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# Formative Study to Develop the Eban Treatment and Comparison Interventions for Couples

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#### **Abstract**

**Objective**—To describe formative and pilot-testing research that generated themes and procedures, curricula, and critical measures for a randomized clinical trial testing a Risk Reduction Intervention for HIV-serodiscordant African American couples (Project Eban).

**Design**—This paper describes the themes that emerged from discussions with African American serodiscordant couples about HIV-related risks from focus groups with 11 couples and pilot study results with 32 couples across four sites.

**Methods**—In Step 1, focus groups examined the need for a Risk Reduction Intervention for HIV-serodiscordant African American couples and confirmed four themes that formed the basis for the intervention curriculum and study format. In Step 2, a pilot study refined the clinical trial procedures for this population and tested critical measures and selected portions of the curriculum for both the treatment and comparison interventions.

**Results**—Based on these findings, stigma and psychological distress, barriers to condom use, insufficient support from community and service organizations, and the lack of skills that emphasize individual and relationship protection were ultimately integrated into the Risk Reduction Intervention.

**Conclusion**—Pilot study findings highlighted the importance of examining gender and ethnicity in HIV- impacted couples along with factors that heightened HIV-related risk behaviors that affect couples' skills and psychological adjustment. The goal was to ensure that a skill-based, culturally congruent, relationship-centered intervention could be understood and of interest to couples. Future analyses in the main trial will be discussed.

#### **Keywords**

Focus groups; Behavioral intervention; African American couples; HIV; sexual behavior; culturally congruent

#### Introduction

HIV-serodiscordant couples, where one partner is HIV-positive and one is HIV-negative, face many challenges. Along with the uncertainty of HIV and its progression and concerns about planning for the future, they struggle to reduce HIV risks in their ongoing sexual relationship. 1<sup>-3</sup> Very few HIV-related services are currently available for heterosexual HIV-serodiscordant couples, and frequently, these couples do not have the skills to address many of the sexual and other challenges that they face. Living with HIV/AIDS is associated with increased likelihood

of engaging in unprotected sex, and as a consequence, risk for transmission of HIV and other STIs to the uninfected partner is significantly increased. The quality of the relationship also impacts couples' emotional adjustment to HIV4 and their safer sex behaviors. As a consequence, couples may avoid HIV-related discussions with each other, and with potentially supportive persons (e.g. service agency personnel), as well. A 2 · 6

Developing an intervention that would facilitate HIV-related risk reduction among African American HIV-serodiscordant couples requires identification of relationship-specific factors that these couples face. All of the Trial principal investigators have conducted clinical trail research, with experience ranging from couples interventions<sup>7,</sup> 8, HIV-positive and negative women9, and health promotion and risk reduction with adolescents10. However, since there were no published studies of interventions targeted at this population, a decision was made as a first step to conduct a series of focus groups with sub-samples of HIV-serodiscordant African American couples. Based on the extant literature<sup>11</sup> and previous research by the Trial investigators, four broad themes were used to organize focus group questions and structured interviews: 1) stigma and distress associated with HIV; 2) barriers to condom use; 3) insufficient support from family and HIV community services; and 4) the lack of skills to achieve both individual and relationship protection. In the following sections we review what we learned about these themes.

## Stigma and Distress Associated with HIV

Men and women are stigmatized because of their HIV-positive serostatus or because they are in relationships with HIV-positive partners. HIV-related stigma<sup>12</sup> often makes disclosure difficult<sup>1</sup>, resulting in social isolation from other non-affected couples. <sup>22</sup> Couples are sometimes rejected by one or both of their families and are often each other's main <sup>13</sup>or only source of emotional support. <sup>14</sup> Stigma can also contribute to the reluctance to seek other forms of support and treatment. HIV-negative partners may face criticism and pressure from family and friends to leave their HIV-positive partner. <sup>6</sup> While problems with depression, safer sex intentions, overall well-being and minimal social support <sup>13</sup> have also been reported by HIV-positive women and men individually, the psychological well-being of both partners in a serodiscordant relationship can be affected by their mixed status.

#### Barriers to condom use

Research suggests that desire for sexual and emotional intimacy may reduce fear of transmitting the virus 15 and may lead each partner to deny risks, rationalize behaviors, and ignore guidelines for maintaining long-term safer sex practices. 6 Studies indicate that even when partners are HIV serodiscordant and aware of the risks, couples use condoms inconsistently. 3 Indeed, rates of unprotected intercourse tend to be higher among regular partners regardless of their serostatus. 16 Studies have also demonstrated that perceptions of a partner's risk behaviors may be inaccurate, depending on the risk behavior of the couple. 17 Poor agreement has also been noted between women's perceptions of their partner's report of ever having had sex with a man. 18 Therefore, couples need assistance in enhancing self-protection skills that do not compromise the quality of their relationship.

