boring. But if you’re talking about someone’s life, then they’re probably going to read it a little faster.”

Isabelle, 44, had the strongest reaction, saying she was “disgusted” by the image and did not understand the text in the middle of the ad. “What was the revolution? And nobody says ‘rubber’ anymore. That is ‘60s stuff.” Isabelle was also frustrated that there was not a dedicated phone number in the call to action at the bottom of the page. “There is an implicit assumption that is so angering to me, that everybody has computers… I’m struggling for bus fare.”

Reactions to Ad #2. The second ad, which featured the tagline “DC’s Doin’ It” in a purple circle with “the Female Condom” written at the bottom, was overwhelmingly unpopular. All of the women supported the idea of promoting the female condom, but most expressed disappointment in the design and message of the ad.
The text is confusing. Four participants did not understand the connection between the tagline and the female condom. Karen, 44, said: “DC is doin’ what? What is DC doing? It doesn’t tell you anything.” Kim, 43, also expressed confusion. “I don’t like it. What are they doing? I mean, DC’s doin’ what? It’s not enough information for me.” Charlene, 40, worried that students would construe the tagline as pressure to become sexually active. “I don’t get that one. Something’s missing. I wouldn’t want my daughter to walk past it. [She’ll think] ‘D.C.’s doin’ it -- I wanna do it too.’” Isabelle, 44, mentioned more specific improvements for the language:

The two messages don’t connect. You have no clue what they’re talking about. [It needs] something that implies that DC is in trouble, and you individually and for your community can help by using the female condom. The message should be more targeted to that.

The ad should be more visual. Eight of the participants suggested adding a picture, either of the condom itself, the packaging, or a woman holding one. “This is not telling you much of nothing,” said Carrie, 44, adding that there is more than one brand of female condom. “It doesn’t have a picture to show you what is it talking about. Which female condom? Can you show me? Can you tell me? We don’t know.” Kim, 43, also requested an image. “Show me some graphics. Show me something just so I can have a concept of what they might be talking about.” Anna, 35, felt similarly: “Most people don’t even know there is a female condom. Maybe there need to be some pictures of something.” Karen, 44, even suggested creating an ad for television. “They advertise the male condom on television and everything else, all sorts of body lotions and KY’s, so why not this?”
Reactions to Ad #3. The third ad’s simple yellow “Ask for the Test” message was a clear favorite. All but two of the participants said they liked the overall feel, and three of the participants’ faces noticeably brightened when they saw it.

The ad is catchy. Charlene, 40, thought the bright colors would grab attention. “It’s colorful. That’s eye-catching.” Dorothy, 40, praised both the color and large font. “You can’t say you didn’t see it because it’s bright yellow and has the big bold letters.” Regina, 42, said the word “test” caught her eye. “That word right there [points to ‘test’]. Because you wanna know what the test is for. You always want to get tested for something -- see if you got it.” Carrie, 44, thought it was so appealing that stickers of the ad would be an effective way to reach students. “When they come in school, ‘Here, stick this on your book bag, stick this on your notebook, your locker. Share it with others.’”

The text needs more detail. While most of the women liked the overall look and feel of this ad, many had suggestions of how to make it more precise. “I like this one but with more detail,” said Kim, 43. “You wanna know: Where do I go? Who do I talk to? Is it confidential?” Anna, 35, suggested pointing out that the test was free because “somebody might say ‘I don’t have money. I don’t have insurance. I can’t pay for it.’” Gladys, 42, said the ad should point out that current tests use oral swabs instead of drawing blood because “a lot of people are scared, thinking [there are] needles for the test.” Similarly, Veronica, 30, encouraged telling people that the tests are “painless and take five minutes.”
For RQ1c, participants tended to request more graphics and responded well to bright colors. In many cases, they also asked for additional clarity, including details about cost, location, and time.

**RQ2: What Do African American Women Living with HIV/AIDS Know Now that Would Changed Their Behavior Before Diagnosis?**

There were four themes related to the kinds of information women said would have inspired them to change any risky behaviors prior to diagnosis. Many respondents reported being unaware of the risks associated with their behaviors, especially those who had been in long-term relationships with the same person. However, some women were aware of the risks but still chose the behaviors, either because they thought infection was unlikely, preferred not to use condoms, or were uncomfortable bringing up a discussion about safe sex. A list of themes is below, along with particularly resonant quotations to demonstrate each topic.

