Jasmine M. Johnson. PERCEPTIONS OF HIV RISK AMONG AFRICAN AMERICAN WOMEN IN EASTERN NORTH CAROLINA. (Under the direction of Dr. Holly F. Mathews.) East Carolina University, Department of Anthropology, May 2012.

This project involved the collection and analysis of data from pre-and post-tests and five focus groups with 54 community-dwelling, middle-aged African American women in Eastern North Carolina, in order to explore the reasons why these women underestimated their level of risk for contracting HIV. This research was conducted under the auspices of the SISTER Talk Project, a part of the REACH Out Program administered through the Brody School of Medicine. Analysis involved determining African American women's perceptions of HIV risk, reported partnership behavior, and the influence of traditional gender roles on risk-related behaviors. Partner concurrency was found to be a common behavior in the groups studied and increased risk of contracting HIV. Homosexual behavior was also found to be heavily stigmatized and often carried out in secret, causing women to be unaware that their male partners might also be engaging in sexual relations with other men, thereby increasing the risk of contracting HIV. A key finding of this study was that traditional gender role expectations inhibit women from confronting men about partner concurrency and from requesting condom use for protection. The data collected in this study indicate that although educating women about HIV does help raise awareness about risk-related behaviors, education alone is not sufficient to solve issues of powerlessness in relationships due to perceived male dominance, poverty, and lack of communication. Women who are in these situations need further intervention, which would require involving their partners in education sessions and in discussions about HIV risk. This necessary step could help reduce the risk of HIV for both men and women, as well as reduce risk due to traditional gender role expectations among partners.

PERCEPTIONS OF HIV RISK AMONG AFRICAN AMERICAN WOMEN IN EASTERN NORTH CAROLINA

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CHAPTER 1: INTRODUCTION

Introduction

While there are numerous education and outreach programs that target adolescents and young adults throughout the state of North Carolina, few have addressed the needs of older or married African American women. Older women do not perceive themselves to be at risk for the disease, and therefore do not feel the need to protect themselves. The HIV/AIDS Community REACH Out Program is one of the few programs that focus their efforts specifically on community education and outreach. The project report here involved the collection and analysis of data from focus groups conducted through the SISTER Talk Project, a part of the REACH Out Program administered through the Brody School of Medicine. These groups were conducted with community-dwelling African American women in eastern North Carolina to explore the reasons why older women underestimated their level of risk for contracting HIV. This study also examined the extent to which assumptions about male behavior, social realities such as a shortage of potential male partners, and gender roles contributed to their perceptions of their partner's and their own risks of contracting HIV. Along with the focus groups, pre- and post-tests were given to the women as a normal part of the SISTER Talk program and the findings from these questionnaires are included in the analysis portion of this research as well.

It is estimated that over 1 million people are currently living with HIV in the United States, with 1 in 5 unaware that they have the virus. The most affected group are African Americans – making up only 12% of the total U.S. population, but accounting for nearly half of all those who are living with HIV (CDC 2010a). The Kaiser Family Foundation states that "Blacks account for more new HIV infections, AIDS diagnoses, people estimated to be living

with HIV disease, and HIV-related deaths than any other racial/ethnic group in the U.S." (KFF 2011a: 1). By far, African American women are the most at-risk for HIV infection in the country. According to the CDC, African American women are 15 times more likely to become infected with HIV than white women, and are the fastest growing HIV-positive group (2010b). Reasons given for these striking statistics are sexual partner concurrency by both men and women (Adimora et al. 2001, 2006; Carey et al. 2006; Whyte 2005), poverty and lack of resources (Brewster and Padavic 2002; Enriquez et al. 2007; Stack 1974), survival sex (Whyte 2006), and lack of condom use (Adimora et al. 2003; O'Sullivan et al. 2006; Whyte 2006).

Whyte (2005) as well as Adimora et al. (2006) indicate that the Southeastern United States suffers disproportionately from high HIV prevalence rates, and the national statistics on HIV and African American women are mirrored in data from North Carolina. The risk for contracting HIV in North Carolina is eight times higher for African American men and fifteen times higher for African American women, when compared to White/Caucasian men and women, respectively (NC DHHS 2009). Eastern North Carolina (ENC) is largely rural and geographically dispersed, with limited public transportation. Due to the lack of major urban centers and jobs, 25-33% of the population is considered at or below the poverty line. Nine counties in ENC also have high HIV prevalence rates of 22-37 percent. These HIV prevalence rates are higher than the North Carolina state average, which is 21 percent. Of those who tested positive for HIV in North Carolina in 2006, 67 percent were African American. The Kaiser Family Foundation says that "women of color, particularly African American women, have been especially hard hit and represent the majority of new HIV infections and AIDS diagnoses among women, and the majority of women living with the disease" (KFF 2011b: 1).

These statistics demonstrate a generally rural area impacted by high poverty and HIV prevalence rates, which disproportionately affect African Americans. African American women in particular are struggling with these issues, as they continue to be the most at-risk group for contracting HIV in both the state of North Carolina, as well as the country. Both a lack of public transportation in the rural areas of ENC, as well as a lack of health care providers in these areas, affects the ability of many African American women (and men) to get routine health care. Along with a combination of other social factors, the disparity in HIV prevalence and number of new HIV cases among African American women is a growing problem for Eastern North Carolina.

Background

Examining the HIV disparity among African American women, it is clear that there are specific social and cultural factors known to increase high-risk behavior which must be taken into account. In a study among high-risk populations of African American women in Florida, Whyte (2005) examined previous studies conducted by other researchers to identify four categories of behavior that significantly increased the risk of contracting HIV among African American women. He then used these categories to create an HIV Risk Behavior Questionnaire for use with this population. The categories he derived included "avoidance of body fluids," "high-risk behaviors," "sexual communication," and "survival and avoidance behaviors" (2005: 50). Specifically, "avoidance of body fluids" was concerned primarily with whether the women were reporting condom use during sexual encounters, and how often (2005: 50). Whyte considered "high risk behaviors" to be concurrency of sexual partners (having more than one sexual partner at a time), drug and alcohol use, and sex with intravenous drug users (2005: 50). The "sexual communication" part of the questionnaire involved factors related to whether the

woman could ascertain the sexual and drug-use history of their partner, and whether (or how) the woman planned to act based on this history (2005: 50). Finally, "survival and violence avoidance behaviors" included many factors, including those related to fear of violence, losing the relationship, and losing shelter/a place to live (2005: 50). Whyte used this category to measure how these factors can influence sexual behavior, and a woman's choices to engage in high-risk sex (2005: 50).

With major categories of high-risk behavior identified, it is important to also consider mode of transmission among African American women. The Centers for Disease Control and Prevention report that heterosexual transmission accounts for 80 percent of new HIV infections among women, making it the most common mode of transmission (CDC 2010a and 2010b). This means that the behaviors of women and their male partners, as well as any other partners those men might have, must be taken into account when assessing a woman's risk for HIV. According to Adimora et al., "Sexual networks and patterns of partner mixing play a critical role in the spread of sexually transmitted infections (STIs) throughout a population" (2002: 320). They explain that the term "sexual networks" refers to a group of people linked together through sexual contact, either directly or indirectly (Adimora et al. 2003: 423).

As previously stated, Whyte (2005) identified partner concurrency to be a "high-risk behavior" among African American women, and multiple studies have shown partner concurrency to be common in the sexual networks of African Americans in the Southeastern United States. Adimora et al. explain that "Qualitative research reveals socioeconomic factors that support these network patterns: low ratio of men to women, economic oppression, racial discrimination, and high incarceration rates of black men" (2006: S39). In their earlier study of

12 rural ENC counties, Adimora et al. (2001) used focus groups to explore the frequency of sexual partner concurrency among African Americans. From these focus groups with men and women ages 18-59, it was found that both the men and women generally reported they or someone they knew had side relationships, although not everyone believed it should be acceptable. Multiple women said "you have to watch your husband" because of the lack of availability of men, and many women will take any man that they can get, even if married (Adimora et al 2001: 73). This disparity in the number of African American men is mainly due to attrition of men from death, incarceration, and drug addiction. Other reasons given for partner concurrency were African American women becoming more liberated, the high number of women available to men, and monetary reasons (Adimora et al. 2001: 73-74).

Another recent study by Carey et al. (2010) supports this normalcy of partner concurrency, specifically among African American men. In this study, Carey et al. used focus groups to examine the perceptions of African American men in the Northeastern United States concerning sexual partner concurrency. They conducted four focus groups with 20 African American men, who were recruited from a public STD clinic in an urban setting. Participants were selected because they had reported risky sexual behavior (inconsistent condom use, concurrent partners, or sex with someone who was considered high-risk). Through this qualitative study, five major themes in the men's perceptions of partner concurrency emerged. First, there was a general consensus among the men that it was acceptable for them to have more than one partner. Second, there was disagreement among the men about whether it was acceptable for women to have multiple partners. Third, it was justified that having multiple partners fulfilled different types of needs, and it was in a man's nature to have multiple partners. Fourth, men described different negative consequences of having multiple partners. And fifth,

the spoken and unspoken rules that govern partner concurrency were discussed among the men (Carey et al. 2010: 38-45). Their study suggests that in this urban situation, African American men felt that it was acceptable and normal for them to have multiple partners.

The perceptions of younger African American women regarding sexual assertiveness, HIV risk, and condom use have also been examined. According to Morokoff et al., (1997) sexual assertiveness is the ability to have control over your own body, sexuality, and sexual experience (791). However, in a study by Rickert, Sanghvi, and Wiemann (2002) conducted with 904 women ages 14- 26, the authors discovered that almost 20 percent of the women sampled felt that they did not have the ability – or the right – to be sexually assertive and make their own decisions about sexual activity (179). In support of these findings, a study of 31 college students by Ferguson et al. (2006) found that young African American women identified men as regularly having multiple sexual partners, and yet felt unable to negotiate condom use. The authors identified three factors as the cause: 1) low self-esteem; 2) agreeing to have sex without a condom to in hopes of obtaining an emotional relationship with the man; and 3) the fear of being rejected by the man due to the gender-ratio imbalance among African American men and women (326-328).

These studies show that sexual partner concurrency, lack of condom use, and issues of sexual assertiveness are fairly common among younger populations of African American women. However, while there are studies that discuss the perceptions of younger African American women, there is a need to discover how older and married women perceive these events. Women who do not believe partner concurrency to be normative or common may not suspect their husbands or male partners of having sex with others and so may not perceive

themselves to be at risk of contracting HIV. Indeed, the CDC reports that being unaware of the high risk behavior of partners can increase women's risk for contracting HIV or other STD's (CDC 2010b).

Another important factor that may increase an African American woman's risk for contracting HIV is poverty. Enriquez et al. state "Compared with the rest of the population, women living in poverty experience many social inequalities known to put Americans at risk for higher disease prevalence, inadequate treatment, and worse outcomes for asthma, cardiovascular disease, HIV infection, and other chronic illnesses." (2007: 687). Poverty is an issue that increases both HIV risk and HIV prevalence in populations by preventing women (and men in many cases) from accessing the resources they need to prevent HIV infection, or receive treatment (Enriquez et al. 2007). According to the Kaiser Family Foundation, "The HIV Cost and Services Utilization Study (HCSUS), the only nationally representative study of people with HIV/AIDS receiving regular or ongoing medical care, found that women with HIV were disproportionately low-income" (2011b: 2).

In *All Our Kin*, Carol Stack (1974) describes the issues of poverty and strategies for survival among African American women in the 1970's. With many struggling simply to pay rent and put food on the table, it was common for African American women to look for new ways to gain resources, both for themselves and for anyone they considered their "kin." In most cases, this led to having concurrent partners, as well as having children with multiple partners, to secure financial aid for themselves and other kin members who cared for the children (Stack 1974: 32-44).

While many African American women are still struggling with poverty, a more recent study by Brewster and Padavic (2002) suggests that African American mothers' reliance on kin for child care has decreased tremendously since 1977. Using eighteen years of nationally representative data, Brewster and Padavic found a direct correlation between level of education, marital status, and employment status. African American women who had completed high school were 37% less likely to rely on kin to care for their children than those women who had not completed high school, and women who were college graduates were 68% less likely (2002: 554). Also, African American women who were married were about 50% less likely to use kin care for their children compared to single women (2002: 554). Similarly, women who worked full-time were about 33% less likely to use relative-provided care than those who worked part-time (2002: 50). The authors report that by 1994, center care was the most common arrangement among African American married-couple families, while less than one-fourth used extended family child care (2002: 559). Brewster and Padavic say "among Black single mothers, however, kin-provided care remained the most common choice, albeit by a much reduced margin compared to earlier years" (2002: 559).

However, this decrease in reliance on kin does not mean that African American women today are not experiencing similar situations with poverty and lack of resources as in the past. In his study of 524 high-risk, low-income African American women aged 18-49 in the Southeastern United States, Whyte (2006) found that "survival sex" is very common in this region. Survival sex is defined by Whyte as "sex that is undertaken in order to meet economic or life needs. Simply stated, survival sex is sex due to need rather than desire" (2006: 237). Using the previously described HIV Risk Behavior Questionnaire, Whyte focused the study on determining the relationship between social variables and sexual relationships in African American women.

He discovered that the majority of the women (68%) who participated in the study reported engaging in unwanted sex (2006: 241). The women reported unwanted sex not only to avoid physical and verbal abuse, but also out of fear of losing their relationships and, in many cases, a place to live (2006: 239-242). Whyte explains that "this is very likely a result of poverty, because this overall pattern of behavior was seen most often in lower income, younger women" (2006: 242).

Whyte's study demonstrates that poverty and lack of resources lead women to engage in high-risk behaviors both out of necessity and out of fear. Research by Toldson, Essuon, and Woodson (2009) support these findings. The authors state that in 2006 the poverty rate was 24.7% for African Americans, compared to an 8.6% poverty rate for whites (2009: 364). The authors also found that it was common for those who were segregated into high poverty areas to experience more "life disruptions," such as marital instability. For women, poverty and lack of power in their relationships seems to go hand-in-hand. The authors explain that many women never reach a level of power high enough to negotiate condom use within their relationship, and being in poverty intensifies this power imbalance between men and women (2009: 369). They go on to say that "cultural values may further exacerbate [HIV] risk. African American women tend to have cultural values that endorse relationships in which personal needs are sacrificed," and so these women "may be less likely to challenge cultural and relationship norms endorsing unprotected sex in order to avoid jeopardizing relationships through which they can satisfy the goals [of marriage and children]" (2009: 369).

Clearly, gender role expectations are implicated in high risk behaviors. Research that finds a majority of women reporting unwanted sex and sex out of fear implies that men are

initiating and possibly even forcing sex on women. These studies also suggest that many of these women who had sex to avoid losing shelter were relying heavily upon their male counterparts for basic necessities, thus giving men a dominant role in these relationships. This in turn caused many women to engage in high-risk behaviors such as unprotected sex, with little-to-no negotiation over condom use (Whyte 2006: 239-242).

In their study of men and women in a high HIV risk neighborhood of New York City, O'Sullivan et al. (2006) aimed to better understand gender roles and how they influence HIV risk and partner concurrency. The authors define gender roles as "culturally defined sets of behavior that differentiate maleness and femaleness and are incorporated into 'scripts,' which are mutually shared conventions that identify the content, sequence or boundaries of appropriate behavior" (2006: 695). They explain that sexual scripts are theorized by many researchers to be key factors in creating the norms of sexual behavior on the cultural, interpersonal, and individual levels. They also say that traditional gender roles show men as initiators in sex, constantly pursuing higher levels of sexual intimacy with partners even outside of their committed relationships. Women, on the other hand, are often considered more passive than men, and have fewer sexual outlets (2006: 696).

To determine how these traditional gender roles were influencing risky behavior among men and women, O'Sullivan et al. chose a neighborhood with high rates of HIV, as well as a 63.3% poverty rate, which the authors identified as a factor greatly increasing the participants' risk (2006: 697). Their sample was urban and comprised of various ethnicities, with 41% being African American. Men in the study reported more sex partners outside of their primary relationship than women, and more men reported "one night stands" (O'Sullivan et al. 2006:

701) supporting the findings of partner concurrency by Carey et al. (2006) and Adimora et al. (2001). O'Sullivan et al. also found that women's "compliance with men to engage in unwanted sex was associated with higher levels of participation in unprotected sex with primary partners," (2006: 702) a major similarity to the findings of Whyte (2006). Their research demonstrates that many men still conform to a traditional view of men as the initiators of sex which leads them to pursue opportunities for sex outside of their primary relationship. Men in the study also had greater decision-making power over condom use than women. These observations, along with many women reporting unwanted sex, suggests that women often conform to a traditional view of women being more passive and having less power in decisions about sex than their male partners, thereby increasing their risk for HIV (O'Sullivan et al. 2006: 702-703).