In one study, 52 male partners of HIV-positive women estimated their risk of becoming HIV infected as low even though they were having unprotected sex with their HIV-positive partner. 
<sup>11</sup> Male partners also reportedly had fatalistic attitudes about the likelihood of HIV transmission because of commitments to their HIV-positive partners, which may have increased their failure to use condoms. 
<sup>19</sup> These behaviors and attitudes about condom use in couples' perceptions of risk and consequences of unprotected sex need to be examined. Cultural and religious proscriptions on condom use also create additional gender and relationship issues 
<sup>20</sup> by further

complicating couples' acceptance of HIV prevention messages. Interventions for HIV-serodiscordant couples are needed to address these barriers.<sup>3</sup>

## Minimal response from community and service organizations

Regardless of HIV status, very few evidenced-based programs that can be offered to couples include strategies to increase their communication. Most HIV risk-reduction research has focused on individual-level interventions. Relationship-based decision-making and risk-taking practices require dyadic level preventive interventions in order to ensure behavior change of both partners.

## **HIV** interventions for couples

The few studies that have tested the efficacy of couple-based HIV risk-reduction interventions suggest that couples' counseling is effective in promoting condom use and reducing the risk of sexual HIV transmission among HIV-serodiscordant, heterosexual couples. <sup>16, 21</sup> However, there are few published pilot studies that detail the process of using focus group findings to develop curriculum objectives.

This paper describes a two-step process for developing the research design for a multisite serodiscordant couple's intervention (Project Eban). The word "Eban" originates from the Akan people in Ghana, West Africa and means "fence," which represents an African concept symbolizing safety, security, and love in one's family and community. Project Eban is the first couples-based, controlled, and randomized clinical trial for African American HIVserodiscordant couples. The study was conducted by the NIMH Multisite HIV/STD Prevention Trial for African American Couples Study Group and sponsored by the National Institutes of Mental Health. The clinical trial uses a modified randomized block design to evaluate the efficacy of two behavioral interventions in reducing the number of unprotected sex acts and STI incidences in a large representative sample of HIV mixed-status couples. There are eight sessions in both conditions - the Eban Risk Reduction Program and the Health Promotion comparison condition. The Eban Risk Reduction condition included sessions on: 1) Preparing for the journey; 2) Enhancing couple communication; 3) Tools for the journey; 4) Sharing the load; 5) It takes a village; 6) Strengthening the village; 7) Expanding the village; and 8) Celebrating our relationships. The Eban Health Promotion condition included the following sessions: 1) Black/African American health issues; 2) Prevention: Exercise and nutrition; 3) Prevention, Early Detection and Screening; 4) Communication with your partner; 5) Exercise and nutrition; 6) Prevention and screening; 7) Medical adherence; and 8) Review and wrap up. (See Methodological Overview of an African American Couple-Based HIV/STD Prevention Trial for a complete description of the interventions.) All four sites (UCLA/Charles R. Drew University, Columbia University, Emory University, and the University of Pennsylvania) utilized the concept through the development of the couple's intervention for the Project Eban main trial.

In Step 1, focus groups examined the need for a Risk Reduction Intervention for HIV-serodiscordant African American couples and confirmed the four themes. They provided qualitative data to inform the curriculum and procedures for the study. In Step 2, a pilot study tested and refined the clinical trial procedures as well as critical measures for couples, and selected portions of the curriculum that reflected the focus group themes. Pilot study analyses also examined gender, ethnic, and HIV-related issues affecting the skills needed and psychological adjustment of serodiscordant couples. The goal was to ensure that a skill-based, culturally congruent, relationship-specific intervention could be understood and be of interest to couples.

# **Method of Focus Groups**

The Ecological Model of a couple-based risk reduction program guided the focus groups' discussion of stigma and psychological distress, barriers to condom use, minimal response from service organizations, and the lack of skills needed for self-protection within a relationship.<sup>11</sup>

After IRB consent was obtained, two sets of focus groups were conducted for 11 African American HIV-serodiscordant couples with the same discussion format (eight couples at Columbia and three couples at UCLA/Drew). The findings from both sites were collapsed to generate the overall themes that were discussed. The Columbia site recruited eight couples from primary health care settings and included eight HIV-positive women and eight HIV-negative men. The UCLA/Drew site recruited three couples through newspaper advertisement and from local community-based agencies and included one HIV-positive woman and two HIV-positive men. Couples were screened and selected if they self-identified as: heterosexual, African American, over the age of 18, were in the relationship for more than 90 days, and one partner had to self-identify as HIV-positive and the other as HIV-negative. The HIV status of each participant was confirmed using OraSure specimen tests, which requires no blood only an oral specimen. Both partners had to know each other's status.

Both Columbia and UCLA/Drew teams conducted the focus groups at a local agency that provided services for HIV-positive persons and was easily accessible. Each site included: (1) a focus group for female partners moderated by an African American female facilitator; (2) a focus group for male partners moderated by an African American male facilitator; and (3) a focus group including men and women, co-moderated by a male and female facilitators. Across sites, each focus group ranged from four to five individuals or couples per group. Based on investigator-driven research and existing literature, four themes were identified in the focus group transcripts (see Chin & Kroesen<sup>22</sup> for a similar methodology for focus group theme identification). While the themes were investigator-driven, they were broad areas. The focus group discussions assisted in further refining the specific areas of discussion used in the pilot study.