**I thought it couldn’t happen to me.** Ten participants reported once feeling as though they were not susceptible to HIV/AIDS. When asked what they knew about the disease before diagnosis, women said they used to believe that only homosexual men (n=5), IV drug users (n=3), and sex workers (n=1) were at risk. Two women reported thinking that their partners were disease-free because they did not look sick. “I wish I would’ve known that not every man is clean,” said Dorothy, 40. “They can look clean, but they could still have an infection and you won’t know about it.” Several women claimed that if they had realized they were at risk for HIV, they would have altered their behaviors.
Anna, 35, thought that HIV infections were unheard of in “normal people like me, who to go school, come home, have a boyfriend… If I knew that everybody who walks around could have HIV, I would have required every single boyfriend, the very few I had, to be tested.” Julie, 38, said that even though she was aware of HIV, she did not think it could touch her. “I did know about it, but you think in your mind, ‘Oh, I’m not gonna get that.’ And you don’t know ‘til you get it that somebody sitting right beside you [had it].” Finally, Regina, 42, said:

People think they can’t catch nothing. They invincible. I thought the same thing, but look where I’m at. I used to be one of them. I said I would never catch it. But look at me: [I] got it.

A striking majority (n=10) of participants expressed an erstwhile sense of invulnerability to HIV infection. This included some women who had been engaged in high-risk behavior.

I thought monogamy meant safety. Half of the women contracted HIV while in long-term relationships. Anna, 35, said that most women do not use condoms with their boyfriends. “If you go out with a guy or a girl for a year, the first few months, you use protection. And then, with time you feel more confident not to.” Anna wished she had known that being with one partner still put her at risk. “You are [faithful], but you are not the other person. You don’t have his schedule 24 hours a day. And people, you trust them and they let you down sometimes.”

Kim, 43, who had just begun working in the HIV field when she was diagnosed, contracted the disease from a 17-year relationship. “I knew he had cheated, but it was just
like ‘We’ve been together for too long.’ You just turn a blind eye to the facts.” Wanda, 44, also thought she was safe because she was in a three-year relationship. “Being with someone like him and trust and love, that’s your only mate that you be with. You never think it might happen to you.” Charlene was similarly surprised to contract the disease from her boyfriend of four years. “He was a homebody. At least that’s what I thought. He was always caring, he did this for me, did that for me… No relationship is safe.”

Women in long-term relationships reported extremely low perceived susceptibility to HIV, often citing factors including trust and love.

**It’s hard to talk about condoms.** Half of the women said they were reluctant to bring up safe sex before diagnosis, often because they feared protestations from their partners. Veronica, 30, expressed that she continues to have trouble introducing the topic even today. “It’s hard to bring up a conversation about safe sex. It really is. Because it’s still hard for me, and I’m HIV positive.” Regina, 42, agreed that condoms can be a touchy subject:

A lot of people, about the condoms, they say they break, they ain’t no good. Men say they’re allergic to it. Some of ‘em say ‘Oh, they ain’t gonna fit me.’ … With some people, they think you cussing ‘em out if you mention a condom. They get offended.

Three women said that the conversation is especially difficult for people who are in monogamous relationships because asking about condoms implies infidelity. “There’s a trust already established,” said Anna, 35. “The other person could say ‘Okay, don’t you trust me anymore? Do you think I’m cheating on you?’” Charlene, 40, stressed that
another challenge for couples in long-term relationships is a desire not to ruin the romantic mood:

If you’re in a monogamous relationship, you’re not gonna want to be putting on no condom every day, all day… We love each other. So to be romantic and everything, the lights are out and then all of a sudden you got to [say] “Hey, wait a minute – you got the condom?”

Half of the women, especially those in long-term relationships, found it difficult to broach the topic of safe sex, which led to almost nonexistent condom use pre-diagnosis.

**I wish I’d known about the female condom.** Virtually none of the women reported using condoms regularly before diagnosis, and this was something that many women regretted. Six of the women reported having used the “FC2” female condom. Five of those six enthusiastically praised the FC2, for reasons including convenience, empowerment, pleasure, and privacy. Isabelle, 44, wished she had known about the female condom before diagnosis because it would have helped her avoid debating about condom use with her partners:

The female condom now is *supremely* empowering… Because if a partner doesn’t want to wear a condom, I don’t have to get into the debate of [him saying] ‘I don’t like to wear one. It doesn’t feel good.’ I’m empowered to protect myself.