Finally, it is important to determine whether there are differences between rural and non-rural African American women in terms of HIV perceptions and risk. Crosby et al. (2002) compared low-income rural and non-rural African American women across Missouri because low-income women experience disproportionately high rates of HIV infection (2002: 655). In their study, the investigators compared urban, suburban, and rural counties, gaining participants through the WIC program (Special Supplemental Nutrition Program for Women, Infants, and Children). All African American women who participated in WIC at the time (1998) were asked to participate in a survey gauging their perceptions of HIV risk, and all those who answered on the survey that they were HIV positive were excluded from the analysis (2002: 656). A total of 571 women were surveyed statewide (2002: 656). Crosby et al. also conducted 12 interviews to supplement their survey. The study found that low-income rural African American women were more likely to report: 1) not being counseled about HIV during pregnancy; 2) that a sex partner had not been tested for HIV; 3) that they had no preferred method of prevention because they

were not worried about STI's; 4) that they did not use condoms; and 5) that they believed their partners were HIV negative even though they had not been tested (2002: 655-658). The investigators concluded from this study that "low-income rural African American women are an important population for HIV prevention programs" (2002: 655).

Research clearly shows that African American women are greatly affected by HIV/AIDS – especially in rural areas like Eastern North Carolina – and continue to be the most at-risk group for HIV infection. Some of the factors implicated in risky behavior are sexual partner concurrency, poverty and lack of resources, survival sex or unwanted sex, and lack of condom use. While many studies and interventions target younger African American women, relatively little work has been done with older and married women, yet they continue to be an at-risk group. This study is designed to address that gap in the research data.

Research Objectives

This project was designed to build upon an existing HIV/AIDS education program in Eastern North Carolina, the Community REACH Out Program. Headquartered in the East Carolina University's Brody School of Medicine, the program is administered through the Infectious Diseases Division, with a mission to provide HIV/AIDS education to the community that is culturally sensitive, increase HIV knowledge, promote HIV screening, and link people living with HIV/AIDS to care. It is run by Dr. Diane Campbell (MD, MPH, RN), who is an Assistant Professor of Gynecology and Medicine at ECU, and who worked as a gynecologist in private practice for many years.

Initially, Dr. Campbell completed two-hour educational sessions with African American women from rural communities across nine counties in Eastern North Carolina. According to Dr. Campbell, these sessions were typically held with community groups who expressed a desire to gain knowledge of HIV risk and condom use. The majority of the women who participated were between 30-50 years old, with 60% married and 20% previously married. The first hour of the sessions was focused on educating the women about HIV and high risk behaviors. The second hour was used for group discussion, so the women were able to discuss risky behaviors with their peers and become more aware about what they themselves, as well as their communities, should do to protect against HIV. After completing these sessions, Dr. Campbell created the SISTER Talk Project with the goal of reaching 500 African American women living in rural Eastern North Carolina to educate them on HIV and raise awareness of their own risk, thereby reducing it.

This research was specifically conducted in conjunction with the SISTER Talk Project and Dr. Campbell. Originally, the SISTER Talk sessions included group discussion during the second hour of the program as a way to raise awareness. It was determined that the best approach for this project was to revamp this group discussion time to become research-directed focus groups. Focus groups have been widely used by researchers to elicit information on health topics. A focus group is defined by Morgan (1988) as a group interview, with reliance upon interaction within the group that is based around topics or questions presented by the researcher (9-10). They are used by researchers to listen to groups of people and learn from them, focusing on the communication and interaction about a given topic between the participants themselves, as well as the participants and mediators (Morgan 1998: 9-10). While focus groups can vary greatly in size, Morgan (1998) states that all focus groups are a research method for collecting

qualitative data, are efforts focused as data gathering, and generate data through group discussion (29).

According to Stewart and Shamdasani, focus groups can be very useful in gaining general information about a topic, and formulating hypotheses to test further (1990: 15). Focus groups, as opposed to individual interviews, involve interaction and are therefore useful in stimulating new ideas, interpreting previous quantitative results, and simply discovering how respondents talk about the phenomenon of interest (Stewart and Shamdasani 1990: 16). Focus groups are also advantageous because the researcher has the opportunity for follow-up questions, explanations of the question, or probing. During focus group discussions, participants have the opportunity to react to other's responses as well as build upon them, which allows the researcher to obtain deeper levels of meaning in group interactions and discover subtle nuances in participants' expressions (Stewart, Shamdasani, and Rook 2007: 42-43).

Focus groups are not without limitations, however. It is often very difficult to recruit a diverse sample and to get them to participate in the groups. It is important for the researcher to determine whether it is possible to recruit a representative sample because if it is not, the results are will not be generalizable (Stewart, Shamdasani, and Rook 2007:43). The researcher also has to take into account that certain participants who are outspoken may dominate the discussion, while those who are more reserved may not talk much or will simply agree with the dominant opinion even if they disagree. Stewart, Shamdasani, and Rook call this "social power" which is the ability to influence others in a group setting (2007: 28). Finally, when conducting focus groups with minority groups, Chiu and Knight (1999) say that it is important for researchers to be "critically aware of their own racial identities, and of the influence of the tensions potentially

created by racial and cultural differences upon the collection, generation, and interpretation of data" (112). However, if the researcher is conscious of these limitations in the methodology of focus groups, then they can still provide useful, detailed information to add to the knowledge base of the desired topic.

The specific objectives for this project were:

1. To discover the women's perceptions of HIV risk by looking at whether they perceived, their partners, or people in their community to be engaging in risky behaviors and, if so, to explore how they defined and categorized behaviors as risky.
2. To examine reported partnership behavior in general among the women, and their perceptions on men's behavior (such as what is socially acceptable, concurrency of partners, condom use, communication about these issues, etc.).
3. To determine how gender roles affected HIV risk among African American women in Eastern North Carolina, and whether gender roles are contributing to the disparity in HIV-risk among African American women in this region.
4. To compare findings from this research with that of Whyte (2005) and his four major categories of high risk behavior in Southeastern African American women.

Precis

The second chapter discusses the research design for this project, which involved developing a focus group interview guide with questions to be asked of the participants. Five groups were then observed and recorded. The analysis plan reports on how the transcriptions of these focus groups were reviewed to determine themes and typologies of risk-related behaviors.

The demographic characteristics of the sample populations for each group are also presented. The third chapter reports on the results of the study, organized in response to each research objective. The final chapter contains issues encountered throughout the research process, a comparison of the results of this research with previous articles reviewed in the literature, the theoretical conclusions reached, and recommendations for future research and improvements to related HIV prevention programs.

CHAPTER 2: SAMPLE AND METHODOLOGY

The goals of this research seek to determine African American women's perceptions of HIV risk, reported partnership behavior, how gender roles influence risk-related behaviors, and how these findings compare to Whyte's (2005) categories of high risk behavior. In order to meet these goals, this project was built upon an existing HIV/AIDS education program in eastern North Carolina, the Community REACH Out Program, headquartered in the East Carolina University's Brody School of Medicine. Specifically, Dr. Diane Campbell directed the Sister Talk component, which consisted of two-hour educational sessions with older African American community women. Participants completed a baseline assessment questionnaire that collected demographic and attitudinal information. The first hour was focused on educating women about their risks for HIV. The second hour was a group discussion centered on different behavioral scenarios for women presented by Dr. Campbell. This research involved modification of the second hour of these programs to become focus group sessions that elicited additional information on how community women viewed their risks of contracting HIV and on which behaviors they viewed as risky in themselves and their partners. The research methodology involved developing a focus group interview guide; implementing the focus group method with five community groups; observing and taking notes on the groups; as well as recording, transcribing and analyzing the group conversations. The objectives to be accomplished by this design included discovering women's perception of HIV risk, examining the reported sexual partnership behaviors of both women and their male partners, and determining how gender roles affected behaviors and the risks of contracting HIV in these groups. Focus groups were selected as the preferred methodology because they fit naturally within the overall project design and because the group format made it easier to solicit information on a controversial topic.

Development of Research Instrument

The first step in this research was to create a focus group guide to use to collect data during the second hour of the educational sessions. This entailed revising the questions that Dr. Campbell used in past SISTER Talk sessions, which were largely composed of scenarios of behavior designed to get women talking on a more personal level. In previous sessions, she asked questions such as, "What if your sister's husband was cheating on her? What might happen?" However, in order to obtain the largest amount of useful information possible, we decided to change this format and instead pose questions and scenarios based around the four categories of risk defined by Whyte (2005). These categories included high risk behaviors, sexual communication, and survival and avoidance behaviors. (The fourth category, avoidance of body fluids, is addressed in Dr. Campbell's survey and is therefore only touched on by the focus group guide.)

The first scenario in the focus group guide and subsequent set of questions addresses the women's perceptions of HIV risk and their definitions of risky behaviors, tying into Whyte's "high risk behaviors" category (see Appendix A for focus group guide). The first scenario states that a married Black woman has been treated by her doctor for a sexually transmitted disease. We then followed with questions about how someone gets an STD; whether or not this woman might be at risk for HIV and why; and what the women in the group believe "risky behavior" to be. The second scenario continues with questions about high risk behaviors, this time stating that a family member's husband is having an affair. The women were then asked whether this woman is at risk for HIV; whether they would tell her about the affair or not; and whether they think sexual affairs are common in their community. These questions are beneficial to the

research because they help to shed light on the women's perceptions of HIV risk and what they believe to be risky behaviors, as well as whether high risk behaviors are common in their community.

The third and fourth scenarios also concern high risk behaviors, but include communication and condom use as well. In the third scenario, the women were told to imagine that their own teenage daughters (sisters/nieces/cousins) said that their friends are sexually active and have multiple boyfriends. The women were then asked if their daughters (sisters/nieces/cousins) are at risk for HIV in such situations, and if they feel they can talk to them about using condoms. They were also asked what the family/community can do to respond to HIV risk in adolescents and young adults. The fourth scenario posed then states that a wife finds out that her husband is also having sex with men. Respondents were again asked if the woman involved is at risk for HIV; why or why not; and whether they are aware of any men who have sex with men (MSM) or men who have sex with men and women (MSMW) in their community. Finally, the women were asked what barriers there are for men admitting to MSM or MSMW behavior. These questions determined whether high risk behavior such as partner concurrency and MSM/MSMW behavior is common in these communities, and what the women's perceptions are on these behaviors. It has also helped us determine whether communication around these issues is common.

After the four scenarios were posed, the women were then asked key questions concerning how gender roles effect HIV transmission (see again Appendix A). The first question asks the women whether they feel they can talk to their partners about HIV and condom use, while the next question asks if talking to their partner about HIV or condom use would be seen

as an accusation that their partner is cheating. These two questions focus directly on sexual communication between partners, and whether the women are afraid to ask the men to use condoms. Finally, the women were asked to describe what might happen if they told their partner they suspected them of cheating and wanted to use condoms, and whether they would choose to stay with their partner in either case (whether they started using condoms or not). Here, the women were again discussing sexual communication with their partners, but also touched on survival behaviors. For example, if women had said that they would stay with their cheating boyfriend/husband whether they began using condoms or not, this most likely indicates survival behavior, such as staying in the relationship because they need a place to live or money to feed their kids. We then attempted to probe in the discussion to find out what exactly these survival behaviors might be.

Administration of the Research Groups

According to Bernard (2006) there are multiple sampling methods for qualitative research that can be used in choosing and recruiting focus group participants. These methods include: quota sampling, which involves choosing a subpopulation of interest and then specifically choosing members of that subpopulation to fill your quota; purposive sampling, where the researcher recruits participants who can serve a certain purpose; convenience sampling, where the researcher recruits anyone who is willing to participate; and chain referral or "snowball" sampling, which entails starting with a few participants, and then gaining more through the participants' recommendations or referrals to others (2006: 187-192).

For the SISTER Talk program, Dr. Campbell chose to use both convenience sampling and snowball sampling, and arranged the sessions to be conducted in community groups

throughout nine counties in Eastern North Carolina. The sessions included any women and community groups from these counties who wanted to participate, and whoever they recruited in their community to join them. This method of gaining the participants through both convenience and referral was chosen because the program's goal is to reach the general population of African American women in this region, and so there are no strict criteria for who can participate. This method also helps the program reach people that it might not have if other methods were used. Having community members and leaders who are willing to participate (and who find others to participate as well) creates community advocates for HIV education and awareness, which is another benefit to the program.

The sessions began with an introduction from Dr. Campbell, explaining the SISTER Talk program, and our reasons for having the session. The participants were then asked to take about fifteen minutes to read and sign the participation agreement form, and fill out the pre-test surveys which were designed to gather behavioral information from the women (refer to Appendix D for a copy of the pre- and post-tests). After these were collected from the women, Dr. Campbell then began the first half of the session, taking about an hour to educate the women about HIV/AIDS and risk-related behaviors. Once this portion was finished, we then moved on to the focus group discussions, and began recording.

The discussions were mediated by Dr. Campbell, as she is the director of the SISTER Talk Project. However, I was responsible for audio recording the five focus groups and taking notes during the sessions. After the sessions were completed, the focus groups were then transcribed into Microsoft Word documents using the recordings. For transcription purposes, the women have been coded by number. This helps us keep track of when each woman was talking

and how frequently, so that we may see if certain people were dominating the conversation, and whether there was a disagreement among the women about certain topics discussed during the focus group. Women who were dominating the conversation have also been noted in the findings. There is not a concern for anonymity as the focus groups were analyzed for general themes, so it was not necessary to keep track of the women's names.

Sample

As previously stated, this research used convenience and snowball sampling. In the past, sessions consisted of 15-20 women each, with the ages of the women generally between 30-50 years old depending on the community group that was participating. For this research, a total of five focus groups were conducted. This quota was set based on what we considered to be a reasonable amount of sessions to conduct, transcribe, and record in the amount of time allotted. (The original goal was to conduct six groups; however, due to time constraints and trouble scheduling sessions, data collection stopped after five.)

Focus group sessions one through three were comprised of women from Church groups in Eastern North Carolina (see Table 1 below for the layout of each focus group). The first session included eight women from local churches in Pamlico County. These women were the wives of Pastors, and therefore represented eight different churches in the area. They ranged from age 40 to over 65, giving them a unique perspective on topics surrounding HIV/AIDS. The second focus group also had eight participants, this time from a church in Wayne County. This group had a fairly similar make-up to the first, with an age range of 25 to over 65, and five of the eight women married or previously married. The third focus group session was at the same church as the second group, this time including twelve new women. While these women had a

larger age range (18 to over 65), the majority of the women who participated were middle-aged. The two young women, between the ages of 18 and 24, brought a different perspective to the focus group than the older women, and were able to discuss sexual education in schools today when the topic arose.

Focus Group #	# of Participants	Age Range	Marital Status	Group Participating
Group 1	8	40 – over 65	Married (8)	Pastor's wives
Group 2	8	25 – over 65	Married (4) Previously married (1) Single/never married (3)	Church group
Group 3	12	18 – over 65	Married (1) Previously married (6) Single/never married (4)	Church group
Group 4	13	Under 18 – 64	Married (4) Previously married (2) Single/never married (7)	Sorority Members/Alumni
Group 5	14	25 – 64	Married (5) Single/never married (9)	Sorority Alumni

(Table 1)

The fourth and fifth focus group sessions differed from the first three, in that they were conducted with two sorority groups in Greenville, North Carolina. Focus group number four, conducted with a Sorority, included thirteen participants, with twelve women and one younger man, who was a boyfriend of one of the young women. The ages of this group ranged from under 18 to 64, with six women identifying as married or previously married, and the rest single. The fifth and final focus group had fourteen participants, all alumni of a different Sorority than the previous group. These women varied in age from 25 to 64. Five of the women were married, and nine were single.

In the five focus groups that were conducted for this research, a total of 54 women participated, as well as one male (in session number four) who filled out the pre- and post-test, but did not actually speak during the focus group. All of the women who participated identified as African American, except for one woman in focus group five who identified as Hispanic. Of the women who participated, about 78% were between the ages of 25 and 64, another 13% were 65 and over, and the remaining 9% were 24 and under. Therefore, the majority of the women who participated were middle-aged. As for relationship status, a total of 57% were either married or previously married.

Observational Procedure and Data Analysis Plan

Before each of the focus group sessions began, I counted the total number of participants, and then assigned each participant a number based in an order that would be easy to remember during the discussions. Once the focus groups began, I took notes to keep track of who was talking throughout the discussions. This way, I was able to match my notes to the recordings during the transcription process, accurately labeling each woman that was talking by their number (with only a few exceptions). For this process, I labeled each woman with a "W" followed immediately by the number they were given. This procedure enabled me to keep track of which women were talking more than others, determine whether certain women changed their minds or their beliefs about HIV risk throughout the course of the session, and distinguish between them when they interrupted each other during the discussion.