Trained facilitators asked interview-guided questions about: 1) societal stigma experienced by HIV-serodiscordant couples in contrast to cultural values and beliefs about living with an incurable disease and caring for an HIV-infected partner; 2) barriers to couple's communication about sex, condom use, and HIV status disclosure; 3) fears about isolation and rejection by one's partner or family; and 4) coping strategies for serodiscordant couples. The responses to themes on an individual, interpersonal or societal level were used to confirm or to select measures and curriculum content for the pilot study and main trial (See Table I).

#### Data management

Audiotapes were transcribed verbatim and reviewed by the facilitators for accuracy and completeness.

#### **Qualitative Analyses**

The aim of these analyses was to identify common themes related to safer sex and HIV infection issues as they pertained to the impact of HIV/AIDS on relationships. Responses from both sites were translated and reviewed for content. Four reviewers used the constant-comparison method to read the transcripts, code phenomena, and apply the codes to other similar phenomena in the text. The line-by-line coding was based on the principles of inductive reasoning in Grounded Theory analysis.<sup>22</sup>

# **Results of Focus Groups**

Overall, focus group findings suggested that HIV-serodiscorant couples were reluctant to discuss difficult issues they encountered because they did not want to appear fearful of being infected by a loved one or were unsure about being rejected by their partner because of their concerns. Thus, one of the strategies in the Risk Reduction format used games and group exercises to minimize pressure on one partner to discuss sensitive topics. For example, societal stigma was discussed using a "fishbowl" technique where regardless of gender; three to five negative partners formed an inner circle with the HIV-positive partners surrounding them in a larger circle. In the exercise and with the facilitator's guidance, the negative partners shared concerns about the stigma they encountered as a result of being with an infected partner and how they coped. HIV-positive partners were asked to listen and discuss what they heard. Then the positive partners formed the inner circle and discussed concerns about being with a negative partner, with the negative partners listening in the outer circle. This format provided support to partners as they discussed concerns, and modeled that these issues were not unique to one relationship and required group discussion. In another example, couples were asked to identify cultural values about protecting each other regardless of serostatus in contrast to traditional messages of self-protection with little regard for the consequences to relationships. In sum, the discussion, homework, session exercises, and weekly cultural themes promoted relationship maintenance, communication and self-protection as essential to HIV/STD transmission prevention.

# Themes Emerging from Focus Groups

Four refined major themes emerged in the focus groups, including: (1) stigma and distress related to living with HIV; (2) barriers to consistent condom use; (3) minimal response from community and service organizations; and (4) the need for skills to increase protection and to enhance the strengths of the couple.

# (1). Stigma and Psychological Distress Associated with HIV

Participants in the focus groups discussed negative reactions and stigma they experienced from others as a result of their HIV status or being with an HIV-positive partner. One HIV-positive partner noted, "Your body is tainted. It is like you are a leper or something." Along with the stigma of being HIV-positive comes the fear of being rejected by others:

"It is like she has the virus (hushed tone), oh, he has the virus, you've got to stay away from him? And it hurts; I mean you just can't come forward and tell anybody. Because if you do, you cut your own throat."

The stigma associated with being HIV-positive or involved in a relationship with a positive partner also makes it difficult to seek out similarly affected couples for social support. One HIV-positive woman stated:

"I probably don't even know it but there are probably a lot of African American couples out there who are living with HIV but they are afraid to let anyone else know... And that is because of the stereotypes."

#### (2). Barriers to Consistent Condom Use

Condom use discussions yielded some contradictory findings. Focus group participants identified fear of infecting the negative partner and associated feelings of guilt as a central theme. Beyond concerns related to HIV transmission, HIV-positive partners did not want to burden their partner with other HIV-related matters. One HIV-positive man expressed these concerns by stating:

"I know that she is there for me but... I still don't want to infect her. That weighs on my shoulders and on my mind... I would cause pain to some person... my conscience still hurts from that... I don't want to have her live her life with something that I caused."

Despite feelings of guilt related to maintaining the HIV-negative partners' serostatus, these couples also openly discussed engaging in unprotected sex. Some expressed fatalistic views related to eventual HIV transmission, while others accepted the risks inherent in engaging in unprotected sex. According to one HIV-positive woman partner:

"He prefers to have sex without a condom. He doesn't care. He says, 'If I get it, I get it. You are the best thing that happened to me so why should I worry about it?"

Maintaining a satisfying sexual relationship was difficult for many couples, and they avoided conversations related to HIV and safer sex. Talking about condoms served as a reminder of one's HIV status and threw a "wrench into the festivities." One HIV-positive man stated:

"You want to have all these good thoughts about how good your baby looks and all this... but every once in awhile you get that thought, 'I am about to make her sick.' So... it throws a wrench in there. That will make you go straight cold. ... there you got your girl sitting there? ... when you start thinking like that you are all upset and you don't feel like a man no more."