Veronica, 30, did not use protection because of an unpleasant experience with male condoms. “I had one pop on me, and it kinda scared me,” she said. For her, the FC2 female condom makes safe sex enjoyable. “One of my male partners prefers for me to use
it… He said he likes the way it feels; he likes the texture of it.” Carrie, 44, who did not use protection before diagnosis, is also a strong advocate of the female condom. “I use ‘em all the time,” she said. “When my husband wants intercourse, he even says, ‘Let me help you put it on.’ We’re very into it.” Wanda, 44, concurs: “They’re good -- so much easier [than the male condom]. You can put it on hours before. Go out to a club, come back home, you’re straight.” She added that she definitely would have used the female condom before diagnosis if she had known about it. “Girl, if I had known, maybe I’d be sitting on the other side.”

Many participants cited positive experiences with the female condom, and participants often seemed excited to have found a prophylactic that they liked.

Much of the data related to RQ2 had to do with women’s pre-diagnosis mindsets that HIV prevention was difficult, unnecessary, or both. Factors including low perceived risk, negative attitudes toward condoms, and the perceived safety of monogamy contributed to these mindsets.
Discussion

Though the current literature did not appear to contain any studies that invited black women living with HIV to critique prevention messages, this study suggests that HIV-positive black women are an extremely advantageous resource for improving communication related to HIV/AIDS prevention. Four key findings emerged from the interviews. First, almost all of the women reported thinking that the disease was something that happened to other people. Second, half of the interviewees contracted the disease while in monogamous relationships. Third, all but one of the women who had used female condoms fervently endorsed them. Finally, many women felt current prevention messages lacked crucial information and pointed out specific ways for health communicators to improve them.

Feeling of Not Being at Risk

All but two of the women thought that they were not at risk for HIV/AIDS before diagnosis. This result correlated with several studies that found African American women tended to underestimate their HIV risk (Kalichman, Hunter, & Kelly, 1992; Roberts & Kennedy, 2006; Nunn, Zaller, Cornwall, Mayer, Moore, Dickman, Beckwith, & Kwakwa, 2011). In the current study, even women who were at clearly elevated risk did not perceive the danger. For example, two women who had been sex workers and one woman who had multiple concurrent sex partners at the time of diagnosis reported feeling that they were not at risk. This finding was similar to Kalichman et al.’s (1992) discovery that black women at high risk were less concerned about HIV infection when compared to white women at high risk.
While almost all of the women in the current research reported feelings of low susceptibility, the reasons for those feeling varied. One woman believed that HIV only happened to sex workers. Another, who was diagnosed in the mid-1980s, thought the disease only affected people in Africa. Almost half of the women believed that HIV only happened to gay men, and one-fourth thought they were safe because they were not IV-drug users. These last two findings echoed a study in which more than one-third of minority women believed AIDS was transmitted only through drug use or anal intercourse (Kalichman et al., 1992).

Interestingly, women in their 30s were just as likely to place credence in the homosexual stereotype as women in their 40s, suggesting that generational differences did not mitigate this belief. For example, Anna, 35, added that the images she saw in popular culture – such as the 1993 movie *Philadelphia*, in which a white gay lawyer contracts the disease – added to her conviction that HIV was virtually nonexistent in the heterosexual community.

In addition to general beliefs about the lifestyles that made people likely to contract the disease, many of the women also formed opinions about the people they encountered at an individual level. For example, some women said the people they encountered did not look “sick,” implying a belief that there would be visual cues if someone had the disease. Others reported that their friends, neighbors, families, and partners never talked about HIV/AIDS, which made it seem as though HIV was not affecting their communities. Similarly, Kalichman et al. (1992) found that black women were 20% less likely than white women to have had a conversation about AIDS in the previous month.
Future health campaigns might benefit from showing statistics indicating how black women are at a higher risk for HIV infection than women of any other race. Communicators might also create short, visual stories featuring relatable black women living with HIV. Demonstrating to black women that the epidemic is affecting people who remind them of themselves could help be extremely effective.

**The Myth of Monogamy**

The second key finding shows that women who are in monogamous relationships are still at risk for HIV infection. It is particularly noteworthy that half of the participants became infected during what they believed were exclusive relationships. Of these six women, all were faithful to their long-term partners, including one woman who was with the same individual for 17 years.