The transcriptions were completed using a foot pedal and with basic transcription software made by Olympus. I did all of the transcriptions for the five recordings, which were between thirty and fifty-five minutes. (The focus group that lasted thirty minutes was group four,

which was cut off earlier than expected due to scheduling issues. The other four groups were between forty-five and fifty-five minutes.) As a result, the typed, single-spaced transcripts were between six and thirteen pages long; group four's transcript was six pages, and the others were between ten and thirteen pages (see Appendix B for full transcripts.)

After the focus group sessions were transcribed, a coding system was developed. I began by reading through all of the transcriptions to get an overview of the topics and variables discussed. I then assigned a separate color code to each of the major factors previously identified from the literature review as increasing HIV-risk for African American women – MSPB (multiple sexual partnership behavior; also called partner concurrency), MSM/MSMW (men who have sex with men/and women) behavior, lack of education and resources, condom use, and gender roles. This system was then used to color code questions and responses that were related to each topic by hand throughout the transcriptions (or, in many cases, multiple topics.) Once this process was complete, it was necessary to compile these data into charts in order to better organize the participants' responses, and in order to look for themes and disagreements within and between each of the focus groups. Finally, the data charts were then related back to the original four research objectives for more in-depth analysis.

The qualitative data analysis for this research was a tedious process, and involved spending hours examining the focus group transcripts for common themes throughout the women's discussions. In order to better visualize the findings relating to each topic, organizational charts were created based on each theme to help determine whether there was a consensus or disagreement among the women in each group, as well as between groups. A total of five charts were created, each one covering a specific topic related to HIV risk. These include

MSPB, MSM/MSMW, education/resources, condom use, and gender roles (see Appendix C for analysis charts). Each row represents a focus group (indicated by the column to the left,) and each column represents a question/topic that was asked of the women, or brought up during discussion (indicated by the row at the top). The questions/topics for each chart were chosen from the focus group guide and transcriptions, based on their relevance to the chart's topic.

The main purpose of these charts was to discover common themes seen across the focus groups, as well as any discrepancies. However, the data collected during the five focus groups was complex in meaning, and many of the questions posed during the sessions addressed multiple topics. This means that some of the data in the charts overlap, and so color coding was again used, this time to demonstrate the questions or topics on the charts that were ambiguous.

After these charts were complete, I was able to return to the original four research objectives and determine whether they had been answered by the focus groups. This process involved finding and pulling relevant data from all of the charts and combining it in order to create a coherent and understandable response to each of the research questions. Although some of the data is repeated while answering the objectives, each research question has a specific focus, and so the same data is looked at from multiple perspectives and angles, rather than simply being repeated.

CHAPTER 3: RESULTS

The four research objectives guided the analyses of the data and are used as an organizational framework for the presentation of the results. These four objectives are:

1. To discover the women's perceptions of HIV risk by looking at whether they perceived, their partners, or people in their community to be engaging in risky behaviors and, if so, to explore how they defined and categorized behaviors as risky.
2. To examine reported partnership behavior in general among the women, and their perceptions on men's behavior (such as what is socially acceptable, concurrency of partners, condom use, communication about these issues, etc.).
3. To determine how gender roles affected HIV risk among African American women in Eastern North Carolina, and whether gender roles are contributing to the disparity in HIV-risk among African American women in this region.
4. To compare findings from this research with that of Whyte (2005) and his four major categories of high risk behavior in Southeastern African American women.

Data was pulled from each of the charts in order to satisfy these research objectives, and to develop conclusions about whether perceptions of HIV risk among African American women in Eastern North Carolina are predisposing them to greater risk for contracting the virus.

Perceptions of HIV Risk and Defining High Risk Behavior

To investigate the first research objective, data were abstracted from all five charts regarding MSPB, MSM/MSMW behaviors, education, gender roles, and condom use. Data were

also taken from the pre-test given to the women by Dr. Campbell before the focus group session took place (again, see Appendix D for pre- and post-tests).

The data indicate that women in the focus groups did indeed believe MSPB is a risky behavior, and identified it as common within their communities. When asked in scenario one what was happening to a woman who had her third sexually transmitted infection, women in all five focus groups reported that it could either be her husband/boyfriend who was engaging in unprotected MSPB, or it could be the woman herself. When Dr. Campbell presented the statistics for condom use and MSPB, stating that over 50% of people who "step out" in their relationship or marriage do not use condoms with either partner, the women agreed that lack of condom use is also common. This was mirrored in the focus group findings, since about 55 percent of the women who participated reported MSPB by previous partners, 44 percent suspected it of current partners, and 20 percent said that they had stepped out on partners in the past. About 79 percent of the women also reported that they do not regularly use condoms in their relationships.

The commonality of MSPB in the communities is not the only factor contributing to HIV risk, however. During the second scenario, women were asked what they would do if they found out their sister's husband was cheating on her. Many of the women in focus group one answered that they would "keep their mouth shut," and "mind their own business" (Appendix B: line 59-65). Dr. Campbell identified this as a typical cultural response for older women (and focus group one was indeed comprised of older women,) because this is what most women in older generations were taught to do. After some debate among the women in this group, most changed their minds and agreed that after attending the SISTER Talk session, they would now tell their

sister to prevent her from getting HIV. However, they did say that in order to tell, they would need to get evidence, or at least "know without a doubt that he's having an extramarital affair" (Appendix B: line 61).

This is also a commonality shared by the other four focus groups; the women agreed that they would get evidence or proof that the man was cheating *before* approaching their sister with the information. Many women stated their hesitation for telling their sister or friend would be the possibility that she would not believe them and get angry, and their relationship with their sister or friend would be ruined. They also said that they did not want to cause drama unless they were certain. For example, a woman from group five (Sorority alumni) said:

> W2: In case I'm mistaken or something, you know, I don't want to go at her with drama when it's not warranted. You don't just take something to somebody without/
> W1: the facts. [Women agreeing] (Appendix B: line 1599-1601)

Some women even recounted times when they were faced with these situations. One woman in focus group one (made up of Pastor's wives) explained how she discovered that her best friend's boyfriend was cheating on her best friend. However, when she told the friend that her boyfriend was cheating on her, the friend did not believe her and refused to talk to her anymore. Later on, the woman's friend discovered that her boyfriend had indeed cheating on her, but by that point the friendship had already been compromised (Appendix B: line 104-109).

Along with MSPB, the women also identified MSM/MSMW behavior as common within their communities. When Dr. Campbell asked the groups, all five answered yes, with one woman (from group three) adding, "oh yeah, it's a big time topic" (Appendix B: line 1142). When prompted further, the women began to explain why they saw MSM/MSMW behavior as

risky. In focus group one, consisting of older women married to pastors, the women stated that MSM/MSMW is still MSPB, and in most cases involves unprotected sex. They went on to say that homosexuality is preached against in the Bible and Church, which prevents many men from talking about their sexual orientation, and keeps the cycle of secretive high-risk behavior going. Women in focus group five, composed of Sorority alumni, agreed, also stating that people who are deeply religious believe homosexuality is wrong, and MSM/MSMW behavior is not acceptable. As one woman in this group said:

> W14: …I mean I know for people who are really into their faith and if they believe heavily in the Bible, no matter what kind of acceptance message you try to preach, certain people are never going to look past that. And so if I were gay, I know for a fact my parents would not accept it, no matter what. You could tell them all of this "who am I gonna have" and blah blah blah, it's just their belief system, know what I mean? And so for people who have that burden on them, I mean, what kind of incentive do they have to come out if they know that their family's going to change their mind or turn their back on them? It's harsh. (Appendix B: line 1881-1887)

In addition to religion, women listed other barriers that prevent men from discussing MSM/MSMW behavior. Women in focus group three, consisting of church group members, said that homophobia is one problem:

> W4: Maybe it's homophobic, I think/
> DC: A lot of women are?
> W4: No, our community/
> DC: Our communities are homophobic/
> W4: Yeah… (Appendix B: line 1130-1134)

Women across the focus groups also said that many men "don't want to be seen as gay," or "don't think of themselves as gay," which prevents them from telling about MSM/MSMW behavior. Women also believe that they are embarrassed, afraid of stigma and being ostracized,

and do not want to be rejected or disowned by their friends and family. For these reasons, the women stated that most men who are secretly engaging in risky MSM/MSMW behavior have no incentive to tell, and will therefore continue to engage in high risk behavior, putting all of their sexual partners at risk.

MSPB and MSM/MSMW are not the only factors identified as increasing risk-related behavior, however. Women in all five focus groups had a lot to say on the subject of sexual education and resources within their communities. When asked where teenagers actually get their information about sex, every focus group answered "from their peers." Not one group believed that adolescents or young adults in their communities receive comprehensive sex education, and many women reported that when they were younger they had not received any, either. The women listed many reasons for this lack of education, including: parents feeling uncomfortable, not having adequate information, or being in denial; schools do not teach sex education because of religious and parental barriers; and most schools and churches teach abstinence only. The women said that today's culture (e.g. music, videos, television,) supports MSPB behavior, and without proper education on how to protect themselves from STI's and HIV, most young adults are engaging in high-risk behavior on a regular basis. While discussing where sex education should be taught, multiple women brought up the issue of teen pregnancy and how it plays a role:

> W1: I think it should start at home, first of all. See that's the problem/
> [Women start agreeing that sex education needs to start at home]
> DC: It needs to start at home?
> W1: Yeah it needs to start at home.
> W8: And people need to stop having kids and expecting everybody else to raise them. [Women agreeing] Look who's having the kids

now though/
All: The kids!
W4: The kids are having kids! (Appendix B: line 1767-1772)

Another woman in focus group two brought up her feelings about this situation, as well. "I have a concern about a lot of young adults between the ages of 17, 25, or 30 that are having children by different partners, so I know that they're not protecting themselves. So you know, if they're having all these children they're not having protected sex, so they have the potential of getting HIV" (Appendix B: line 766-769). The rest of the women in the group agreed that this was a major problem. Another woman explained that this behavior is why many parents do not have the capability of talking to their children about safe sex, saying that "the young ones are having babies, and you can't teach anybody anything you don't know" (Appendix B: line 772-773).

The last factors discussed by the women as increasing high-risk behavior are gender roles and condom use. According to the pre-test taken by the women at the beginning of each SISTER Talk session, 79 percent said that they do not use condoms regularly/in their relationships. From the focus groups, we discovered that women believe trying to reintroduce condoms into a relationship or marriage implies cheating, or that there is a problem. The women said that it could either mean you are accusing the man of cheating, or that *you* are cheating which is why you want to start using condoms. Women in focus groups one and five also said that it brings up trust issues in the relationship. Another exchange in focus group three explained why many women struggle to negotiate condom use in relationships:

DC: Well ok, now I think he's/ I suspect he's stepping out, my intuition's kicked in. How am I gonna tell? What kind of conversation is that?
[Silence]
DC: Nobody's gonna tell him?
W7: Men like to tell everybody about … how they don't like to use

> condoms/
> W6: Yes/
> DC: Why do they say that?
> W12: Because it don't feel good. (Appendix B: line 1240-1245)

This dialogue clearly shows the women's perception on why men do not want to use condoms, and that they are reluctant to bring up the subject of using them. When Dr. Campbell asked the focus groups if having a conversation with their husband or boyfriend about using condoms was possible, most women said that the men would need to have the information from these sessions. During an exchange in focus group number two, this point was clearly stated:

> DC: …If you have that conversation, does it mean that you were cheating? I think we think that initially [Women agreeing.] We think that they think that, or/
> W2: We think it. [Laughter]
> W1: And them too until they come into this session and hear all that we've heard, they're gonna think that *you're* cheating. Because they don't have the information to know why you would ask for this. They don't have the information that you now have. (Appendix B: Lines 866-872)

This point was also brought up during the other focus groups, and most women agreed that unless the man was given the same information about HIV/AIDS they were, then the conversation probably would not happen.

Overall, we can see clear perceptions of HIV risk and what is defined as high-risk behavior by the women who participated in these focus groups. MSPB is considered a major risk factor by the women, and all participants agreed that it is common in their communities. Women also agreed that many couples do not use condoms, and have the perception that men will not use them whenever they can get away with it. The women perceive lack of education as contributing to HIV risk-related behaviors, particularly among teenagers and young adults. The

women perceive MSM/MSMW behavior as common yet generally unacceptable in their communities, and believe it causes increased secretive high-risk behavior among these men. Finally, the women recognized gender roles as another factor increasing high-risk behavior in their communities, particularly for those women who do not have safe relationships or the power to negotiate condom use.

Reported & Perceived Partnership Behavior

The second research objective was "to examine reported partnership behavior in general among the women, and their perceptions on men's behavior (such as what is socially acceptable, concurrency of partners, condom use, communication about these issues, etc.)" Questions one and two asked in the focus groups were designed to meet this objective. The transcriptions were also scrutinized for any discussions about condom use or side comments about men's behavior. Finally, the pre-tests were examined for further reports and assumptions made by the women about partnership behavior.

As seen with the first research objective, MSPB is reported among the women as a very common high-risk behavior in their communities. Specifically looking at the women's reports of men's behavior, there was a consensus among the focus groups that men in long-term relationships or marriages do not use condoms, and even single men practicing MSPB make excuses for not using them. As stated in the previous section, women in focus group three explained that "men like to tell everybody about … how they don't like to use condoms," because "it don't feel good" (Appendix B: line 1242, 1245). All of the women also agreed that, because men typically don't like to use condoms, it is very hard for women to reintroduce condoms in their relationship or marriage to reduce their own risk of infection.

Both during the education session and the focus groups, many women also made comments (or agreed with other people's comments) saying that African American men are proud of MSPB, and as Dr. Campbell puts it, having multiple partners is like a "badge of honor" for men (Appendix B: line 801). The women's perception on this behavior is that most men just want to have sex when they can get it, and with the current gender imbalance among the African American population, it is easy for men to have multiple women partners since the women outnumber them.

Some of the focus group participants from groups one, three, and five also discussed whether a woman knows when the man is cheating. Most of the women focused on behavioral changes in men that might indicate that he is engaging in MSPB. A woman from focus group one mentioned that, "they may be wearing a different cologne, or dressing a little differently, or wearing fancy drawers/ I mean, the little things. And you start going 'wait a minute now…'" (Appendix B: line 139-141). Other women mentioned intuition, saying that most women just have that gut feeling that their husband or boyfriend is cheating on them, or that something isn't quite right. During these discussions, Dr. Campbell reminded the group that some women do not know when their partner is cheating, because many affairs and relationships start at work:

> DC: Well the sister here implies that women have intuition, do you think that most women know when their mates are stepping out? [W7-12 are saying yes. Then jumbled discussion erupts as some people are unsure if they agree, followed by laughter. Some women are saying "you just know."]
> DC: So everybody's stepping out at night so their behavior's changing? Do you know where most of your affairs occur? Where do most people start their affairs?
> W1&7: Work.
> DC: At jobs. So do you think that two people can get busy from 5 to 6 and then come on home? [Women agreeing] So how do you

know?
W1: You never know/
W7: You just never know/
DC: Oh! What did you just say?
W7: You never know.
DC: Right, you never know. (Appendix B: line 1187-1200)

This was a turning point for these women, as their perceptions of men and MSPB changed. They had believed that men engaging in MSPB would exhibit obvious behavior that the woman would pick up on. After discussions such as this, however, many women changed their responses, realizing that they might not be able to tell whether their husband or boyfriend was actually cheating.

Reported partnership behavior was also included in questions on the pre-test given by Dr. Campbell. When asked whether they believed their current or previous partner had ever "stepped out" on them, 44 percent of the women answered yes for their current partner, and 55 percent answered yes for their previous partners. The women also reported on condom use, with 79 percent stating that condoms are not used in their relationships.