# (3). Minimal Support from Community and Service Organizations

Couples in the focus groups expressed feelings of isolation and a lack of support from others aside from their partner. They often noted that they did not know of other couples like them. Couples also expressed lack of traditional social support from family. One HIV- negative woman stated:

"I can't tell my family, you know. They ask why he is always in the hospital and what is wrong with him. ...but I can't tell them... I feel that they are going to say, 'We don't want to come to your house no more.' ...For me I always thought that the support comes first from your family. But it doesn't.... So they don't know about him. They just know that I have been with him for 7 years and he has been in and out of the hospital and all."

Couples also noted the scarcity of programs for couples in the community. One HIV-negative partner described not only a lack of services for HIV-serodiscordant couples, but also a lack of support for negative partners in AIDS Service Organizations in particular:

"There are not a lot of couples' stuff around anywhere and I have looked. The HIV organizations always told me that... he is the person, he is the client. He is the one that has got to receive services. ... I have been looking for couples' services for two years."

Other HIV-positive participants described being reluctant to seek help at AIDS Service Organizations due to fears of being perceived as gay and not wanting people to know their "business." This fear may be particularly high for African American men because of the greater stigma of being gay in the African American community.<sup>23</sup> One HIV-positive male participant stated:

"We have an ego. Like we talked in our group, HIV might be something we don't have to disclose or we don't want to. It is really hard for us men to say it. As men we get these questions we don't need. I don't like questions. I get offended by them about how did you contract HIV. They ask, 'Are you gay?'... You know, because I have a wife, I have a problem with being asked about my sexual orientation. Normally a straight person doesn't want to hear that."

# (4). The Need for Skills to Protect Themselves and Enhance Strengths of the Couples

Couples demonstrated a great deal of love and commitment to each other, and a willingness to persevere together. For example, one HIV-negative participant stated:

"I said, I'm here for life. ... I wanted her before she told me and I wanted her after she told me about her HIV."

Partners' support for each other and their spiritual beliefs were sources of strength. In focus group discussions, couples were excited about the intervention and eager to meet and support other couples. According to one HIV-positive man:

"I wanted help for me and my girl, that is why I am here. I am trying to find out more but we need to have more groups. All I can say is try to get to as many groups as possible."

These themes were integrated into curriculum materials for the intervention, and examined in the pilot study data.

# **Pilot Study**

#### **Research Design and Questions**

Consistent with the conceptualization of the main trial (see Methodological Overview of an African American Couple-Based HIV/STD Prevention Trial), the purpose of the pilot study was to conduct all aspects of the randomized trial, facilitator and staff training, recruiting and couple screening, baseline and post-testing for STDs and behaviors, randomization to the 2 eight-week conditions—the Eban Risk Reduction and Health Promotion Interventions. Of particular concern to the investigators was the question: Does the integration of the four themes into the Risk Reduction Intervention ensure that the cultural, gender, relationship and HIV skills training form the content of the sessions?

# **Methods for Pilot Study**

#### Sample and Selection

Investigators at each of the four sites utilized various recruitment strategies including HIV/STD clinic referrals, newspaper ads, and community advisory boards (CAB) referrals, to identify eligible couples. A total of 64 participants (32 couples) completed baseline assessments, and 52 (26 couples) were randomized into intervention groups. At Columbia University, 11 couples completed baseline and nine couples were randomized. At Emory University, six couples completed baseline and all six were randomized. Six couples completed baseline at UCLA/Drew and four were randomized. At the University of Pennsylvania, nine couples completed baseline and seven couples were randomized. Randomization occurred when at least three couples could make it to the first session of the 8-week intervention, which is when the intervention officially began. To ensure that as many couples that wanted to attend were included, the facilitators waited for 15 minutes after the start time to begin the session. No couples were added after the intervention formally began. Only those couples that were able to attend the first session at randomization were included in the pilot study. There were 12 individuals (six couples) of the 64 baselined participants that could not attend randomization due to transportation, scheduling conflicts, health, or relationship issues.

Relationships in which the woman partners were positive were twice as common in the sample (n=20). African American couples were defined as those in which at least one person self-identified as African American. Two couples were interracial: in one couple, one partner was African American and the other Latina, and in the other couple, one partner was African American and the other European American. The average age of participants was 42 years old.

On average, participants had been in the relationship for 7.25 years. Eighty-two percent of participants were living with their study partner, 44% had children in the home, and 48% were unemployed. Participants varied in educational background. Forty percent had no high school education, 27% had a high school or GED, and 33% had a college or graduate degree.

#### **Intervention Content**

While the pilot study curriculum was similar to that of the main trial, analyses of data pertaining to the four themes are presented here.

## **Evaluation Methods**

Although the main trial included assessments at baseline, immediate post-test, 6- and 12-months, the pilot included only baseline and post-test assessments, so that information gained could immediately be utilized to refine the main trial procedures. Couples were randomly assigned to the Eban HIV/STD Risk Reduction Intervention or to the Eban Health Promotion Intervention for the pilot. Two trained facilitators conducted the pilot groups with the curriculum and materials designed for the main trial.<sup>24</sup> After completing the baseline questionnaire, participants received their random assignment to one arm of the trial and subsequently completed post-intervention measures. Participants were debriefed and asked to comment on the clarity and interest of selected portions of the curriculum offered in the pilot content. This information was used to modify the intervention and assessment protocols.