This finding is especially concerning since international HIV prevention campaigns have stressed sexual monogamy as a way to protect oneself from the disease. For example, according to the CDC’s National Prevention Information Network (2011), one of the most reliable ways to avoid HIV infection is to “be in a long-term, mutually monogamous relationship with an uninfected partner.” The National Institute of Allergy and Infectious Diseases (2009), which is a part of the National Institutes of Health that oversees $1.36 billion in funding for HIV/AIDS research, advises “remain[ing] faithful to your spouse or partner” to reduce HIV risk.

One particularly worrisome result was that all of the monogamous women reported not using condoms in their relationships. Many referred to a level of trust that reduced their fear of contracting any sexually transmitted diseases and made them more comfortable not using condoms. This echoes findings of Bowleg, Lucas, and Tschann
(2004), in which partners tended to end condom usage after reaching a level of trust. As with the current study, the intensity and scope of this trust depended on the relationship.

This implied trust also made it difficult for the women in the current study to initiate discussions of condom use with their long-term partners. Previous research has also shown that women with regular sexual partners endured increased resistance to condom use (Nunn et al., 2011). Perhaps most strikingly, one-fourth of the women reported that bringing up safe sex to their boyfriends was a divisive conversation, tantamount to either accusing the boyfriend of infidelity or admitting to cheating themselves. Similarly, Wingood and DiClemente (1998) found that monogamous women who thought requesting a condom implied infidelity were drastically less likely to use condoms.

Feelings of love were also strongly associated with assumed invulnerability to HIV in the current study. Several women described the thoughtful, kind gestures their boyfriends made during their relationships; some grew visibly upset while recounting how betrayed they felt by their partners. Women repeatedly said that they loved their boyfriends and that stopping heated encounters to find a condom would ruin the romance of their relationships. Perceived emotional intimacy has proven to be a negative predictor of condom use in other studies (Wingood & DiClemente, 1998; Bowleg et al., 2004).

One final trend was that five of the six women did not know that their boyfriends had been unfaithful before diagnosis. The fact that almost all of these women believed they were in “mutually monogamous” relationships is particularly troubling. This study demonstrates that women who follow current prevention guidelines by remaining faithful to their partners are still at risk. In fact, the suggestion that non-condom use is normative
in monogamous relationships might mean that these women are at greater risk than their single counterparts. This finding suggests that the emphasis on monogamy as a way to reduce HIV risk in current NIH and CDC guidelines is misleading and incomplete.

Future campaigns should aggressively and unequivocally target women who are in long-term relationships, explaining that they are still at risk and providing tips for bringing up safe sex with their partners.

**Strong Endorsement of Female Condoms**

One intriguing finding was the degree of enthusiasm many women felt about the female condom, especially considering that all of the women in the sample did not consistently use condoms before diagnosis. It is particularly noteworthy that of the six women who had used the FC2 female condom, five gave eager endorsements of the product. The other woman reported difficulty putting the female condom on due to flexibility issues, though she mentioned hearing “rave reviews” from friends who used it.

In the current study, the female condom appeared to address many of the frustrations black women expressed about condom use in the current literature. For example, the FC2 female condom, which the FDA approved in 2009, can be inserted into the vagina up to two hours in advance, staying in place until intercourse (Female Health Company, 2009). Some women appreciated the convenience of early insertion, expressing particular relief in not having to interrupt heated encounters to use protection. This benefit directly addressed findings in previous literature that the vast majority of black women think condoms affect the romantic mood (Roberts & Kennedy, 2006).

Women in the current research also reported that the FC2 made them feel empowered. Whereas traditional condoms require the male partner to agree to put one on,
women felt that they were able to protect themselves without needing to convince their partners to do anything differently. Some women felt a shift in power that made it easier to practice safe sex. These feelings offer a possible solution to several studies that suggested black women felt disempowered about condom use (Bowleg, Lucas, & Tschann, 2004; Wingood & DiClemente, 1998; Wingood, Hunter-Gamble, & DiClemente, 1993). Further, two women specifically noted that the female condom allowed them to avoid arguments over condom use because they could make the decision on their own. This addressed findings that a desire to avoid conflict prevented many black women from challenging what they perceived as their partners’ ultimate control over condom use (Wingood, Hunter-Gamble, & DiClemente; Roberts & Kennedy, 2006).

Finally, women in the current study expressed that intercourse with the FC2, which is lubricated and made from a material that warms to body temperature, was pleasurable for both themselves and their partners (Female Health Company, 2009). One woman’s report that her partner requests the female condom because he takes pleasure in the texture was a striking example of mutual enjoyment. Promoting the pleasurable effects of the female condom has the potential to change people’s minds about safe sex. For example, Roberts and Kenendy (2006) found that almost half of women believed condoms reduced their personal pleasure, while two-thirds believed it reduced their partners’ pleasure.