Along with MSPB and lack of condom use, the women also gave insight into MSM/MSMW behavior in their communities. As previously stated, all of the focus groups reported that MSM/MSMW behavior is a common occurrence, and that rumors and speculations about men in their communities who they think might engage in these behaviors is also common. Two women in focus group five reported that they actually knew men who practiced MSM/MSMW behavior. Both women said that the men were engaging in high-risk MSMW behavior before "coming out" to their friends and family as being gay. The first woman to speak explained her situation with a friend she had during college:

W8: He was undercover. He was a homophobe/
DC: So he was against homosexuality/
W8: Yeah/
DC: But he was/
W8: He masked it/
DC: But he was. Ok/
W8: …It's just like, *we* knew, we wanted him to just say/ just tell us. But we didn't feel comfortable letting him know that we kind of knew/
DC: But he had women friends?
W8: Oh yeah, oh yeah.
DC: So he was also putting other women at risk/
W8: Yeah. (Appendix B: line 1842-1854)

Another woman who decided to speak about her experience with MSM/MSMW described the unfortunate situation with her brother:

W4: Honestly, I've been in a situation/ my older brother was actually gay, and he actually died with me disliking him. And I regret it now…
DC: So he had relationships with men and women?
W4: Mmhmm. No, not/ I don't think/ towards the end he didn't have women/
DC: But he started out/
W4: He started out/ yeah. (Appendix B: line 1870-1879)

Just as this woman admitted that she shunned her brother for his MSM behavior, many other women said that they believe homosexual behaviors to be wrong as well. They also reported that it is not acceptable behavior within their communities and social/religious circles. The women perceive this to be a major reason for why many men engaging in MSM/MSMW behavior continue to do so secretly, which in turn prevents many women from knowing that they might be at risk for HIV.

In general, the women participants from these focus groups have reported "typical" male behavior to be much like findings in the literature. Women perceive single men as regularly

engaging in MSPB, and say that they regularly hear about married men or men in relationships engaging in MSPB as well. MSM/MSMW behavior was also reported among the participants, with some stating that they personally had male friends or family members who engaged in this behavior. The women perceive men who engage in MSM/MSMW as having no incentive to tell others about their behavior, due to many social and religious barriers. The women also report that men do not like to use condoms, and that most of the time they will not use them – especially in their relationships.

Gender Roles and HIV Risk

Looking at the women's perceptions of HIV risk, as well as reported and perceived partnership behavior, leads to a discussion about how gender roles can (and do) influence high-risk behavior among African American women. This is the focus of the third research goal, which was to "determine how gender roles affect HIV risk among African American women in Eastern North Carolina, and whether gender roles are contributing to the disparity in HIV-risk among African American women in this region." This was done by examining the women's reports of their own behavior, the behavior of their male partners and other men, and what they consider to be common behavior among couples within their communities. Questions were also asked during the focus groups regarding gender roles and gender-specific situations, and the women's responses to these questions were also taken into account.

As the previous sections have extensively shown, MSPB is a major factor involved in HIV risk and prevalence in African American communities. Discussions about MSPB during the focus groups led to some women stating that most people know when their partner is cheating on them. However, after Dr. Campbell brought up the example of affairs at work, many women

realized that they might never actually know. These women then changed their minds, stating that it is possible their partner could be engaging in MSPB without them ever knowing.

The discussions about MSPB in relationships led Dr. Campbell to ask the women what they would do if they thought their partner was cheating. Throughout the focus groups, a few women said that they would talk to him, and/or confront him about whether he was cheating. However, all of the women who participated in the focus groups agreed that due to certain barriers, many women could not (or would not) confront him. The older women in focus group one, explained that "we have been told that if you're married, you just stay married. Whatever happens, happens, and just let God take care of it" (Appendix B: line 73-74). In focus group two, the issue of confronting your partner came up early in the session:

> DC: [Multiple people talking] But certainly, the conversation has come up that somebody has been doing something/ but when you bring up a conversation that something is broken and someone has stepped out, it brings out all the rest of the stuff. What you going to do about it?
> W3: Pack my bags. [Laughter]
> DC: And we can say that, but when you end up in those real situations that may not be what you do. [Women agreeing]
> W1: Right, and something else, that may not be what you do and depending on that poverty level, you maybe can't do that. Because you're like, where am I gonna go? I can pack my bag all day but/ you know, women and these children, where they gonna go? And so they be quiet, and stay right there. (Appendix B: line 482-491)

This exchange shows the situation that many women find themselves in when they are reliant upon the man. In some cases, women are put in a position where they know that their partner is cheating, but are unable to do anything about it because doing so would mean losing their livelihood. In other situations, women might be worried about physical violence:

> DC: …how does that woman go home? I mean/ from all the things that you learned, can every woman go home and have that conversation with her mate? [Women saying "no"] Why not?
> W7: Someone might get beat. (Appendix B: line 1300-1304)

Whether it is the fear of having nowhere to go and no way to put food on the table for their children, or the fear of being physically beaten, women in these situations are essentially powerless, and are often left with no good options.

Not surprisingly, this lack of power in the relationship carries over into the women's ability to protect themselves. When asked if they could reintroduce condoms into their relationships or marriages, all women believed it would be difficult, and many said it would be impossible. When Dr. Campbell probed for an explanation for why not, the most common reason given was that asking your partner to start using condoms implied that something was wrong in the relationship. In focus group number one, comprised entirely of married, middle-aged women, Dr. Campbell asked if married women can talk about condom use. One respondent stated:

> W2: No, because they all get upset. At least I know my husband would, he would get mad. … condoms, after thirty years? [Laughter] No, that won't work. He'll say something's wrong. (Appendix B: line 328-331)

Other women mentioned that the partner might take it as an accusation, or that he might even think the woman asked because *she* was cheating:

> DC: Well okay, do you think that you or most women can come home after you've left this program, and say okay, we're gonna talk about condoms… Do you think all women can do that? [More women saying no] What will stop some women from doing that?
> W13: Trust/
> W2: Being embarrassed/
> DC: Being embarrassed/
> W2: Or the feeling that he's gonna think that maybe I'm doing something inappropriate/

> W13: …he might be thinking you're doing something. (Appendix B: line 1931-1943)

The accusation of cheating, along with the issues of reliance upon the man as the provider and fear of physical abuse, are not the only barriers in asking men to use condoms. The women in focus group one also pointed out another gender dynamic in relationships:

> DC: …do you think if you talk about this, do you think that's an accusation to your mate? Does it imply that you are saying that you suspect it?
> W?: I think Black men feel that way/ [Multiple women talking at same time]
> DC: You think Black men feel that way. [Woman agreeing] And why do you think they feel that way?
> W?: Trust.
> DC: Interesting – trust. They expect women to trust them. [Women all say yes.] [Laughter] They expect us to trust them. [Women still agreeing]
> W?: Even when they're doing it. (Appendix B: line 340-351)

This woman's last comment, "even when they're doing it," was stating that, even when the men actually *are* cheating, they still expect women to trust them. Of course, many women want to trust the man just as much as he wants to be trusted, and some even turn a blind eye when they know he might be cheating. In focus group one, a woman explained that "sometimes women are in denial. They suspect something, but you just don't want to believe/ you want to trust your husband, because marriage is built *on* trust" (Appendix B: line 138-139). And as a way of displaying this trust, many couples often stop using condoms, even when they suspect something is wrong.

Besides this issue of trust, there was another factor identified by the women as adding to lack of condom use. At the end of focus group five, Dr. Campbell asked whether more women would use condoms if they knew how to put them on [the man]. One woman spoke up and said,

"it's not the issue of knowing how to do it, it's the fact that women want to please men, and most men do not want to wear condoms, and therefore the women don't make them" (Appendix B: line 1973-1975). The other women in the group loudly agreed, saying it is simply the fact that women are more worried about pleasing their men than protecting themselves.

The findings from these focus groups indicate that gender roles do indeed influence high-risk behavior among African American women. In most cases, stereotypical gender roles increase risk for HIV by causing the women to engage in high-risk behavior, such as not using condoms, and knowing that their partner is engaging in MSPB and continuing to stay with them (and generally continuing to not use condoms.) These findings demonstrate that poverty also plays a significant role in enforcing gender norms. For women who do not have financial security, or who rely upon their male partner for shelter, food, and other necessities, there is little-to-no ability to demand or negotiate condom use. This issue becomes even more exacerbated when there are children involved, as most women will put the welfare of their children before their own – even if it means putting themselves at risk for HIV.

The Four Categories of High Risk Behavior

The fourth and final research goal for this thesis was to "compare findings from this research with that of Whyte (2005) and his four major categories of high risk behavior in Southeastern African American women." It was through his own research that Whyte determined these four categories of high-risk behavior, and developed the HIV Risk Behavior Questionnaire to determine whether populations met the criteria to be considered at high risk for contracting HIV.

As discussed in Chapter One, Whyte (2005) conducted his study among African American women considered to be at-risk for HIV in Florida. He first examined previous studies conducted by other researchers to identify the four categories of behavior which significantly increase HIV risk for African American women. After these categories were identified, Whyte then used them to create an HIV Risk Behavior Questionnaire, which were given to high-risk populations of African American women. The four categories were "avoidance of body fluids," "high-risk behaviors," "sexual communication," and "survival and avoidance behaviors."

Whyte's first category, "avoidance of body fluids," is specifically concerned with whether women report condom use during sexual encounters, and how often they claim to use them with their partner(s). The second category, "high risk behaviors," examines the women's reported concurrency of sexual partners, any drug and alcohol use, and whether they have sex with intravenous drug users. "Sexual communication," which is category three, is the part of the questionnaire that determines whether the woman could ascertain the sexual and drug-use history of her partner, and whether (or how) the woman planned to act based on this history. Finally, the fourth category, called "survival and violence avoidance behaviors," included factors related to fear – including fear of violence, fear of losing the relationship, and fear of losing shelter or a place to live. Whyte used this fourth category to measure how these factors can influence sexual behavior, and a woman's choices to engage in high-risk sex (Whyte 2005: 48-50).

Based on the focus group research conducted, as well as the pre-test data collected, the findings from this research do seem to correlate with that of Whyte and his four categories of high risk behavior. Using Whyte's first category, "avoidance of body fluids," we can determine whether the women who participated in the focus groups were potentially at-risk for HIV based

on their reported condom-use behavior. Most women throughout the focus groups agreed that women in long-term relationships or marriages stop using condoms, and that in many cases reintroducing condoms into those relationships is nearly impossible. The women agreed that there is a severe lack of education about condoms for teens and young adults, and with so many young people getting pregnant, and people having children by multiple partners, it is obvious that condoms are not being used. Women from multiple focus groups also mentioned that men do not like to use condoms, and that since women want to please men, they will agree not to use them. The results from the pre-test also demonstrated this fact, since 79 percent of the women stated that they do not use condoms regularly. The finding that condom use is severely lacking among the African American women who participated in these groups demonstrates that these women, and their communities, would be considered at-risk for HIV based on Whyte's first category.

The second category, focused on "high-risk behavior," examined anything reported by the women that involved MSPB, MSM/MSMW behaviors, and drug or alcohol use by themselves or their partners. Examining the discussions during the focus groups as well as the pre-test data, there is little mentioned about drug or alcohol use. However, MSPB and MSM/MSMW were major topics discussed by the women, and were both reported as common behaviors within their communities. Discussing MSPB, the women brought up concerns about the amount of young women who were getting pregnant at such an early age, and how common it is in their communities for women to have children with multiple different partners. The women also said that they knew of men who engaged in risky MSM/MSMW behavior, and that there were many more men in their communities who were married to women but were rumored to be "on the down-low." Through discussion with their peers, the women who participated in the focus groups came to the realization that they might not be aware if their partner is practicing

MSPB or engaging in MSM/MSMW behaviors, meaning that they could be at risk without knowing it. The pre-test data demonstrated that MSPB was indeed common, since 44 percent of the women suspected their current partners of MSPB, 55 percent reported it by their previous partners, and 20 percent reported practicing it in the past themselves. All of these factors clearly indicate certain high-risk behavior by either the women or their partners, placing them into this second category as well.

Moving on to Whyte's third risk category, the women's reports of "sexual communication" are taken into account. This involves the women's ability to talk to their partner(s) about things such as condom use, MSPB, testing for HIV, etc. This also includes any sexual communication within their communities, such sexual education and/or discussing condom use and HIV testing with young adults. Based on the findings from the focus group discussions, women reported having a hard time talking with their male partners about condom use (specifically reintroducing condoms into the relationship,) as well as MSPB. There was also a consensus among all of the focus groups that there is basically no comprehensive sexual education in their communities for teenagers and young adults, and a severe lack of communication about sexual issues between most parents and children. While the women could list many places where they thought these types of communication *should* happen, they could list very few places where it currently does. Based on this information, the women participants and their communities again fit into this high-risk category.

The fourth and final risk category, "survival and violence avoidance behaviors," specifically focus on the women's fears of losing shelter/necessities and/or their relationship, as well as their fear of violence. This type of fear greatly increases a woman's risk-related

behaviors, including having unwanted and/or unprotected sex. Based on the responses of the women who participated, it is clear that some women in their communities have experienced fear of losing their relationship and/or their place to live, causing them to engage in risky behavior. The most common reports from the women were the inability to confront their partner about cheating (MSPB), and the inability to reintroduce condoms. They explained that some women struggling with poverty would have nowhere else to go if they were thrown out, and that some women might even be afraid of physical violence from the man if they confronted him or accused him of cheating. Although no women admitted to having experienced a similar situation to this themselves, many of the women did state that reintroducing condoms would be a problem for them. The women believed that asking their partner to start using condoms again after they had stopped would either indicate that they had cheated on their partner, or that they were accusing the partner of cheating. Although more of the women who participated identified with the issue of reintroducing condoms, the women still brought up the issues of poverty and fear, along with unsafe relationships. This means that women in these focus groups do not seem to fit into the fourth category of risk as much as the first three. However, because the women identified these risk-related behaviors within their communities, the community is considered to be high-risk.

Overall, Whyte's four high-risk categories for African American women fit the participants of the focus groups well. The women's reported behaviors for both themselves as well as their partners demonstrates that risk-related behaviors are a commonality in their communities. Although not all of the participants reported high-risk behaviors, the majority of the women fit into at least one of the high-risk categories, meaning that they are quite possibly at-risk for contracting HIV.

CHAPTER FOUR: DISCUSSION AND CONCLUSIONS

Discussion

The findings from this research indicate many important things about perceptions of HIV risk and reported risk-related behavior among African American women – and African American communities in general – in Eastern North Carolina. Looking back at the literature, there were five major factors found to increase HIV risk for African American women: MSPB, MSM/MSMW, lack of condom use, poverty and lack of resources, and gender roles (specifically, unwanted or survival sex.) Each of the issues presented were reported by the women to be quite common within their communities and/or relationships, and many women began to view their own risk behaviors differently while discussing these topics with their peers.

As seen in the literature, MSPB was found to be a common practice among African American communities in Eastern North Carolina, and was supported by the data collected in the pre- and post-tests. The women also identified MSM/MSMW as a topic of concern within their communities, since this behavior is generally viewed as unacceptable, mainly due to stigma and religious beliefs. This leads to African American men engaging in secretive behaviors, increasing their own risk as well as the risk of all of their partners; many of whom have no idea they are being put at risk. Since the majority of women also reported not using condoms regularly, this indicates that many of these women could be at serious risk for HIV. When tying these findings in with the discussions regarding gender roles, it becomes even clearer that women who are unable (or too afraid) to introduce condoms into their relationships would be classified as high-risk, just as Whyte (2005) describes.

The severe lack of sexual education and resources in ENC communities that was identified by women further adds to risk behaviors. As many women brought up, it is common for African American women to get pregnant at a very young age, and many have multiple children by different fathers. This means that, along with practicing MSPB, these young men and women are not using protection, and often continue these behaviors throughout their lives. The participants strongly believed that this was due largely to the lack of sexual education and resources available in their communities. With many churches and schools teaching abstinence-only, and with many parents too uncomfortable to discuss safe sex with their children, these young adults are getting very little comprehensive sex education. As many of the women also stated, this furthers the issue of HIV risk in communities, since these young adults who are not receiving proper information will not be able to discuss issues of safe sex, STI's, and HIV with their own children in the future. This will in turn continue the cycle of high-risk behavior and lack of awareness that is present within these communities.

Taking into account the other risk factors identified by the women as present within their communities, the findings on gender roles gave a clear representation of HIV risk for African American women in ENC. The data from this research indicate that there are still many stereotypical gender norms in place in these communities. Men are still generally seen as the providers and aggressive initiators of sex, while women, especially married women, are expected to be more passive. In many instances, poverty plays a huge role in amplifying these gender barriers for women. Many respondents reported on situations where they were unable, or afraid, to confront their partner about cheating, or reintroduce condoms into their relationship or marriages because they were reliant upon them for food, shelter, and other necessities. Women also felt they lost the power to make demands or ask for changes in their relationships. In these

cases, the woman's choices may be to either give the man what he wants so that she continues to have his financial support, or to be thrown out when she brings up partner concurrency or condom use. In cases where the woman does not say anything to the man and stays in the relationship, she is also continuing to have unprotected sex, even if she knows he has other partners. This not only puts her at continued risk for HIV and other STI's, but also leaves the woman powerless to reduce her own risk, even when she has been educated about HIV.