# Measures Analyzed for Pilot Study

The measures were read to participants in the pilot trial using paper and pencil questionnaires to ensure that they were clearly worded and understood, conveyed the strengths of individuals and couples within a cultural context, and allowed for variance in responses from men and women. In some cases, some measures had not been used in couples-based studies or with African Americans in research. In addition, the more sensitive information was administered on laptops using the ACASI program, which was designed to increase respondents' willingness to provide frank responses regarding these questions<sup>25</sup>(see Designing an Audio Computer Assisted Self Interview (ACASI) System in a Multisite Trial: A Brief Report for detailed description of the ACASI). For the purposes of the pilot study, a subset of the measures was analyzed to determine their utility for the couples. The rationale for each measure is provided.

#### **Demographics characteristics**

included age, education, employment, length of relationship, gender of the seropositive partner, cohabitation/marital status, and ethnicity.

# Measures Piloted for a Couples Study

# Sexual behavior

Participants were asked to report the number of episodes of vaginal and anal sexual intercourse with their study partner in the past 90 days, and how many of these times was a condom used. These questions were piloted to determine consistency of responses between partners.

#### Depression

was assessed by participant ratings of symptoms over the past week using the brief version of The Center for Epidemiological Studies Depression Scale.<sup>26</sup> This scale contains eight items rated on a 0 (less than 1 day) to 3 (5–7 days) scale, with a score of 7 or above indicative of depression. While this scale has been used with predominantly African American women and

has high internal consistency (alpha =.81), the pilot data helped to confirm its validity with African American men.

#### Trauma symptoms

The PTSD Checklist - Civilian Version (PCL-C)  $^{27}$  included 17 items rated on a five-point Likert scale for degree of trauma for each symptom in the last month (1 = not at all, 3 = moderately, 5 = extremely). The inclusion of this measure in the pilot helped to examine patterns of trauma within couples, which has yet to receive adequate attention within a relationship context.

## History of physical abuse

was assessed with two items from the Revised Conflict Tactics Scale (CTS2),<sup>28</sup> one combining five items representing different types of minor physical assault (e.g., pushing, slapping, grabbing) and the other combining seven items representing different types of severe physical assault (e.g., punching, beating, choking, using a knife or gun) by an intimate partner (Cronbach's alpha = .86 for both types). The CTS and CTS2 have been used in many studies with diverse populations including African Americans,28 but few studies have included these modified items in a couples study.

# Measures Piloted for Clarity with a Sample Ranging in Literacy

## **Commitment to African American community**

was assessed with six items measuring participants' commitment to and identification with the African American community (e.g., "I am committed to enhancing the health and well-being of African Americans"). Items were rated on a five-point Likert scale ranging from strongly disagree (1) to strongly agree (5). These items were included in the pilot to ensure that the items are clearly worded.

## Social support

Satisfaction with social support was assessed by asking participants to rate how satisfied they were with the social support they receive (from their partner, friends, family or others) and relationship satisfaction. Participants' satisfaction with their relationship with their study partner was assessed with seven items rated on a five-point Likert scale<sup>29</sup> (e.g., "How well does your study partner meet your needs?") These measures were included in the pilot to ensure clarity of wording.

# **Measures Adapted for the Main Trial**

#### **Quality of life**

(QOL) was assessed through the "Ladder of Life" scale .30 This scale provided a global rating of life satisfaction.1 Participants also rated their overall quality of life on a five-point scale from Excellent (1) to Poor (5). The use of the ladder was of interest in a sample ranging in literacy to determine their ease in using this method of scaling.

#### **Health status**

HIV-positive participants provided self-reported CD4 counts, viral load, and the length of time they had known their HIV status. Studies of self-reported HIV measures have described their validity<sup>31</sup> and use of these measures was confirmed in the pilot.

#### History of sexual abuse

was assessed using a subset of the Wyatt Sex History Questionnaire.<sup>20</sup> Which has nine screening questions and 14 descriptive items to assess the circumstances of each event. A brief version was used containing seven of the original nine screening questions and six of the original 14 descriptive questions for child sexual abuse (CSA) to assess the severity of incidents for each participant. This measure required adaptation from the original format and was piloted to ensure the desired data could be obtained for individuals and couples.

#### History of substance abuse

The frequency and amount of alcohol use in the past 3 months and age of first use was assessed with the CAGE<sup>32</sup> (see Methodological Overview of an African American Couple-Based HIV/STD Prevention Trial). This measure had four Yes/No questions. A positive response on two or more items qualified as positive for alcohol dependence and has been used with HIV-positive African American women (alpha = .77). The TCUDS II assessed drug dependence.33 This measure included 15 items in Yes/No format. Scores ranged from 0 to 9, and a score of 3 or higher was indicative of drug dependence based on DSM and NIMH Diagnostic Interview Schedule criteria. Given the use of the CAGE as a screening measure for more in-depth questions, these items were selected for the pilot.