The striking enthusiasm with which women endorsed the FC2 suggests promising potential for the female condom as an alternative to the male condom. Promoting the pleasurable, empowering properties of the female condom could be a powerful way to encourage black women to increase their condom use.
**Importance of Precise Messages**

While much of the existing literature stressed the importance of cultural tailoring for effective messages, the women in the current study often stressed a need for precision as well. This finding offered valuable insight into crafting useful health communication.

Several previous studies found that black women respond better to HIV/AIDS prevention messages that are tailored to their culture (Herek, Gillis, Glunt, Lewis, Welton, & Capitanio, 1998; Kalichman, Kelly, Hunter, Murphy, & Tyler, 1993; Wechsberg, Lam, Zule, & Bobashev, 2004; DiClemente, Wingood, Harrington, Lang, Davies, Hook, Oh, Crosby, Hertzberg, Gordon, Hardin, Parker & Robillard, 2004). Thus, in the cases where human beings appeared in sample health messages, the researcher used ads that featured African Americans. However, findings from this study suggest that cultural familiarity is not the only important factor to consider when crafting messages for black women. Precision, catchiness, and clarity also proved important to study participants.

When reviewing the sample advertisements created or distributed by the D.C. Department of Health, comments often criticized the text for being clever rather than substantive. For example, the “DC’s Doin’ It” tagline of the second ad used a phrase that was culturally familiar to the women, but participants felt that it was inappropriate and confusing. Women suggested more detailed information about where to go for testing or to learn about condom use. They requested phone numbers and physical addresses in addition to websites because more than half of them never used the Internet. Participants also wanted pictures to help them visualize foreign concepts (such as the female condom) and increase the likelihood that an ad would catch their attention.
Future campaigns should be as clear and complete as possible. Readers should know how long a test will take, exactly where they should go to request services, what a new product such as a female condom looks like. Communicators should provide a phone number that readers can call for more information, rather than only providing a website address. Many women pointed to a cloud of confusion surrounding HIV infection. Prevention messages should help alleviate this confusion with clear, direct information, rather than contributing to the current perplexity with imprecise language.

Limitations

Although the interview method is an excellent way to probe sensitive topics in detail, its results do not provide insights that can be generalized to the general public (Rubin & Rubin, 2005). As with all qualitative methods, which do not use systematic, large-scale sampling, interviews produce data that is only representative of the participants in the study. Therefore, researchers should not assume that similar thoughts and feelings would apply to the greater population (Dayman & Holloway, 2002).

Some important limitations were specific to this study. The interviews were anonymous in order to reduce the risk of participants’ HIV status being unintentionally disclosed to individuals who were unaffiliated with the study. However, because the research could contain no record of participant names, the researcher could not independently verify participant ages (by requesting to see a driver’s license, for example) or obtain written informed consent. In many cases, clinic staff members were able to confirm that interested women fit the age criteria before recommending them for an interview, but in other cases, women who saw the recruitment flyer contacted the researcher directly.
Variance in the amount of time since diagnosis was also a limitation of the current study. It had been 20 years or more since some of the women discovered that they were HIV-positive. Because so much time had passed since some participants were diagnosed, there was a potential for response bias due to women’s limited ability to clearly recall distant events. Further, due to changes in both lifestyle trends and general public knowledge of HIV, women who were recently diagnosed might have had very different prevention recommendations than women who contracted the disease in the 1980s or 1990s.

**Implications for Future Research**

This study appears to be the first to ever use the insights of black women with HIV to help improve HIV/AIDS prevention messages. The revelation that half of the women in the sample had been infected with HIV through unprotected intercourse with men they thought were long-term monogamous partners is especially significant because it calls into question an extremely common prevention recommendation. Further, none of the women in long-term relationships reported using condoms in the current study, and many considered condom use verboten in monogamous relationships. Future research should explore condom use habits of black women aged 25-34 in monogamous relationships, and test what types of messages effectively increase condom use among this group.

Women in relationships were also extremely likely to consider themselves invulnerable to HIV. Future prevention campaigns should aim to increase HIV risk awareness in women with one partner. Campaigns should feature the experiences of
monogamous women who contracted the disease and provide sample language and scenarios for women to model when broaching the topic of safe sex with their partners.