Considerations

This research took an already established HIV prevention program and made changes to incorporate a focus group portion from which data were collected. While this was convenient for reaching African American women, and beneficial to both the research and SISTER Talk program, there were some issues that arose throughout the course of this project as well. These included problems finding focus group/SISTER Talk participants, inconsistencies in how and if questions were asked, and exceptions to the typical mediation style used in focus groups.

The first issue that arose with the focus group research was the inability of the program to get participants to schedule sessions and carry through with them. This may have been largely in part due to the SISTER Talk project losing its program coordinator shortly after the first session took place. By losing the coordinator, contacting women and scheduling sessions was a difficult process that was taken over by Dr. Campbell and others who worked with the project. As they were unprepared for this sudden change, it set the SISTER Talk project back in their schedule, and meant the focus group sessions were completed much later than originally anticipated.

Along with problems within the SISTER Talk system itself, the other issue gathering participants was on the end of the women. Although many sessions were scheduled between the end of August 2011 and January 2012, at least six were cancelled by the groups of women due to participants backing out, or the need to reschedule due to other reasons. Since the SISTER Talk project was already having problems with scheduling, this meant that setting up focus group sessions became even harder. The first session was held at the end of August 2011, and the next session was not until October 2011. Similarly, after two sessions at the beginning of October, another session was not conducted until the middle of January 2012, when the last two sessions were finally carried out. There had been many sessions scheduled during these large gaps, but all were cancelled or rescheduled.

The second issue with the project concerned inconsistencies in the focus group guide and questions that were asked by the moderator. In focus group one, the question that asked women what barriers men practicing MSM/MSMW might face in telling women about their behavior was cut off, and never answered. In group number four, the session was scheduled to be held at a local library with a sorority group. While this was a good idea, Dr. Campbell had not been told ahead of time that the library closed at 5:00pm. Due to this error in scheduling, we were forced to end the focus group early, and the final set of questions pertaining to gender roles was cut off. While all of the findings on gender roles and responses to the gender role questions were very similar, it was still important information that was left out, making the data slightly inconsistent. Another inconsistency issue involved the fact that Dr. Campbell talked more during the focus group discussions than a normal mediator would, making the way that questions were asked, and how much the women talked inconsistent across the groups.

This, however, is an issue that needs special consideration. Since the SISTER Talk project was an already-established HIV prevention program working to educate African American women and raise awareness about risk-related behaviors, it is important to realize that this research had to be carried out without disrupting the goals and setup of the program. This meant that it was actually necessary for Dr. Campbell to talk more during the focus group sessions, because the original group discussions the program had implemented were used for raising awareness about personal risk through peer discussion. Even though the group discussions were replaced by focus groups designed to produce research data, this needed to be done without taking away the important awareness-raising element that had been present originally.

Along with the amount of talking during the focus groups, another issue was that Dr. Campbell was not entirely familiar with focus group research and the methods to mediating, which also may have added to the inconsistencies. However, I felt it imperative that Dr. Campbell still mediate these focus group sessions, as I knew that the benefits would outweigh the costs. Due to her own past experiences, her work as a gynecologist, and her previous work educating women in these communities, I knew that the women would feel more comfortable and be more apt to open up to Dr. Campbell that they would have if I had played the role of mediator. I was also more capable of observing the women's reactions, and recording the discussions by not acting as mediator, which was an important part of the research process.

Conclusions and Recommendations

Overall, what resulted from this research was a hybrid between focus group discussions, and HIV education sessions to raise awareness and reduce HIV risk among African American

women. While it is important to note that this research was largely carried out among religious groups and therefore may not adequately represent the entire population of African American women in the ENC region, these findings do demonstrate that women belonging to religious communities are indeed at risk for HIV. Despite the few inconsistencies and issues encountered throughout this process, the participants' responses displayed clear themes relating to perceptions of HIV risk, as well as common risk-related behaviors within their communities. The data closely mirrored risk factors cited within the literature, and further validated their discussions of MSPB, MSM/MSMW, lack of condom use, poverty and lack of resources, and gender roles.

However, further research and improvements to HIV prevention programs targeting African American women are still necessary steps that need to be taken in the future. Specifically, the findings from this research demonstrate that more must be done to target the barriers presented by traditional gender roles, which clearly increase HIV risk-related behaviors. While issues such as partner concurrency, lack of education and resources, and inconsistent condom use are all important factors that we must continue to address, barriers to action and communication that stem from traditional gender role expectations need to become a bigger priority for both researchers and prevention programs alike. There are still few studies that focus directly on this issue of gender inequity in relation to HIV risk, and more information on this topic would be an important asset in improving HIV prevention programs targeting African American women, especially those who are married or in long-term relationships.

The women participating in the study also made a number of recommendations to the SISTER Talk program about what could be done to help them decrease their risk. All of the women recommended that similar educational sessions and focus groups on HIV be conducted

with men from their communities, especially their husbands and partners. They felt that if the men were given the same information about HIV, then it would easier for the women to initiate discussion with them afterward about using condoms. They also felt that if the men realized their own risk for HIV, they might be less apt to outright reject the use of condoms, and might even start using them. An important second step after conducting groups with the men would then be to invite spouses and partners to a joint group meeting where they could engage together in conversations about HIV risk behaviors and actions, since it seems apparent that there is a lack of such communication in the home.

Unfortunately, the SISTER Talk project is currently limited by grant funding to focusing only on African American women. However, the program administrator is now well aware that HIV prevention sessions with men in these communities would be an important future step in reducing risk due to gender roles. Improving and continuing focus group research as part of the SISTER Talk project would also be beneficial, since the program could use the data to improve their own prevention strategies. This would include determining how the REACH Out Program as a whole can target gender roles as a risk factor for HIV, and work with both men and women to decrease this risk.

For others working elsewhere with HIV prevention programs targeting African American women who are married or in long-term relationships, traditional gender roles need to be seen as a factor that increases their risk of contracting HIV. According to Kerrigan et al. (2008), it is also important for prevention programs to keep in mind that "gender ideologies associated with vulnerability to HIV/STI are often examined and addressed without sufficient attention to the larger socioeconomic context within which they arise and evolve" (717). The authors suggest

that interventions focusing on creating gender equity to reduce the risk of HIV and other STI's for women may be more effective if socioeconomic issues are also taken into account and addressed by the program (Kerrigan et al. 2008).

The data collected by this study indicate that although educating women about HIV does help raise awareness about risk-related behaviors, education alone is not sufficient to solve issues of powerlessness in relationships due to perceived male dominance, poverty, and lack of communication. Women who are in these situations need further intervention, which would require involving their partners in education sessions and in discussions about HIV risk. Further research in this area is also a necessity, especially in order to both design and evaluate programs to specifically address gender role expectations as a risk factor for HIV. Since the factors of MSPB, MSM/MSMW, and condom use are entwined with the issue of gender inequity in relation to HIV risk, a holistic and culturally competent approach must become the focus of HIV prevention in the future. If these issues are not addressed, then HIV prevalence rates may continue to increase in African American communities, causing even greater health disparities than are already present for this group.

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APPENDIX A: FOCUS GROUP GUIDE

(Written by Dr. Diane Campbell, edited by Jasmine Johnson)

Focus Group Guide:

Scenario one: Ms X is a married Black female treated by her doctor on three occasions for STD. Her doctor has made it clear that this is sexually transmitted.

Q1. How do you get a STD?
Q2. Why is this woman at risk for HIV exposure?
Q3. What do you think is "risky behavior"?

Scenario two: You become aware that your sister's husband is having an extramarital affair.

Q4. Is she at risk for HIV and why?
Q5. What will you do? Will you tell her?
Q6. What do you think others will do?
Q7. Do you think affairs are common in your community?

Scenario Three: Your teenage daughter (sister, niece, or cousin) tells you her friends are sexually active and have several boyfriends.

Q8. Is your daughter (sister, niece or cousin) at risk for HIV? Why?
Q9. Do you feel like you can talk to her about using condoms?
Q10. How can the family/community respond to HIV risk in adolescents?

Scenario Four: A wife (college student with a longtime boyfriend) finds out that her man is also having sex with men (MSM).

Q8. If a man has sex with men and women (MSMW) why is a woman at risk for HIV?
Q9. Are you aware of MSM or MSMW behavior in your social network?
Q10. What are barriers for a man admitting his MSM/MSMW behavior?

Key Questions:

How gender roles effect HIV transmission

Q11. Do you feel that you (or other women) can talk to partners about HIV or condom use? How would you bring it up? Would there be a discussion or would your partner not want to talk about it?
Q12. For those who think their partner wouldn't want to talk about it or would not be comfortable bringing it up, do you feel that talking to your partner about HIV or condom use is an accusation that he is cheating (having an affair)?

Q13. If you feel your man is ‘cheating’ (having an affair) what will happen if you told him about your suspicions and that you wanted to start using condoms?
Q14. If he was having an affair, would you choose to stay with him? Why or why not? (Would it depend on condom use?)

Promoting HIV screening, prevention and SISTER TALK

Q15. What can I (and you) do to encourage women to get a HIV test so that they will know their HIV status?
Q16. Do you (and/or the women you know) know how to apply condoms? Are you (and/or the women you know) comfortable applying condoms? If more women knew how to apply condoms would that increase condom use?
Q17. Can you identify a workshop sponsor or an organization that would be interested in promoting and or participating in a SISTER TALK workshop or other HIV/AIDS prevention programs? Give name and contact information if known.

APPENDIX B: FOCUS GROUP TRANSCRIPTIONS

FG10001 – Transcription | Grantsboro, NC | Recorded 8/20/11 (10am-1pm)
8 Participants | New Bern Eastern Missionary Baptist Association | (Represent 8 Churches)

DC = Dr. Campbell | LD = Lynda Dawson
W# = woman/participant # | [ ] = side notes/commentary of what is happening
… = unintelligible
/ = pause or break in the sentence/ interruption/ sudden change in topic direction

(00:00:00 - 00:00:46) *[Introduction to focus group discussion]*

- DC says she is interested in the women's ages if they feel comfortable, since older women tend to say different things than younger women. She says they do not have to, but to still please share with everyone what they are thinking because it is important. DC says she shares a lot of information with them during the session and she is interested to see how they incorporate that into their own life experiences. And at the end, she is also going to ask them to brainstorm with her about what other groups she can bring this information to, and where she should go.

(00:00:55) DC: So the first scenario, a woman, Mrs. X, is married and she has been treated by her doctor on three separate occasions for a sexually transmitted infection. And her doctor is very clear with her that this is sexually transmitted. It didn't come from a toilet seat, it didn't come from/ it is sexually transmitted. How do you think she got this infection? How did she get these infections? She's married.

(00:01:22) [Muffled - A few women say it came from her husband]

(00:01:34) DC: Do you all agree?

(00:01:36) [Some women say yes, one clearly says no.]
W?: She could have went out and got it herself!

[Many women agreeing loudly]

(00:01:43) W?: Oh, okay.

(00:01:44) DC: He could have stepped out, or *she* could have stepped out

(00:01:48) W7: I am 67 Years old, either one of them could have contracted it.

(00:01:53) DC: The key is, it's not monogamous now. Someone stepped out in that relationship. When you're in the doctor's office that might be hard to wrap your head around, but as a friend if she is coming to you with this, the first thing you've got to think about is what is she exposed to? What is she being exposed to? We just talked about it for the past hour. If she's in a relationship and it isn't closed and she's a black woman, what is she at risk for?

(00:02:19) [multiple women]: STI's

(00:02:21) W2: HIV, STD's, gonorrhea, chlamydia…

(00:02:28) DC: Uh huh, and this is not uncommon. We talked about this earlier, increased risk. So we've talked about what she's exposed to. What did you say?

(00:02:42) W2: HIV, Chlamydia, gonorrhea/
DC: Anything sexually transmitted/
W2: Anything sexually transmitted

[DC Moves on to scenario 2]
(00:02:55) DC: You become aware that your husband, or your sister's husband, is having an affair. Do you think she's at risk?

(00:03:05) W2or7: Yes.

(00:03:07) DC: Why?

(00:03:08) W2or7: Well if he's having an affair, obviously he's having sex with this other woman, and all the partners that she has had, and chances are he's not using a condom. And he's bringing all that stuff back to her. And if she contracts an STI it makes her more vulnerable to HIV

(00:03:37) DC: What would you do? Would you tell her?

(00:03:40) W?: I would tell her. That's my *sister*, I would tell her.

(00:03:45) DC: What would you tell her?

(00:03:47) W? (same woman as line 41): that her husband is having an affair. And you know, to wake her up, to help save her life

(00:03:57) DC: How do you think she'll handle that?

(00:03:59) W? (same): She probably would be mad. She'd be mad, but she would have to accept it, at least it would be coming from her sister. You're sister tells you the trust. I'm not telling her no stories. I'm being honest.

(00:04:15) W7: Well I would think that she would probably already be aware that he might be out doing that and if you talking to her she'd probably already be aware. And she might take it well, and she might be embarrassed because her sister knew about it/
(00:04:35) W? (different): /You'd best have some facts, too./

(00:04:37) W7: /Most women/ married person knows when their husband's out doing something they shouldn't

(00:04:43) DC: She says that most married women know when their husbands are out having an affair. Do you all agree with that?

(00:04:53) [Multiple women]: you might have some suspicions

[…Multiple women talking at the same time]

(00:04:57) W2: No. I mean, I've always been of the mind that, believe none of what you hear and half of what you see. And if you're going to be telling somebody, because you can ruin some lives unless you *absolutely know*, without a doubt, that he's having an extramarital affair with another woman. [Several women agreeing.] *I* feel you ought to keep your mouth shut.

(00:05:22) DC: And you? You said you wouldn't?/
W3: Mmhmm./
DC: So you think you should just keep your mouth shut?

(00:05:27) W3: Well I wouldn't/ I wouldn't tell my sister. I wouldn't/
W?: /You hear that, Jackie? …That's her sister down there/
[Laughter, women joking …]

(00:05:45) DC: So you don't know how she'd take it? Ok.

(00:05:48) W2?: Well I hear Miss Jackie down here saying she'd better tell her.
[More laughter]

(00:05:54) W8?: Well the bigger question is, are you willing to risk your relationship with your sister, or your family member. Especially in the religious community. You know, we have been told that if you're married, you just stay married. Whatever happens, happens, and just let God take care of it. And when you do that, it takes the other person out of the equation because now you are praying secretly, when this thing is taking place you're praying secretly, when you know for a fact that everything is sure, and you have actually seen the person and know of the incident, and you have heard things talked openly about it. That's when I think you should/ yes you should pray about it, but then ask God to help you to shield the relationship with your sister, that you can tell her openly and still walk in love with her and keep the relationship intact. Because either way, you gotta know. [Women agreeing.] Because the worse thing is to be ate up with guilt if something was to happen to your sister/ and that your sister passed away, then you will always/ that combination would be on you after the fact.

(00:07:27) DC: So today you knew it, so when I say you were aware you say you've seen it /[Woman: Yes]/ So you know, this is a "know." [Women agreeing.] This is not gossip in the street, you *know*. [Many women agreeing.] So now that you *know*, how do you handle that? And even if you/ You know I think those things are very, very valid and suppose that person didn't have HIV today/ and then 2 years later, you didn't say anything, and now she has HIV. [Women agreeing.] Because you don't get HIV every time you have sex with someone who's infected, you never know when it occurs. Maybe your immune system was great that day. So *today* you didn't have HIV. If you delay not telling her how does that feel if she then gets HIV/ It's a difficult decision/ [Women agreeing] /and it's in our communities, so we may have to go through this whole process of how to do this. And we've talked about being in a mutually monogamous relationship, it's not always there. It doesn't mean people are bad people, it doesn't mean anything other than that's happening. But that people are still at risk.

(00:08:33) W?: But you know, I think I would rather have them tell me/ I think that I would tell her, because I think that I would rather for her to tell me than for them to be gossiping in the street. You know, I don't want to hear it in the street, let me hear from somebody who really knows me and loves me that is concerned about me enough to come tell me.

(00:08:51) DC: So you guys have permission [Talking to the two sisters in the group] / [Laughter] / But having this conversation in general, even when it's not the thing you're talking about, at family reunions or wherever you're going to be, it begins/ the dialogue/ that people begin to know what to say/ If something happened. Because if you never have this kind of dialogue, even at your family reunions with a couple family members, people may not know that people think it's ok and that you prefer that.