In using self-report measures, there are two psychometric properties that are important: (1) reliability - which indicates that the results are consistent and not random, and (2) validity - which indicates that the investigator and the respondent understand the meaning of the question in the same way. Findings from the cited studies indicate that there is a fair to good concordance for whether the instruments chosen would yield appropriate results. Face-to-face validity supported that participants understood the questions being asked.

# **Results of Pilot Study**

#### (1). Stigma and Psychological Distress Associated with HIV

Histories of child sexual abuse were common in this sample (see Table 2). Both partners reported histories of child sexual abuse (CSA) in four couples (13 percent). Sixteen couples (53 percent) had one partner with a CSA history: 13 in which only the woman partner had CSA (43 percent) and three in which only the man partner had CSA (10 percent). Ten couples (33 percent) reported no CSA histories. Women were more likely to report CSA (57 percent) than men (23 percent). Among participants with CSA histories, women reported a greater number of CSA incidents than men, M's = 1.61 and 1.10, respectively. As shown in Table 3, CSA was more common among HIV-positive participants, but only for women (65 percent of HIV-positive women reported CSA compared with 40 percent of HIV-negative women).

Histories of intimate partner violence were common among both the women and men in the overall sample, with 65 percent of participants (68 percent of women and 63 percent of men) reporting ever having experienced intimate partner violence (IPV). As shown in Table 3, HIV-negative women were more likely to report a history of intimate partner violence than positive women. However, HIV-negative and HIV-positive men were equally likely to report IPV. When physical abuse was subdivided into less severe (pushing, slapping, grabbing) and severe incidents (punching, beating, choking, using a knife or gun), results indicated that a greater percentage of women than men reported histories of severe physical abuse (60 percent versus 37 percent). A greater percentage of men than women reported histories of less severe physical abuse (26 percent versus 11 percent). Both partners reported histories of intimate partner violence in seven of 41 couples (17 percent).

Analyses examined patterns of differences in measures of emotional adjustment by gender and HIV status. As depicted in Table 3, HIV-positive women and HIV-negative men scored higher on measures of distress and lower on measures of resilience than HIV-negative women and HIV-positive men. For example, among HIV-positive participants, women had higher scores on depression than men; however, among HIV-negative participants, men had higher depression scores than women. Positive women and negative men reported more trauma symptoms, a lower quality of life, and less commitment to the health of the African American community than positive men and negative women.

Among seven couples, 24 percent met the criteria for depression, two couples met the criteria for PTSD, three met the criteria for drug dependence, and six reported alcohol dependence. Thirty-two individuals or 50 percent of pilot couples drank alcohol in the past month, five drank daily, and six used drugs in the past month.

Integration into the Curriculum—The exercise of teaching couples how to listen to each other and to communicate regularly (the "Talk and Listen" technique) encouraged partners to share and listen to each other's perspectives. They practiced methods of communicating about difficult issues such as condom use and being HIV-positive. The Risk Reduction Intervention also included exercises to examine the ways couples make decisions in their relationship, safer sex practices, and how past experiences and gender roles influenced their choices. The intervention helped couples identify triggers that could lead to unsafe sex, including emotions, and substance use. Cognitive strategies to address past experiences in relationships or histories of child sexual abuse that could influence sexual decision-making and communication between partners were also discussed. This exercise included skill building and role-playing and was designed to help women and men recognize the impact of past experiences, regain mastery, and increase self-protection (condom use).

# (2). Barriers to Consistent Condom Use

Baseline data indicated that condoms were sporadically used in the pilot study population. Couples reported an average of 42 episodes of sexual intercourse in the past 90 days, of which 43 percent were protected using either a man or woman condom. Participants' reports of the frequency of sex and condom use with their study partner were often inconsistent. Reports of proportions of condom-protected sex were lowest for HIV-negative men and HIV-positive women (see Table 3).

Integration into the Curriculum—Both the pilot and focus groups highlighted challenges in communication and safer sex practices that couple dynamics present. The Risk Reduction Intervention encouraged communication about safer sex, including eroticizing and romanticizing condom use and utilizing games that clarify myths and present facts about condoms and HIV transmission. For example, an exercise termed the Eban Café included a menu where couples listed preferred sexual behaviors and selected possible activities prior to sexual activity. This exercise helped couples to problem-solve barriers to condom use by promoting affection and bonding. The intervention targeted factors affecting risk at multiple levels, and addressed HIV-related misinformation. Couples learned to educate themselves and others regarding the transmission of HIV and STDs.

# (3). Minimal Response from Community and Service Organizations

In the pilot study, HIV-positive participants reported only slightly higher mean levels of satisfaction with social support than HIV-negative participants (M's = 3.47 and 3.27, respectively). This is consistent with the difficulty some HIV-negative focus group participants reported in finding services in Community-Based AIDS Service Organizations (CBOs). Although HIV-negative participants may have had difficulties finding social support outside

of the relationship, they felt connected and committed to the African American community. Pilot participants reported high levels of commitment to the health of the African American community (M = 4.1 on a 5-point scale). This trend will be examined in the main trial.