Additional research should use also use a generalizable quantitative method such as surveying to test relationship history of a larger sample of HIV-positive black women. While the D.C. Department of Health’s HIV surveillance system notes basic information about cause of infection, the categories are currently limited to men who have sex with men, heterosexual contact, IV-drug use, unknown, and other (HAHSTA, 2010). Additional qualitative research might also explore perceptions of the FC2 female condom in African American women who are HIV-negative, in order to see if their experiences are as encouraging.
Appendix A

Initial Phone Call to Program Staff

Voicemail script if they did not answer:
My name is Carolyn Perry, and I am a graduate student at Johns Hopkins University. I am planning a research study about health messages related to HIV/AIDS prevention for my thesis. For the research study, I would hope to speak with some of the women at the clinic. I wanted to get in touch preliminarily to see how this could work and discuss with you how I would go about ensuring that all responses remain anonymous. My phone number is 202-271-7245, and I will send you an email with more information. Thank you for considering my request.

Conversation script if they did answer:
My name is Carolyn Perry, and I am a graduate student at Johns Hopkins University. I am planning a research study about health messages related to HIV/AIDS prevention for my thesis. For the research study, I would hope to speak with some of the women at the clinic. I wanted to get in touch preliminarily to see how this could work and discuss with you how I would go about ensuring that all responses remain anonymous. Are you the correct person I should discuss this with?

[If no, and they aren’t sure who I should speak to]
I will send you an email with more information – would you be able to discuss it with the appropriate person or people at the center? My phone number is 202-271-7245, and I thank you very for considering my request.

[If yes]
Once the recruitment phase began, would someone at the clinic be able to provide adults who fit the criteria with my recruitment flyer? That way, potential participants could decide to get in touch with me if they were interested. I will send you an email with more information, but do you have any questions about me or about the research study in the meantime? My phone number is 202-271-7245, and I thank you very for considering my request.
Appendix B

Initial Email to Program Staff

Good morning:

My name is Carolyn Perry, and I am a graduate student at Johns Hopkins University. I am planning a research study about health messages related to HIV/AIDS prevention for my thesis. For the research study, I would hope to speak with some of the women at the clinic. I wanted to get in touch preliminarily to see how this could work and discuss with you how I would go about ensuring that all responses remain anonymous.

I would be speaking with Washington, D.C. women aged 18 or older who are living with HIV/AIDS and were not infected when they were born or through a blood transfusion. Each audio-recorded interview would last approximately 30-60 minutes, and I would hope to conduct them in-person at the clinic. If conducting them at the clinic is not possible, could you suggest any community centers or other locations nearby?

The Homewood Institutional Review Board at Johns Hopkins would approve the process, and all responses would remain anonymous. Once the recruitment phase began, would someone at the clinic be able to provide adults who fit the criteria with my recruitment flyer? That way, potential participants could decide to get in touch with me if they were interested. (I would not have their names or contact information unless they chose to contact me and provide it.)

Please let me know if I can provide any additional information, and thank you for considering my request.

Best,

Carolyn Perry
202-271-7245
cperry16@jhu.edu
Appendices C and D

Recruitment Flyer 1

If you are a black woman living with HIV/AIDS and:
- You are between ages 25–44
- You live within 15 miles of D.C.
- You did not contract HIV/AIDS when you were born or through a blood transfusion

We would like your opinion on how to inspire other black women to protect themselves.

If you join our research, we won’t use your name, and you will get $25 for your time.

For more information, contact Carolyn at 202-271-7245 or cperry16@jhu.edu

One out of every 36 black women in D.C. has HIV/AIDS.
We need your help.

Recruitment Flyer 2

If you are a black woman living with HIV/AIDS and:
- You are between ages 25–44
- You live within 15 miles of D.C.
- You did not contract HIV/AIDS when you were born or through a blood transfusion

We’d like your opinion about how to inspire other black women to protect themselves. If you join our research, we won’t use your name, and you will get $25 for your time.

For more information, contact Carolyn at 202-271-7245 or cperry16@jhu.edu

One out of every 36 black women in D.C. has HIV/AIDS.
We need your help.

Both flyers will include the following note on the back: Photos on this flyer contain stock images of women who are not associated with flyer content.
Phone Conversation with Potential Participants

Hello. Thank you very much for getting in contact with me. I am conducting anonymous research interviews related to the HIV/AIDS information that is currently provided in Washington, D.C. I am researching whether that information is helpful to black women or not. Are you an African American female? What is your age? Would you be able to speak with me in person for about 45 minutes?