(00:09:20) W4: But how does it make you feel when, like/ I have a friend, I met her when I first joined the navy… [Woman talks about how this woman was her best friend, and she saw her friend's boyfriend with another woman buying her a ring in a jewelry store, and her friend would not believe her. Friend got angry at her and they didn't speak for a long time. Woman felt betrayed that her friend would not believe her. Talks about how she didn't want a man who was either already married or had a bunch of kids, so she never thought she'd get married.]
(00:12:06) W4: [Continuing from previous] This is kind of hard, because I've been here where my own sister knew things about somebody and they didn't tell me. I knew. Well I felt bad because I knew. Woman I think have that gut feeling. And I had already cut it off way before my family even knew. You know, I told him you gotta go I'm not/ that's just not me. But when I told him and my family finally realized he was gone and not in the picture no more, then my sister come to me and say well I knew all along what he was doing. And it made me feel bad. Actually my whole family, my sister, cousin/

(00:12:43) DC: So… the question would be when you decide to tell your sister, you do risk your relationship, we have to make these personal decisions, is it still the right thing to do? Whether people are going to be mad at you, not speak to you, whatever, but have *you* walked the better life and made the better decision? Because you didn't withhold anything, and basically, hopefully the *intent* is to know that someone can be at risk. So it depends on *how* you tell people, but it's a difficult decision, and we all may be faced with it. So part of this is to have you think for a little bit of that in case it hits on your plate, and it obviously hit your plate twice [talking to woman #4] so you know people get over it, they don't get over it, you've fought both sides. You felt when you told them you were ostracized but also when things weren't told to you, you felt bad. So you guys mentioned that you think that most women know. Is that kind of the consensus, you think that most women know when their mates are stepping out?

(00:13:53) …[Many women talking at once. Most seem to be saying they think the woman at least has some idea]

(00:14:04) W?: When I know you did not go out a certain time of the night/ [Laughter] Because number one, you always stayed home. So if that starts changing, you've gotta look out [More laughter]

(00:14:18) DC: Do you think adults can be like adolescents and they have sex from 3 to 5 at work? [Women saying yes, more laughing]

(00:14:26) DC: So it's not as clear as you think, that's a traditional way of thinking relationships/ most relationships start at work. [Women agreeing] That's the number one zone where relationships start, so people have sex on the way home. And when you look back and ask, they're having sex from 5 to 6 from 4 to / So we may or may not know. And we just need to be sensitive to that. I certainly didn't know there was in mine. You may. And I think I'm a very smart woman, you never know, and again it was from 3 to 5. When they finish work at 3, before I get home at 5.

(00:15:06) W2: I think sometimes women are in denial. They suspect something, but you just don't want to believe / you want to trust your husband, because marriage is built *on* trust. And little things, like they

may be wearing a different cologne, or dressing a little differently, or wearing fancy drawers/ [Women laughing] I mean, the little things. And you start going wait a minute now, when did you start/

(00:15:33) DC: And maybe it's none of those but I think it's difficult to be a detective in your own relationship. And so I would say not all women know, and I certainly didn't know. So there are some women who suspect some things, wonder. And that's a different conversation, have you ever suspected someone stepped out, because you may have thought about it that one time or that time, and then everything's back in place so you're not thinking about it again, and so therefore you're not investigating. So you never know. [Women agreeing] And I think we answered this last one, [the last question for the scenario] what do you think other women will do? Some will tell, some won't tell. It's a double-edged sword, it's a difficult discussion.

[Moving on to Scenario 3]
(00:16:17) DC: Ok, this comes to your kids. You've got a teenage daughter, /could be a sister, could be a niece, could be a cousin/ and she tells you that all her friends are sexually active, and they've got a lot of boyfriends. [Women laughing] Do you think your daughter is sexually active? Do you think this person is at risk who shared that with you?

(00:16:45) W2: Peer pressure is a monster and if her friends are doing it/
W?: I know mine was, and I didn't know it/
W2: Chances are/

(00:16:54) DC: And kids might talk in 3rd person [Women agree]/
W2: She could be talking about herself [Women agree]

(00:17:00) DC: So when you hear that, is she at risk, what goes off in your head when you start to hear that conversation?

(00:17:06)… [Multiple women talking]
W?: I would think that we need to talk [Women agreeing]

(00:17:13) DC: Would you talk or would you take them somewhere?
W?: both
…[Multiple women talking]/
(00:17:26) W? (woman who said her daughter was sexually active line 156): /and she didn't tell me anything, what I discovered … and this is pretty true, too, it's an old wives tale, but when they start having that *one* boyfriend, and they're always with that *one* boyfriend, it's them. Something's happening. [women agreeing] Something's gonna happen or it's happening.

(00:17:54) DC: So this brings us to the larger picture. We don't have any comprehensive sex education for adolescents. They don't get it in school. Where do they get this?

(00:18:05) W?: From each other. Peers.

(00:18:06) DC: And do you think/ is that good?
[Multiple women at once]: no
DC: So where do they learn how to have responsible safe sex?

(00:18:13) [Multiple women at once]: At home, where they should / [One woman]: It's where they should, but they don't.

(00:18:20) DC: And how do you think they learn that at home?

(00:18:23) [Many women begin talking at once]: by their parents / the parents talking to their children / but do they? / [laughter…] / But I did talk to mine / I talked to mine, too /

(00:18:44) W?: I talked to both of them. They were small / […Multiple women talking, laughter] / but many parents don't, they don't feel comfortable. Their parents didn't talk to them, you know, like my folks didn't talk to me, and it's just learned behavior/

(00:19:00) DC: What do you feel down at this end of the table?

(00:19:03) W?: You know I had a […] and I did a survey with teenagers, and they didn't feel comfortable talking with their parents and parents didn't feel comfortable talking to them. They would talk to them about "the birds and the bees," and you don't have sex with boys. But when it got into having like a […] so we get a sexually transmitted disease, the conversation was cut off. So most of the information that they received was from one of their peers. They talked among themselves. And with some girls, they took the initiative to find out about these diseases and though out what was their risk factor. But see, they were very aggressive. But then there was another set of teenagers that they didn't do anything about it. They was just like hush-hush and they didn't know anything /

(00:20:02) DC: /So with that information and that background information, do you have any thoughts or recommendations as to where these young people can get this information?

(00:20:11) W1: From counselors. You know, from counselors at the school/ no /[Multiple women begin talking, saying they don't talk about that at the school]/ that's true. Well, from the Chur/ the church? Well/
[Multiple women]: No! No, no […Laughter]

(00:20:27) DC: Why are you saying that, because [women still talking at same time] you don't think the church is the place to teach … [multiple women trying to talk over Dr. Campbell. Some saying that it's not.]

(00:20:43) DC: So I've heard that we know that people are sexually active, we've had a teammate here who's done some surveys and so have I, and they don't really get the information from their parents, we're talking to them, but we're not really talking real stuff that they get, they don't get it at schools [women agreeing], they can't get it at church/ [women agreeing]/ So my question to you as a group: where are they getting it? And we say peers. So they're getting it from people who are just as young as they are who may not know what they're doing. [Women agreeing] So if that's the case, and we've all got young people in our lives, what is our recommendation as to where we want to recommend that they get some comprehensive sex education? What would you do? What would you say to your granddaughter or your/ we've talked about where it's not and not and not, so what would you recommend doing?

(00:21:35) W2: The health department has some pamphlets on sex education and they do have nurses that do talk about this at the health department. If you don't feel comfortable as a grandmother or a mother/

(00:21:50) DC: So going to the health department for brochures. Any other recommendations?

(00:21:54) W3: If the parent is alright with it, why come we couldn't have someone come in to church, you know, someone like you to come in and talk to our young people about sexual activity and

transmitted diseases and stuff like that because if they don't get it at home, they don't get it at school, they've got to get it from somewhere and they're in church most of the time so/

(00:22:23) DC: Would your church advocate it?
[Silence for a few seconds, then laughter among the women]

(00:22:31) W3: Maybe. I do. I mean, my husband, he's the pastor; I believe he would if he had more information about it.

(00:22:41) DC: And what information would he need?

(00:22:46) W1: He would need the information that would get him right here. You know, that we could go back and talk to our young teenagers about this kind of thing. And as a matter of fact he'd have to have permission from the parents to even do it because some parents don't want their children learning about sex and stuff at church.

(00:23:05) DC: Ok, so if I came to your church and I was going to do a prevention program, what is the prevention for sexually transmitted infection? Either don't have sex or have responsible sex, which means you've got to use condoms. Would I be able to talk about condoms in your church?

(00:23:21) W8: In most churches, no.
DC: Can you say that louder?
W8: In most churches, no. [Other women also saying no.]

(00:23:27) DC: You all represent a church, would I be able to come into your church and talk about condoms to the adults or the young people, especially the young people?

(00:23:34) W?: Probably not …

(00:23:38) DC: Would you like to speak on it a little bit because you are out trying to get this program/ because this is the first part of the program. The second part is all the teaching. So for two hours in our session two, that's what we do is role play, we have fun, we've got dildos, we're making sure they know how to do it, put it on, we're going through the games, we've got poles. And so that's session two, and the question is where can I bring that session because there's nothing difficult about it, it's for girls and boys, it's just the art of doing it.

(00:24:14) W?: A lot of our young people in the church are getting pregnant [Laughter]

(00:24:18) DC: I'm just asking, can I come to your church and do that program?

(00:24:23) W?: Well since Magic Johnson came out with this, it's really brought this to the forefront and a lot of people/ they took it in

(00:24:37) DC: You guys represent eight different churches, you know I ask a question can I come into your church and talk about the next two hours and it's all about teaching people how to use condoms safely, role play, how to be talked in and out of a situation, and that's all that two hours is about, can I come to your church? And I think you represent all the other people that we're trying to reach to go into church and what we hear is, you can do the first two but not the last two.

(00:25:04) LD: And that's where Dr. Campbell was saying for me to talk about the second half, because I'm the one that's out in the community and I do the coordination, and when I talk to pastors, actual pastors not the wives but I go to the pastors, I'll say here in the information, I hand it to him, put it in his hand, get back in contact with me, and let me know. I've not had one pastor, not one pastor, contact me back. The pastor's wives yes, or a representative for the pastor, but nobody has said yes, come and talk. And what I said to them was yes, it's raw but it's real. And we're not going to be doing anything nasty or anything out of the ordinary, we're just talking about saving and protecting lives. And who's in the church? Women. And we're talking about protecting our women. But they just don't want to participate. So what do we need to do? What do we need to do to say here's a condom, and I'm not telling you to go out and have sex, I'm telling you to save your life. What do we need to do?

(00:25:53) W2: Well I can tell you this: the pastors are preaching and teaching abstinence [all of the women chime in on "abstinence"] abstinence, abstinence. So it's kind of against their grain, because this is what they're preaching and teaching. [Women agreeing] Now, I don't know/ My husband will talk about HIV from the pool pit (?) but I can count on one hand pastors that I've heard preach and teach about HIV and AIDS. He used to work with it and he knew I worked with it so he's apprised of it. And we had a health fair a few months ago, and had a lady there talking about it, an RN, and he said/ and the girl was passing out condoms, too/ and he said I preach abstinence, but he *knows* young folks as well as old folks, if you know you're gonna have sex, this is the best way to do it. But all pastors don't feel that way [Women agreeing] and it's because of what they/ the Bible says. [Women agreeing] It's like homosexuality. It's preached against in the Bible. So when we have homosexuals that come to our church and we know/ we don't know everybody that is/ but those that we know, we are all kinda [woman leans away] you know, you don't want to sit by/ so it's just/

(00:27:13) DC: So two or three things that I just want to summarize. To me, adolescents don't have good choices. They're young. They rely on our choices to help give them the information and the guidance. And we have no consensus on how we're going to impart that/ not that we have to because if the church is their dialogue or their philosophy for abstinence, that may not be the best place. But neither can we as a group identify *any* place to take our young people. That's a problem for our young people [Women agreeing] We are the guardians of our people. And I don't have an answer for this, I'm just saying, it's not in schools it's not in church, the surveys document that parents talk about it but not at it. So they're not really getting the information that they're leaving the house with safe sex because it's a difference. I mean, a child should know that there are two separate things. You should not have sex, but you should also not come in here with a pregnancy. [Women agreeing] That meant you chose to have sex and you chose to be irresponsible. But if you're not teaching people to cross the street the right way, can you judge, can you say something? So where do our young people who start their debut with sexual activity that carries on to adulthood, where are they learning? And it is a difficult thing.
[Women agreeing]: It is.
(00:28:30) DC: But we still have to solve a problem because it's not only young women, it's black people getting this disproportion of infection, especially HIV, and our young people, and we're the guardians of our young people, and we have no consensus as to how we're going to teach them and guide them. I don't have an answer, but just think about that because we're the guardians and when you leave here today you have all the information, and now know that you have to guard yourself and all the women that you know, but then you have this whole other group, the youth. How are we gonna protect them?

(00:29:03) W?: What you gonna do? What you gonna do? [Laughter]

[Dr. Campbell moves on to Scenario 4)
(00:29:08) DC: I think I alluded to this one, but sometimes I find this in college. They've been going together with someone since they were sixteen. They hit college and they've been dating somebody for

five years. And they're all in college and then they find out that their boyfriend is having sex with men. Because he's debuting, he's coming out to who he is. Or who she is. And also, I just shared with you about my brother. A married woman can/ suddenly you wake up and that's in your back yard, I mean, when that occurs, and if he's having this behavior/ I think you'll all agree with this/ If this man who has this behavior, why is this woman at risk? And I'll add one more thing when you tell me the answer to it. So why is she at risk? The man is having sex with men, so why is the woman at risk?

(00:29:58) [Multiple women talking. Someone says unprotected sex with multiple partners.]

(00:30:06) DC: Multiple partners. Multiple partners and unprotected sex [women agreeing]. And there's a different rate of infectivity depending on the type of sex you have. And that is because the rectum is like your upper of your eyelid, that kind of tissue, very delicate. Soft tissue. The vagina is like this [making a gesture] you rub it a little bit, it's not gonna happen. But you rub that, it abrades. So because the insertion into the rectum and that type of tissue being softer, you have more breaks, just like the STI's, anytime you have a break it can get in. So that is why that mode of sexual activity/ and it's not just men having sex with men anally, a lot of women like anal sex. So that is why we don't just call it men who have sex with men, because that behavior, that's the only insertion and mode, but people who like anal sex are at increased risk because of that tissue difference.
[Pause]
(00:31:09) DC: I wanted to know, do you think that you have men who have sex with men behavior in your social networks? And I think a lot of us today were just talking about you hear the pastor down the street's having that. [Women agreeing] Somebody's saying you put yourself with men. So in your networks do you hear about this? [Multiple women: yes] So it's not an alien thing. If something was so uncommon you wouldn't hear about it, right? [Women agreeing] So if something is common, it is out in the community. [Multiple women: yes] So whether you want to judge it or not, it just means it increases risk. So it's not a question as to what to do, I just want a consensus of whether or not it's in your network, if you know about it.

(00:31:57) W?: Yes, it is.

(00:32:05) DC: So what barriers do men have telling their women about their sexual preferences? What barriers do they have?

[Two of the women (W2 and W7) are leaving for a funeral, DC asks them to make sure to fill out the posttest before they go.]

(00:32:48) DC: I think when you have barriers it's very difficult for men who may have this behavior to talk about it. Do you think women, especially married women, can talk about condom use?

(00:32:59) W?: No, because they all get upset. At least I know my husband would, he would get mad. … condoms, after thirty years? [Laughter] No, that won't work. He'll say something's wrong.

(00:33:15) DC: Do you think women who may suspect that their mate stepped out, even if you just suspected it, that you can reintroduce condoms in your relationship if you are married? Even if you know, can that happen? Do you think that that's an easy thing to happen? [Women: no] So that leaves that gender thing that we talked about. Women sometimes lose power in their relationship. You can be at risk, now you know you're potentially at risk because you're wondering about this in your head, but you can't really negotiate a change. So married women may have more risks than single women. [Women agreeing.] That's interesting. That's not listed as a risk factor according to the Centers for Disease Control: "marital status." [Laughter] So it's hard to talk with partners about condoms if you're married,

but that doesn't mean the relationship is closed. And I think I was asking that earlier, do you think if you talk about this, do you think that's an accusation to your mate? Does it imply that you are saying that you suspect it?

(00:34:23) W?: I think Black men feel that way/ [Multiple women talking at same time]

(00:34:26) DC: You said Black men. You don't think other men feel that way?

(00:34:30) W?[same woman]: Well, I've never talked with them. [Laughter]

(00:34:35) DC: You think Black men feel that way. [Woman agreeing.] And why do you think they feel that way?

(00:34:37) W?[same woman]: Trust.

(00:34:39) DC: Interesting – trust. They expect women to trust them. [Women all say yes.] [Laughter] They expect us to trust them. [Women still agreeing]

(00:34:48) W?: Even when they're doing it. [Laughter…]

(00:35:04) DC: So it's a challenge. So women have some challenges and especially married women. In a world today where being in a monogamous relationship is a very difficult thing to maintain.