**Integration into the Curriculum**—The Eban Risk Reduction Intervention addresses issues of stigma, disclosure, and condom use. The curriculum helped couples support each other and work together to decide to whom they should disclose. In addition, they participated in an exercise that asked them to actively think of persons in their lives and how much support they received from each. The assignment required couples to focus on those whom they thought could strengthen their relationship and provide support.

#### (4). The Need for Skills for Self-Protection and to Strengthen Relationships

The couples' strengths and resilience were also evident in the pilot analyses. They reported high relationship satisfaction (M=28.76, an average rating of 4.1 on a 5-point scale). They reported moderate satisfaction with social support they received from others including their partner (M=3.37 on a 4-point scale, SD=.78). They rated their overall quality of life as "Good" to "Very Good" (M=2.5 on a 5-point scale), their present quality of life at 7.3 and their future quality of life as 8.6 on the 10-point ladder scale. As shown in Table 3, women reported higher levels of optimism about their future quality of life (one year from now) than did men.

**Integration into the Curriculum**—The focus groups and pilot study revealed the couples' commitment and resilience in the midst of challenges. In one Eban Risk Reduction Intervention exercise, couples talked about what they loved about each other and why they wanted to protect each other in order to build on their love and commitment. Finally, the intervention enhanced strengths of couples. The Eban Program's use of Nguzo Saba<sup>7</sup> represented protection of family and community, and cultural values of interdependence, intimacy and care for each other's safety. These concepts will help couples to retain the positive aspects of relationships and family life along with the HIV/STI prevention skills so necessary today.

# **Discussion**

Focus group discussions and pilot study findings provided some understanding of how the intervention could teach and strengthen couples' relationship skills. The pilot study provided insight into effective recruiting of HIV-serodiscordant couples, and methods of maintaining collaborations with service-providing CBOs that provide referrals to the study. The pilot also assured us that the questions asked were clear and that the intervention was informative, relevant, and entertaining to both woman and men participants.

The focus groups and pilot study confirmed that a Risk Reduction Intervention for African American serodiscordant couples is needed. Couples identified a lack of resources, both for the couple as a unit and for the HIV-negative partner, which often minimized the HIV-positive partner's motivation to seek available services. Families of mixed-status couples sometimes did not know how to respond in a positive way due to misinformation about HIV and homophobic attitudes about the possibility that HIV-positive men may have become infected by male partners. These concerns contributed to the stigma and rejection that couples faced in their relationships. The couples perceived that the community-based agencies were willing and eager to help individuals, but lacked the infrastructure and staff needed to offer appropriate services. If proven effective, the Eban intervention could assist Community Based AIDS Services Organizations to better meet the couples' needs in their communities.

Interviews with 32 couples and focus groups with 11 couples highlighted a contradiction between the couples' love and commitment to each other, the need to practice safer sex, their

desires for a satisfying sexual relationship, and the skills needed to prevent HIV/STI transmission. The Eban intervention was aimed at clarifying these contradictions, maintaining the quality of relationships and utilizing the strengths of couples while increasing HIV/STI transmission skills.

The focus group and pilot study results also highlighted a contradiction between couples' high rates of unprotected sex, their fears about HIV transmission and guilt regarding the risk of infecting their partner. These couples were concerned about protecting their partner and experienced high levels of distress because they lacked resources and skills to maintain relationships. The findings are consistent with literature suggesting that psychological distress can interfere with condom use among HIV-serodiscordant heterosexuals, <sup>34</sup> and point to the need for services and an effective intervention that addresses these issues.

Histories of intimate partner violence and child sexual abuse were common in the pilot sample. Child sexual abuse histories were particularly common in HIV-positive women. Histories of CSA can influence risky behaviors and condom use, <sup>8, 35</sup> and experiences of IPV can interfere with the ability to negotiate condom use. <sup>9</sup> The main trial will examine these histories as moderators of behavior change in couples. Future analyses in the main trial will also examine how these histories in either or both partners impact condom use, self-efficacy, and psychological adjustment.

Pilot data strongly suggest that the burden of being in an HIV-serodiscordant relationship may be greater for HIV-positive women and HIV-negative men. This trend is important to investigate in the larger clinical trial. We will also examine the extent to which the Risk Reduction Intervention has an impact on these mediating vulnerabilities.

Research should assess factors that influence the emotional adjustment of positive and negative partners in HIV-serodiscordant relationships. The greater vulnerability of HIV-positive women is consistent with previous literature. Among HIV-positive individuals, women reported lower levels of well-being and social support than the men, despite less advanced disease status. Because little research has been conducted with serodiscordant couples, however, we lack information about what to anticipate regarding the adjustment of HIV-negative men in such couples. In one HIV-infected couples study, women reported more distress than men regardless of serostatus. However, only 15 percent of that sample was African American. In the current predominantly African American sample, both positive women and negative men reported the most distress. We will examine whether HIV-negative men, particularly those who are African American, face greater rejection and pressure from family and friends to leave the HIV-positive partner. We will also examine whether negative partners who choose to stay with positive partners experience stress due to stigma and negative social reactions in the main trial.