[If yes, then continue.]

I can meet with you at the _____ center on ______. Would XX time work? The conversation will be recorded, but the research is anonymous, so I will not record your name. At the end of the interview, you will receive $25 for your time. What is the best way for me to get in contact with you? Thank you again for agreeing to meet with me, and look forward to seeing you soon.

[If no.]

That is absolutely fine. Thank you for calling, and please let me know if you change your mind.
Appendix G

Interview Guide

*Start by giving an introduction:*

Thank you very much for taking this time to speak with me. I’d like to remind you that your age and your responses will be used as data for this research study, but I will not record your name so that your responses remain anonymous. I hope that you are feeling well today. If it any time you start to feel unwell, please let me know, and we can end the interview for today and either continue talking later or leave it there. Also, please keep in mind that you do not have to answer any questions that make you feel uncomfortable. Just let me know if you feel uneasy, and we can move on to another question. Are you comfortable with these conditions? [Wait for verbal affirmation.]

I am asking these questions to get a sense of what types of information you knew about HIV and AIDS before you were diagnosed, what information you wish you had known, and how you feel about the messages you’ve encountered related to HIV/AIDS prevention. The idea is that your responses might help us get better information about HIV/AIDS to the people in your community.

1. To begin, could you tell me what you wish you had known about HIV/AIDS before you were diagnosed?

2. What knowledge do you have now that would have changed your behavior if you had known it before you were diagnosed?

3. What did you know about HIV/AIDS before you were diagnosed?

4. What messages or information about HIV/AIDS did you hear before your diagnosis?

5. Where did these messages come from? Friends/family/TV/magazines/ billboards?

6. Can you remember one particular message related to HIV/AIDS that you read or saw on a billboard, TV, Metro ad, etc.? How did you feel about it? Did you like it? Why/why not? How would you improve it? What did it do right or wrong?

7. In the messages you’ve seen about HIV/AIDS, what is not clear? What was not forceful enough? What does or doesn't connect?

8. What do you think is the best way for the people you know to learn about HIV/AIDS?

9. If you were going to warn people in your community about not contracting HIV/AIDS, what one thing would you tell them? How would you encourage them to change their behavior?

10. Now I’d show you some examples of the information that is out there right now. These were made by the D.C. agency that studies HIV/AIDS in the district. [Show first image.] How does this make you feel? What is good about it? What is not good about it? What could make it better? [Repeat for second and third images.]
11. Where do you get your health information? Billboards, Metro ads, cell phone texts, bus ads, newspapers? Friends, family, church? Facebook, Twitter? How often do you use the Internet? What are some of your favorite sites?

12. I have just a few questions left. What is your age? What is your highest level of education? And what is your weekly income?
Appendix H

Samples of HIV/AIDS prevention messages created or supported by the District’s HIV/AIDS, Hepatitis, STD, and TB Administration.

Ad #1
Ad #2

DC’s Doin’ It!
The Female Condom

Ad #3

ASK FOR THE TEST
HIV Testing
Appendix I

Oral Consent Script

I have provided you with a research statement that talks about the research study. Please take a moment to read through it. Do you have any questions about the research study?

<If yes, answer the questions>

<If no, continue>

You should be aware that there is a confidentiality risk present in this study, primarily that your HIV status could be disclosed to individuals not involved with this study. Disclosure of your HIV status could cause negative consequences for you, including loss of health insurance, loss of employment, or other types of discrimination that cannot be foreseen at this time. In order to minimize this risk, I will not record your name in any way. I will use an audio recorder to tape our conversation, but your responses will remain anonymous. You should not say your name once you are being recorded. I will report your age and the fact that you live within 15 miles of Washington, D.C., but your name will not be associated with anything you say. After I transcribe the interview, I will erase the tape of our conversation.

Your participation in this research study is entirely voluntary: You choose whether to participate. If you decide not to participate, there are no penalties, and you will not lose any benefits to which you would otherwise be entitled.

If you choose to participate in the research study, you can stop your participation at any time, without any penalty or loss of benefits. If you want to withdraw from the research study, please say so at any time during the research interview.

If you decide to withdraw after the interview is over, you can call or email me to let me know.

Do you understand the information I have just explained?

<If yes, continue>

Are you between the ages of 25-44?