(00:35:18) W8: But then on the other hand, black men may feel that when a woman asks them to use a condom, black men, and I say black men because I know them mostly, they feel like that woman has stepped out on *them*. There's something there, there's some infidelity[?] there if that woman all of a sudden now, they had not been used to asking them to use condoms, and you ask to start using condoms, "why you want me to use condoms?" you know?

(00:35:48) DC: So it works both ways/
W8: It works both ways.
DC: So it presents some challenges.
W8: It sure does.

(00:35:56) DC: Especially when seventy percent of the new HIV cases are black women. [Women agreeing] So how are we going to address this issue and how are we going to protect ourselves? And ourselves meaning if it's not you, it's two of your daughters, your sisters, and your sisters friends, and how are we going to protect ourselves with some of these barriers? So it's a real challenge. I think this is a carry on: you now think your mate is stepping out, how do you address that?

(00:36:24) W6: I'd give them what you brought here today, and if we take this home and share it with our husbands, he will get the same feeling that we got here today, you know, we need to be protected on both sides. And I think he would accept it more by me bringing this here home, and we sit down and we discuss this. Not saying that, you know, what we might do afterwards/ [Laughter]

(00:36:51) DC: But that's just a point of conversation is what you're saying [W6: yes.] You have gained a lot of information, and you're thinking, your wheels are turning, so it may be an opportunity to bring this up. Do you think men need this education? [All women: Yes.] Could a woman stand up and give this information and/

(00:37:11) W?: Oh yes, yes they could. [Multiple women also saying yes in the background]

(00:37:15) W?: Yes, but they would listen to a man more/
[Different woman]W?: And they'd listen to a woman too. [Laughter]
[Woman from line 377] W?: Yes, that's true.

(00:37:28) DC: So there may be some avenues to pursue. So I think there's an opportunity to present the information. And take this opportunity when you go home, because it's a point of discussion at home, for it will help you to invite us back to speak at another group that each one of you could now find another group of eight women that we/ because it's a chain reaction. You're part of that network to disseminate this information in your community. Even the things that you can't say, you have enough to know that if you had another group that I'd be able to entertain that group and keep them focused, and they will also leave with knowledge and information, so we're asking you to help us promote the program.

(00:38:04) W4: I don't think it's taught enough to men. [DC: What?] I don't think it's taught enough to men, or boys, because as girls we were always taught not to get pregnant. I was never taught about sexually transmitted disease, I was just taught not to get pregnant. But as a boy I don't think we talk to boys diseases *or* getting someone pregnant. I mean, you know, I did. I spoke to my son about it all the time, and I was shunned for that even from the school, you know, when he would talk about it at school because he was a little boy. But the school sent me a note home telling me I shouldn't say such things. Like when he was five, he asked me where babies came from. I told him the truth of where they came from, not a stork brought them, because a stork don't bring no babies. And the school told me I shouldn't have said that. But I felt like if you're old enough to ask me, someone has told you out there so you should know the real answer. But I don't think we talk enough to/ because we're afraid of it.

(00:39:07) DC: You look like you want to say something.

(00:39:10) W5: Yes because I have a son that's thirty-three years old and I would love for him to come to a place like this, because he's dealing right now with young teenagers, they call them street boys. You know, thirty-three, they're out there in the streets doing their thing. It would be nice for/ at least I would get out in the community and bring as many as I could, but they would be adults not children. And especially men, Black men, and they could turn their friends on to coming because, you know, their hip with each other. And it would be something good to promote for them.

(00:39:48) DC: Ok, well we're gonna keep that going/ this is recommendations that you're giving. I mean, this particular grant or this outreach was targeting black women because of the seventy percent risk. And this is no different than what I heard when I did the first trial with this, is that we need programs for men. I just wonder if men take this information well from other women, versus other men. You know, it's kind of like if you're hanging out and your sister tells you don't be hanging out you're like "yeah, right." Different than a man telling you, "yo man that's bad behavior." Do men take this information from another woman, or do they take this information differently from a man? You say it doesn't make a difference. I think that's what I'm hearing.

(00:40:34) W?: A professional, I think they would.
(00:40:35) [Different woman] W?: They would, they would receive you. I believe/ Bring them in here today/ [Multiple people talking]

(00:40:43) DC: I can definitely do presentations to them, they may not be/ well twice[?]…. I actually included them. And I'll tell you what happened with the last thing. But how are we going to get women to be tested?

(00:40:53) W5: You know, on my husband's job, I guess we just/ they had like a health fair and they had a booth for HIV so we went and got/ I just went and got tested.

(00:41:07) DC: People that you know other than in that setting, how would we get women that you know to get tested?

(00:41:12) W5: Well like I said a health fair or like you're doing today. Do you do those type of/

(00:41:17) DC: Mmhmm we have testing for anybody that wants to be tested.

(00:41:23) W5: We could invite, you know, more adult women. I believe that, you know/

(00:41:27) DC: So you would help us sponsor something and do something, because this is what we want from you guys to help us disseminate and invite us and tell us where to provide these types of presentations to increase the knowledge in the community and offer testing.

(00:41:42) W5: Because I know with children you have to get consent from their parents to be able to/
(00:41:47) DC: And that's why this is older. *This* particular group, what we're doing is for targeting that older population, eighteen and above. Because there's some special things you need for adolescents and they learn differently. So when I've done adolescent programs there's not a lot of Powerpoint. They just learn differently. So when you're targeting that group it may be one or two key points that you're trying to make but it's a different presentation according to how they accept information. So it's usually a little more interactive and you're usually just trying to get one or two or three points across, as opposed to this is more just like you were taking a lecture or anything, you're seeing a bigger spectrum. But young people don't necessarily get that information that way.

(00:42:32) W4: Do you offer classes like that? For the parents to come in with their kids?

(00:42:38) DC: I'm smiling because I did this program… [DC talks about how people in the first SISTER Talk program were asking for parenting classes, and how she would go about teaching parenting and adolescent classes, and that they need to be separate. DC asks the group to fill out the post-test, and to please give recommendations about where to take the program next. One woman suggests taking this program to the fraternities and sororities to reach the younger people.]

(00:49:50) [END RECORDING]

DC = Dr. Campbell [ ] = side notes/commentary of what is happening
W# = woman/participant # “” = paraphrasing
… = unintelligible
/ = pause or break in the sentence/ interruption/ sudden change in topic direction

(00:00:00 -00:04:00) [DC finishes the end of the educational section, and begins the focus group portion]

[DC Begins scenario 1]

(00:04:15) DC: As a gynecologist, this is something that I see all the time. That a woman comes in that is married or in a long term relationship and she has her third sexually transmitted infection, and she’s sitting there with me trying to assess this. So, you know, it’s not like I didn’t talk to her the second time or the first time. And she’s married, and she has her third one, you know. What’s going on with that? How is she/

(00:04:42) W8: I have a question. So, I work with teenagers in my church, so young women who repeatedly get BV … they are sexually active, is that part of that make up?

(00:04:57) DC: Yes. BV is just bacterial vaginosis, it/ this particular organism is in the vaginal canal whether you’re sexually active or not. But we do know, that once again it’s because it’s there, and when you’re sexually active you’re doing this for a while [DC making a gesture/rubbing hands together] and the vagina has to equilibrate. And when it’s trying to equilibrate from that normal kind of reaction it overshoots with this normal flora, and you get what’s a little bit that doesn’t bother you, to a lot more that bothers you. And so it’s kind of listed as something that occurs from sexual activity. [Referring back to scenario 1] But what do you think is going on with this woman? I mean, is she getting this from the toilet seat?

(00:05:40) W1: Either she’s got somebody else over on the side, or her husband got somebody on the side/ [Some women laughing, talking at same time]

(00:05:48) DC: And sitting here is a woman who’s getting this for the third time, so as her doctor I’ll ask, are you out there, do you have/ you know. The statistics are 70% of times it’s the man and 30% it’s the woman, so it’s not that we’re *not* out there, but in my situation, just like in counseling, women are pretty much/ maybe it’s not the truth, but are likely to say “yeah, I slipped up once” or whatever, and it’s a conversation about how to be safe. What happens when you have to say it’s your mate? What does that mean when you have to say, “well I’m not,” and I’m saying this is sexually transmitted? What does that mean for that woman?

(00:06:28) W2: Time to go home and talk to their husband.
DC: Or at least to deal with it/
W1: or something! [Laughter: Women repeating “or something!”]

(00:06:37) DC: Do you think it would be an easy conversation? [Women saying no.] Do you think it's even going to happen?
[Many women talking at same time. Most are saying yeah, it's going to happen.]

(00:06:48) DC: As a mature woman, how do you think/ not for you but maybe other women you know, how do you think women of your age are going to handle that? [Laughter] A conversation needs to occur, is she going home, she's sixty years old, is she going home/ [Laughter …] It's not an easy conversation.

(00:07:13) W5: It might not be a conversation; it'll probably be a fight. [Laughter]

(00:07:21) W6: And I think we need to go to the doctor. *We.* You go and I go with you. That's the most sure thing/ […continues talking at the same time as DC]

(00:07:28) DC: [Multiple people talking] But certainly, the conversation has come up that somebody has been doing something/ but when you bring up a conversation that something is broken and someone has stepped out, it brings out all the rest of the stuff. What you going to do about it? You know, so it's/

(00:07:44) W3: Pack my bags. [Laughter]

(00:07:50) DC: And we can say that, but when you end up in those real situations that may not be what you do. [Women agreeing, talking]

(00:07:56) W1: Right, and something else, that may not be what you do and depending on that poverty level, you might can't do that. Because you're like, where am I gonna go? I can pack my back all day but/ you know, women and these children, where they gonna go? And so they be quiet, and stay right there.

(00:08:12) DC: There you go. So you want to say it, and you know you should, but all these other social things hit you [women agreeing] and as you're riding home, whether on the bus or in your car, you're already making the decision not to address it. [Women saying "that's right"] and I think it's more common than not. Because any time you start to address it, then you've got to address the rest. [Women agreeing]

(00:08:34) W1: I'd probably plan the whole situation out: now I'm gonna go home, and I'm gonna say this and it could either turn out this way, or that way. [Women agreeing]

(00:08:41) DC: And some of it could be threatening to you. Some of them could be physically threatening. If you're not in one of those safe relationships and you think you have some physical stuff or mental abuse, you know, what is the old thing; you can catch a man with his pants down and he'll say "wasn't me, wasn't me." I mean we laugh about that because we've seen that and heard that, but you can imagine that that's part of the conversation, too. And then people are turning stuff around, because if it wasn't me, it was who? [Women: you.] Right. So it's not easy [Women agreeing.] but this woman has had her third infection/

(00:09:18) W8: Now I could take this situation and hypothetically just think of it being a black female who's high ranking, has a good job, and she goes to the doctor and he's just told her, and then she *does* go and talk to the husband, and kind of have a conversation with him, and say "ok, this is what I would like for you to do." And then say she gives him a time frame but he doesn't do it, and then he comes back by

saying “but I haven’t cheated on you, dada da da” but then he wants to cater to her to make her feel good because she’s taking care of the kids, and he decides he wants to/ and she says “oh we’ve got to use a condom” and he says “I’m not doing that.” Well then he just left mad, so then if it progresses on like that and he still doesn’t get with her, and doesn’t do what she asked him to do, then eventually its/ you said ride a bus…/ this is when she said “you gotta get out of my house.” It still brings a lot of, like, issues.

(00:10:27) DC: Absolutely. It’s very complex. You it’s/ we’re all agreeing that there’s really no easy way that it’s gonna be handled, and all of those things come in, whether it’s poverty, or their class, or children/ all of those things. So it’s not this poverty and low-education women having difficulty responding to that, there are educated women having difficulty responding to that and they’re responding to keep one. You know, “I finally got one, I’m trying to keep one.” Because they lose that economic support.

(00:11:03) W8: You made the statement earlier “well I’m doing this for the children.”

(00:11:05) DC: Yes, there you go, there you go. So it’s complex, but it effects our sisters.
[Moving on to Scenario 2]
Alright, how is this one, what would you do? You find out your sister’s husband is having an affair, you know this.

[….Multiple people say something at the same time. Laughter.]

(00:11:23) DC: … You said you’d tell her, how you gonna tell her, what would you tell your sister?

(00:11:27) W2: I would make sure I had the proof/
DC: So you’d get proof? How you going to get your proof?

(00:11:31) W2: I got my ways. [Laughter…]
W1: [Multiple people still talking] Camera… pictures/

(00:11:42) DC: So after you get all your information, what are you going to do with it?

(00:11:45) W2: Bring it to her and let her know what’s going on, and then like I said/
W1: Go and pack my bags/ [Laughter…]

(00:12:00) DC: You think that’s what she’ll do. You think if you told her and you showed her all this information, that she’s leaving.

(00:12:05) W1: Well you’ve got to pack her bags for her. [Laughter]

(00:12:08) DC: Why do you think you may have to do that?

(00:12:11) W1: Because of all the things we talked about. You don’t know what’s going on in their household and what they’re talking about and what he might say, and what she’s afraid of, and about the children and all of that, so you go ahead and do it for her.

(00:12:26) W2: But even still with that, if my sister has four kids, and she’s packing her bags, her and her four kids aren’t coming to stay with me. [Laughter] Whatever you need to do, you make that decision [laughing, hard to hear] …and I’ll help *you* with that decision, but I would still present the information.

(00:12:42) DC: So somehow some of your strategies is also making sure that *you* don't get overwhelmed. [Women saying: "right." Laughter.]

(00:12:48) W1: But you do have to think that. I'm telling her this and what does she say, "well ok, can I stay with you?" Right?

(00:12:58) W2: Because the truth is a lot of/ when the wife finds out the husband is having an affair, in their mind the first thing they think is "I'm leaving." But reality sets in and most women don't leave. They work through it or try to get through it/ just leaving doesn't change the fact that she was still exposed, you still need to deal with that.

(00:13:18) DC: Absolutely. So I think you made some good points, that knowing still doesn't determine what you're going to do. And we talked about the one button, and we talked abuot the many button which you don't want me to get to know a little bit of that too, so they're trying to work through that, and also as/ hopefully you'll either recognize that/ if they grew up from poverty as men they need all this counseling and these skills to be built up to, and people do have better responses with counseling, so men play a role in helping that process as well. But certainly/ I just want to ask the other side of the table, would *you* tell? Do you think women of your age would tell?

(00:13:55) W3: I would/
W5: I would, too.

(00:13:59) W3: I think I would be/ I would, and if there are children involved, at my age, I would do what I could do to help her in that situation. I would not come out and say "he had an affair, what you gonna do?" But I might say, "well you can come live with me for a while and see"/

(00:14:19) DC: The grandmother stuff to make sure they're all safe, right. And men?? may be different from the woman with a husband, moving four kids with another woman, even your sister, in with your husband may also present some challenges, too. Now you present them another particular busy situation, although it's your sister. Maybe/ [Laughter] Why are you all looking at me like that? [Laughter] But certainly, she may be thinking, "I'm not thinking that my sister's going to do that" but she's not putting anything off the table because we live in a world where anything can happen, so she got protective, where as a grandmother or an older person needn't feel threatened by that, so you were thinking more of safety.

(00:14:59) W3: Right.
W1: Exactly.

(00:15:04) W6: I've got eleven sisters and/ grew up with none of them[??] [DC: Okay.] So I've got one, she wouldn't listen to anybody if they said jesus was/
(00:15:18) DC: Even with the pictures she's not/
W6: …you would tell her, and and she wouldn't/
DC: Alright, that's a good thing/
W6: So you'd have to know…

(00:15:30) DC: That's valid and I hear that. That some people will say, I know this person and I'm not going to tell. Because they're not going to believe me./ [Someone talking in the background but it's muffled.] What do you think the reaction of that person is once you tell them, and they now have to deal

with it. Do you think they're always glad you told them or do you think some people are mad?/ [Many women saying "mad"] So now if you lied, do you think you'd get that reaction too?

(00:15:55) W2: Yup, do you.

(00:15:59) DC: So sometimes you might risk losing a friend for a while. [Women agreeing.] Because people are reactive.

(00:16:04) W5: They get upset with the messenger. [Women agreeing.]

(00:16:06) DC: Absolutely.

(00:16:08) W1: And that is a little understandable, being upset with the messenger, because sometimes a messenger/ every messenger is not your friend. [Multiple women talking…] Every messenger their intentions are not good, and so when a person is in a stressful situation, you can't really decide for who has good intentions and is coming to you with this information, because you're already/ you're thinking about the fact that someone's having an affair. You don't have time to stop and say, "ok, now is this my friend? Or did this person never like this person anyway? Or is this person just telling me this because they want some drama and have something to talk about on the phone to everybody?" You don't know. You can't think of the secondary, you don't have time, and you don't have enough/
(00:16:51) DC: You've got too much on you/
W1: Yeah, too much, yeah/ So that I think is why a lot of/ sometimes, people get upset with the messenger, is because they're just mad at everybody. And so you know, that can be sometimes/ so it's hard to decide whether or not you want to *be* the messenger. Because you're like, "okay are they going to be mad at me or not?" And it's just/ it's a difficult situation for everybody involved.