We will assess whether roles of masculinity are particularly important for African American men, especially given the level of departure from violations of gender norms (such as the strain of caregiving for an HIV-positive partner, or sexual difficulties resulting from HIV). Women living with HIV tended to assume more responsibilities, including greater burdens of caretaking roles. Chronic stress may be experienced differently by men and women and be exacerbated by role-strain in the relationship due to caregiving. High caregiver burden has been associated with depression and poor health among caregivers of HIV-positive individuals. Recent research reports that compared to cancer caregivers, AIDS caregivers reported receiving less support from their families, 38 a finding consistent with focus group themes. Stigma and lack of support may contribute to the strain of caregiving and depression of these relationships will be further examined in the main trial.

Future research should also focus on potential differences in social support for HIV-positive and -negative partners in serodiscordant relationships. Satisfaction with social support was

slightly higher for HIV-positive participants in the pilot study. This is consistent with literature suggesting that family support is more limited for HIV-negative partners in serodiscordant heterosexual relationships, particularly for African Americans. <sup>40</sup> HIV-negative partners in the focus groups found it difficult to access services in AIDS Service Organizations. The main trial will examine how serostatus influences the ability to find support that meets the needs of both partners in HIV-serodiscordant relationships. HIV-negative partners may experience high caregiver burden and may find themselves as the providers, rather than as recipients of support. They also may find it difficult to express their needs for support, feeling that their partner's needs are paramount. Social support will be examined as a moderator of the impact of the intervention in the main trial.

Focus group trends suggested that woman partners were the initiators in support seeking by discussing their experiences with a wider array of people (i.e., friends, partner, family) than did men. This trend is consistent with the literature on gender differences in support seeking 42 and with research reporting that women in HIV-serodiscordant relationships report more family awareness and support than men. 40 The differences in men's and women's coping with the common issue of HIV is also consistent with research on couples facing other common stressors. 43 These relationships will be explored in a comprehensive way.

The African American couples in the focus groups and pilot study demonstrated a commitment and resilience in the midst of life challenges. Relationship stability will be assessed in the main trial. These preliminary results suggest that Risk Reduction Intervention involving African American serodiscordant couples is feasible and considered useful by couples. By implementing Project Eban, we hope to contribute to the creation of developmentally appropriate, culturally congruent strategies to empower African Americans affected by HIV to reduce STI risks while developing skills and maintaining relationships that can help couples face challenges together.

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**Table 1**Three Levels of Questions that Helped Develop Pilot Themes

LEVELS	QUESTIONS	
Individual/personal	1) What is it like to be a partner of an HIV-positive person?	
	2) What are your concerns about discussing risks for transmission with your partner?	
	3) How has HIV affected your relationship, intimacy, and communication?	
	4) How do you support each other?	
	5) What topics are hard to discuss with your partner?	
	6) What cultural beliefs or values influence you to do things that are healthy or unhealthy?	
Societal	1) How do couples support each other and decide whom to tell that one is HIV-positive?	
	2) How do couples make decisions about sex?	
	3) What difficulties do couples have relating to using condoms?	
	4) What helps couples to use condoms?	
	5) What are the best recruiting strategies for a program like the Eban Project?	
Interpersonal	1) What are the challenges couples face when one is HIV positive?	
	2) How might couples differ depending on whether the HIV-positive person is man or woman?	

Table 2

Partners with History	Prevalence of CSA	
Both partners	4	
1 partner		
Women	13 (43%)	
Men	3 (10%)	
No history	10 couples (33%)	

	Dependent		
Measure		HIV positive	HIV negative
	M's (SD's)		
Overall QOL (1=excellent,	Men	2.50 (.40) n=10	2.70 (.15) n=23
5=poor)	Women	2.80 (.21) n=20	2.44 (.34) n=9
Ladder of Life (current)	Men	6.80 (.63)	6.87 (.33)
	Women	7.70 (.42)	7.22 (.70)
Ladder of Life (1 year from now)	Men	8.11 (.59)	7.81 (.33)
	Women	8.78 (.39)	8.78 (.55)
Depression	Men	2.90 (1.86)	4.57 (1.10)
	Women	4.05 (.88)	3.67 (1.37)
Trauma symptoms	Men	30.20 (4.82)	35.3 (3.50)
	Women	32.15 (2.51)	32.4 (4.23)
Commitment to Health of African	Men	27.10 (.59)	22.5 (.94)
American Community	Women	23.85 (1.14)	27.6 (1.06)
% Condom-protected sex acts	Men	.47 (.50)	24 (.37)
	Women	.24 (.37)	52 (.41)
	%'s (N's)		
Interpersonal violence	Men	67% (6/9)	61% (11/18)
	Women	63% (12/19)	83% (5/6)
Severe IPV	Men	44% (4/9)	33% (6/18)
	Women	53% (10/19)	83% (5/6)
Less severe IPV	Men	22% (2/9)	28% (5/18)
	Women	11% (2/19)	0% (0)
CSA	Men	20% (2/10)	25% (5/20)
	Women	65% (13/20)	40% (4/10)