<If no.>

I am sorry, but you must be between 25-44 to participate. Thank you for your interest.

<If yes, continue>

Do you agree to participate in this research study?

<If no.>

That is absolutely fine. Thank you for your time, and please give me a call if you change your mind.

<If yes, begin interview.>
Appendix J

Research Statement (for participants to read before providing oral consent)

Johns Hopkins University
Research Statement

Title: Perceptions of HIV Prevention Messages: Interviews with HIV-Positive African American Women

Principal Investigator: Erika Falk, Ph.D.

Date: 9/16/2011

PURPOSE OF RESEARCH STUDY:
The purpose of this research study is to examine what kinds of HIV/AIDS prevention messages might resonate with HIV+ African American women in Washington, D.C.

Approximately 10-12 people will join this research study.

PROCEDURES:
You will be asked a series of questions about what you wish you had known about HIV/AIDS before diagnosis, and will be invited to give your opinions about current HIV/AIDS prevention messages in D.C. You will be interviewed one time in-person; the interview will last between 30 and 60 minutes.

RISKS/DISCOMFORTS:
Since this research study delves into a sensitive topic, thinking about HIV/AIDS prevention might you or make you feel anxious. There is also a confidentiality risk present by participating in this study, primarily that your HIV status could be disclosed to individuals not involved with this study. Disclosure of your HIV status could cause negative consequences for you, including loss of health insurance, loss of employment, or other types of discrimination that cannot be foreseen at this time. In order to minimize this risk, I will not record your name in any way and you should not say your name once you are being recorded. I will use an audio recorder to tape our conversation, but your responses will remain anonymous. I will report your age and the fact that you live within 15 miles of Washington, D.C., but your name will not be associated with anything you say. After I transcribe the interview, I will erase the tape of our conversation.
BENEFITS:
Providing this insight could make you feel empowered that you can help prevent someone else from contracting HIV/AIDS. The research can also help health educators and communication professionals create more effective HIV/AIDS prevention messages based on your feedback.

VOLUNTARY PARTICIPATION AND RIGHT TO WITHDRAW:
Your participation in this research study is entirely voluntary: You choose whether to participate. If you decide not to participate, there are no penalties.

If you choose to participate in the research study, you can stop your participation at any time, without any penalty. If you want to withdraw from the research study, please say so at any time during the research interview.

CIRCUMSTANCES THAT COULD LEAD US TO END YOUR PARTICIPATION:
Under certain circumstances we may decide to end your participation before you have completed the research study. Specifically, we may stop your participation if we learn that you contracted HIV when you were born or through a blood transfusion, that you are not between the ages of 25 and 44, or that you are not fluent in English. There may also be other circumstances that would lead us to end your participation.

ANONYMITY:
There will be no records of your name, but I will document your age. I will audio-record the interviews. After the interviews, I will transcribe the data myself, assigning each participant a code name. I will then erase the audio recording of the interview. I will lock the printed transcripts in a safe in my home and will password-protect the digital version of the transcript file.

COMPENSATION:
If you satisfactorily complete the research study, you will receive $25.00 to compensate you for your participation. If you end your participation before completing the interview for the research study, you will be paid $10 for your participation up to that time. Payments are made in cash at the end of the research study.

IF YOU HAVE QUESTIONS OR CONCERNS:
You can ask questions about this research study now or at any time during the research study, by talking to the researcher(s) working with you or by calling Carolyn Perry at (202) 271-7245.

If you have questions about your rights as a research participant or feel that you have not been treated fairly, please call the Homewood Institutional Review Board at Johns Hopkins University at (410) 516-6580.
References


Roberts, S. T. & Kennedy, B. L. (2006). Why are young college women not using condoms? Their perceived risk, drug use, and developmental vulnerability may provide important clues to sexual risk. *Archives of Psychiatric Nursing* (20)1, 32-40.


preventive intervention. *AIDS Education & Prevention, 2*, 305-312.


Curriculum Vitae

Born in Nashville, Tenn., Carolyn Elizabeth Perry received a bachelor of arts in philosophy and writing from Spelman College in Altanta, Ga. After graduation, she worked as a national writer and reporter before branching into health communication consulting and government service. She has created campaigns targeting groups ranging from low-literacy black women in rural areas to widowed military spouses. While studying in the communication program at Johns Hopkins University, she focused on persuasion, planning and evaluation of health communication campaigns, and inspiring behavior change through communication. She lives in Alexandria, Va., with her husband, Geoffrey.