(00:17:12) DC: Yes, yes. But today she didn't have HIV, and you made a decision, and a year later she comes to you and she tells you she's positive and she's acutely infected. How do *you* feel?

(00:17:26) W5: I'd feel terrible.

(00:17:28) DC: So now that you've got this information, you are a messenger who has information, who knows what consequences of behavior is, and you're not struggling or you say you're not, but in hind sight, today she wasn't infected when you were struggling with this personal decision, and you made a decision based on whatever, I don't want to be the messenger or whatever, and a year and a half later she still didn't know, and now she's infected. How does a family… so there's lots of things that you're now going to have to deal with in your decision on what you're going to do, because these things may hit your plate, because HIV is very common in our communities, right? And affairs are very common in our communities. So having people, breakage of relationships, are things that we're going to have to deal with, with knowledge that we're going to see in our family stuff and have to make a decision on what to do. And it's no easy decision, it's not to give you a decision, but you now know that there's consequences of not telling, that can put your sister at … profound, isn't it? [Women agreeing.] Big decisions.

[Moving on to scenario 3]
(00:18:37) DC: Alright, here's your kids now. You know, they're tough to deal with, right? So you've got a teenage daughter that's coming home and she's/ I say this may be her talking in the 3rd person. "You

know, all my friends are busy and they got lots of friends and they're sexually active." And you're sitting there listening to this. What do you think this means about her?

[Many of the women starting saying "she is too." Laughter.]

(00:19:00) DC: She might be busy, too. Certainly when you're sitting there listening to this, if she's hanging out with friends who are that busy/ [Women agreeing] And so, hopefully you're thinking "does she know what she's doing? Does she know how to protect herself? Does she know about HIV?" Now that you've come to this presentation, what you gonna do?

(00:19:21) W1: Send her to Soleigh Sisters [?] we have a program for that. [Laughter]

(00:19:26) DC: There you go, so community resources. Because sometimes as a parent, it may be a hard discussion for you. [Women agreeing] You know, and it's not what you want someone to do, but what they may be doing will be putting them at risk, so you need to now know the resources in your community if you don't feel that you can have that conversation. But certainly in your mind you're saying, "uh oh! [Women agreeing] Something's on my plate." And I now know information, you know, she doesn't know how to protect herself, she's at risk for sexually transmitted infections, any of them. And we talked about HIV threatening your life, but what we don't talk about is all those other sexually transmitted infections causes infertility. [Women agreeing] So when she's ready to have children in the future she's not going to be able to. [A few women echoing DC] Because you get one infection, twenty five percent, every time you get another sexually transmitted infection, that infertility risk increases and it may be why we see a lot of infertility in the thirties. Because you're not accident prone because you're …. So you know, it certainly represents I think the discussion is, "how does a community educate its youth?"

(00:20:36) W2: When I was a teenager, my parents never had/ *never* ever, ever talked about sex. My grandparents, aunts/ they wouldn't/ if I even hinted about asking them/ "just don't do it! Just don't do it!"
DC: Okay.
W2: And that impacted me a lot as a teenager because I didn't get it from my parents but I sure heard from my friends and what my friends was tellin me I know *now* is wrong, but then I didn't know it was wrong…. [Laughter] I just did like you said, crossing the street wasn't even looking, just crossing the street. But now as a mother who has two teenage children, they get tired of the sex talk from me. [Laughter] I tell them/ I'm telling them everything and then my parents and my grandparents are like, "you don't think they're too young to hear that? You don't think"/ Well, um, a couple of years ago the herpes commercial came on TV and so my son was like, "oh mom that's what you was talking about this …" My mother was like, "what?!" [Laughter] "he's just eleven!" I'm like, "he needs to know!" [Other women agreeing, saying "absolutely"] "It's not a conversation you *want* to have, but it's a conversation that you *have* to have because my parents and grandparents didn't talk to me about sex at all, now I'm in overkill talking to *my* kids about it. But I think if I would have had someone to talk to me about it/ especially my family whether it was an aunt, uncle, whatever/ it'd made a difference in some of the choices that I made. So it's very important that we talk to them. They gotta know, whether we're comfortable with it or not, you just gotta draw a picture, a diagram, or something. [Laughter] They need to know. [Women agreeing]

(00:22:05) DC: So as a follow up of that/ now thinking, putting on a community hat, would we say that in our communities, wherever those are/ our communities of families, our communities of churches, wherever/ that most of the women in those communities would feel comfortable with that kind of conversation? Having those conversations/
[Women start saying "no"]

(00:22:22) W1: I think it's based off of/ I think it's maybe your occupation. I've been thinking about my friends and we're in our late thirties, early forties, and the ones of those who are comfortable are those that are addressing this every day. So I have a girlfriend that works in the infectious diseases department at Duke, and she's comfortable. I'm a counselor and the ones that are social workers, counselors/ we're comfortable. But I think most people are not. I mean, it's evident by who's here in the workshop today. [Women agreeing.] You know/

(00:22:53) DC: And so, if we're saying that in many of our communities that we move in, it's by that and most people are not in these professions/ [W1: Right] So, as a follow up of that, do we think that most people are getting this information?
[All women: no]
DC: We've got a lot of people … in the room…/ [Laughter… multiple women talking] So you know, we may be called upon as community members to have some inputs and some different boards in different places [women agreeing] because even if you know, we have many hats. We can have our spiritual/religious hats, we can have our mother hats, we can have our counselor's hat/ but there has to be a hat on to say what's good for the community's education of responsible sexual decisions of youth, and then if we're thinking about that/ because we want them to survive past their crazy years, you know, their youthful years, where are we going to recommend that happen? I mean, are you going to invite me into your churches, put a hat on to teach that, are you gonna send all of them to Soleigh? Where are we going to advocate for that to happen, as communities? And if we're not part of solving the problem, then we're what?
[All women: Part of the problem]

(00:24:10) DC: So sometimes we have to close our doors on ourselves and recognize the areas that we're either solving something or part of something, and hopefully more programs like this help us to be more solving, and you know separate from/ because we can take this hat off, because that's an important hat, but we've got to put *this* hat on for right now, the community hat, and make/ and be a real advocate to help make those decisions, because we're still saying no. This hat over here says you should say no, but this hat over here says, information, safety in crossing the street, safety of responsible decision. And making that available.

(00:24:44) W1: I think that's a great analogy or a great example that you gave about the whole crossing the street/
W8: You don't want your child to cross the street but you do teach them how to cross the street.

(00:24:59) DC: I have one last scenario, and I think I touched this a little bit/
[Technical difficulties]

(00:25:40) DC: We talked a little bit about this, because I gave you a personal story, but I think, or maybe I should ask you, do you think this happens more than what we like to think? So it not only happens to

married women, because you know, we think that this is safe, it's our marriage, this person wasn't doing that/ we see this a lot in colleges. Because people have boyfriends and girlfriends from high school, then everybody goes to college and they're trying to figure out who they are, and they're exploring different things, and so you could look [wake?] up as a married woman or as a college student/ you know, young and your sexual activity, 22, 23, 24/ and realize that your man is having sex with men. And you know, I think I covered that very clearly, this person really at risk, and not everybody makes the decisions on what they do with this/ it's very different. So it brings up the discussion that, 1) How common do you think this is, do you think that people just might know this [?], have you wondered about someone who's having bisexual behavior? You know, in your sexual networks, and networks of where you see someone's married and then you wonder what else they're doing. Because sometimes we act like this doesn't exist, and this is the time to think for a moment, you know, we really need to touch more situations/ we know most of us have thought about this at one point or another, thinking that this person is exposed. And I think I bring this up because I think that sometimes we're exposed to some infections and some things and it has nothing to do with you.

(00:27:17) W1: I think that we don't really think about exposure.
DC: Okay.
W1: Because I know that I've said, and I've seen in the past – not recent – but people that are married that you think that the man may be gay, but we just say, "oh, everybody always/ he's always acting like that…." [Phone is ringing in the background making it hard to hear] I don't think people really about, "does she know and does she know that she's at risk?" I think we just said, you know? We just say oh I'm married and everybody always knew he might be gay or everybody knew he might/ MSM/
(00:28:00) W8: The way he might walk, the way he might talk/
W1: And people, "yeah they used to say that, but he's not gay anymore, and you know, he's been cured so that means that he can't be/ and I think people are saying/ but are we just all turning a blind eye to the fact that she could be at risk? I don't think we think that far. I just think we just stop with the, you know/ who his boyfriend's supposed to be, and/

(00:28:36) DC: But if the transmission of this is multiple sexual partnership behavior and it's both heterosex/ same sex and opposite sex, and the one that's *most* at risk is the person that's with someone who's having a cross-over to/ you know, they're at risk, and you're right, I don't think we think about it. So this is an opportunity not to have an answer but/ some of this will stick forever. You know, I'm not sure what we can do, but this is to say this is more common than you like to think, and all of those women or people are somebody's sisters or brothers/ and so it's like you have that situation where what would you do if you find out your sister's having an affair, that affair could be with another man or another woman, and that's/ that person in that situation is somebody's sister.

(00:29:28) W1: Right and it takes it to a different level, a higher level, when it's a man. So when you find out that your sister's husband is having an affair with a man, her response has to be different by me telling her that, because 1) it's going to be based off your/ the way you're telling/ just all of that stuff, it may be a little more acceptable if it's a woman versus a man, so now she has to act a certain way, because of how you came and told her about it, and who else knows, and now it turns into a larger issue and just/ I think it might not be the response you would have had if she had found out herself. It might have been a conversation, but now that everybody knows and all of that you gotta act a different/ and maybe she needs

to do something different/ which then keeps it a secret, he denies, and then he goes onto the next partner and is sleeping with…/

(00:30:28) DC: It's real complex. It's not easy to deal with either side. It's not easy to be the woman where you're exposed to that, or be the family members or community members that know. But HIV is increasing in our communities, and so maybe some of the ways we've responded in the past/ we'll have to rethink the ways we respond to that. We may want to have more relationships with her so we're bringing people to her. [I believe DC is pointing to W1, who is a counselor.] [Laughter] "I want you to go to a counseling session…" [Other women start talking too] So there's joking, but it's serious, that we/ because when it's my sister and that's happening, I really am now going to have to respond differently. And I may not feel that safe saying it and I maybe misinterpret it, so we're gonna have to find community ways to deal with it. Because reality is maybe we don't care as long as everybody just use condoms. Because that's really what this is all about. This is really not to judge any behavior, because maybe if he's busy with him or her he's not that busy with me and I don't feel like being that busy, it's alright. [Laughter] I mean, that's the stuff you never know, when you're working the story, and the information, they all/ we use condoms…/ [?] the paycheck, the rent being paid…/ So it really/ and that may be the message that we're coming across. I just think you need to protect yourself. You know, knowing that …. People are just getting busy with everybody. [Laughter] However you want to say it, I'd just like to make sure that you're protecting yourself, you know, and that's the same [?] with making sure your relationship is closed. Be the first in the conversation. This is really to take away the judgment about who was having sex with who, because wouldn't we all be just sad if we woke up and trying to be monogamous was never what it was supposed to be. I mean, we're taught to think that way, but you know, in other animal kingdoms that's not correct. It's not that it's not correct, it's that it's not the norm. We're making it the norm for the human beings, but maybe it isn't. And maybe it's not. But mainly the only thing the message is today, is that people need to protect themselves, they need to learn the skills to protecting themselves, if your relationship was tightly closed and you know about that, that's fine. We have ways to make sure that's occurring, you know, you can have people do polygraphs every six months, they might not like it/ [Laughter] But, it's closed. Whatever you gotta put on the table to be safe.

(00:33:12) W5: I have a concern about a lot of young adults between the ages of 17, 25, or 30, that are having children by different partners, so I know that they're not protecting themselves. So you know, if they're having all these children they're not having protected sex, so they have the potential of getting HIV.

(00:33:34) DC: Absolutely. And on both sides, where do men learn their sexual behavior from? Where do they learn their behavior from? I'm throwing this out, where do you think they learn it from?

(00:33:52) W6: Parents or children themselves. The young ones are having babies, and you can't teach anybody anything you don't know.

(00:34:03) DC: Well that's true, so we have generational/

(00:34:06) W4: Sometimes it might be out in the community/
[Multiple women: peers]
DC: And where else?

(00:34:15) W1: TV
DC: TV? [Women agreeing] Where else?

(00:34:19) W8: At the church
DC: At the church? [Laughter]

W8: You think about it, you got families, generations of families and it's a cycle that just repeats/

(00:34:34) DC: So this is their community you mean/
W8: Yeah in their community/
DC: So the church is their community and that's where the cycle is starting [?] from/
W3?: It's maybe where they live…/

W8: Well, they don't live in the churches… [multiple people talking] it's in the churches, not where they live, but like, that family, they might have a large family, it started from the great grandmother or whatever, and it made that cycle/ it just came down the line, I mean it might not have happened with every single male or female, but the majority/
(00:35:04) W1: So that's what they're doing/ [Multiple women begin talking]

(00:35:09) DC: So it's in the church but it's because it's that family, but it's really that it's in the family where it's teenagers, having teenagers, having teenagers [W8: That's right.] Where else do you think boys learn their sexual behavior from? There's one big one we didn't put on the table.
[People start talking at the same time]

(00:35:37) W2/W8: Older men.

(00:35:38) DC: There you go. They learn it from other men. [Women start talking at same time] Look at other animal kingdoms. The females learn behavior from females, and males from males. So, men are gonna learn sexual behavior norms from other men. No matter what you say to them as females, they are looking at what the other men are doing. Right. So if we're not having men who are taking the leadership like these things and teaching other men and getting away from that badge of honor and slapping five and whatever, no matter what we say as women/ that's the norm. And you know, we start out by saying sex feels good, it's an orgasm, so you telling people to defer and modify something that to them, it is a way of feeling good, and it feels great. So it's a hard thing to/ it's almost like you have to be mature enough to give up a little bit to get something else. You give up a lot of different orgasms, a lot of different people, for stability, calmness, one on one dealing with other things/ it's still choices. And teaching people to make those choices comes from their environment, and what they begin to value. So if we're bringing them up in a one-parent household, are they valuing relationships? [Women answering: no] And no matter what we say as women, they're looking at daddy. And boys see/ just like we see our mother's stuff/ boys don't see some of the stuff that the women are doing, because we're picking up the women's stuff. They're picking up the daddy's and the uncle's stuff. And I say all these uncles and daddies are somebody's husband. So all those things to help address, to motive our men to get in counseling/ to be better men, take leadership, and also share their stories. Because unless they start to share their stories and the things that they learn, even from the bad behavior that they used to do and don't do now, they're not sharing that with other younger men so they know the price. That's why everybody's making the same mistakes. And then they're blowing up their relationships, they're blowing up their house for the orgasms.

And then it just leads to more and more stuff. And so back to the teenagers, I think those are cycles, maybe. And we still as a community have to come together and address that.

(00:38:16) DC: So how do you think that the gender role, being a male or female, affects the way you can talk about this sexual behavior? We're almost finished. I mean, do you think that it's easy to do this, do you think that men have an easier role than women, or women have an easier role than/ and in a relationship that's married, how are you gonna talk about condoms? I think my husband's trying to step out. I'm not sure yet. How am I gonna introduce condoms to protect myself?

(00:38:46) W1: You can always say "the doctor said..." [Laughter]

W8: I think you have to have a comfort in yourself, because any health, nutritional health, and just wellness, some things that I dealt with in my …. is just come out and say it. I mean it's not …. I mean you have to be matter of fact, you know, when working with teenage girls and pre-teenagers, I mean, I'm like, okay, let's have a conversation. I mean …. This one time talking to a teacher about my son at school was about what they did in school, and who's trying to talk to who, and trying to keep them from learning all about them, and so I end up finding things like, "well I didn't even know that and I'm thirty something" [Laughter] You have to have a comfort level, because then she mentioned about her teenagers, and the grandparent. Well, my grandmother is not gonna talk to you about sex and stuff, and I'm forty. But she's not gonna talk to you about it, but she's gonna motivate you to get a good job, but you've gotta have that comfortness to go to/ it doesn't matter who it is, and say, you know look, I see you got two kids and you're struggling, do you need to talk to somebody? I mean, you got to just have that ability and concern as you/ you've gotta have the concern and care and you want to see that person better and improved. Because if you don't have the care and concern it's not gonna change anything. And that's not just from us …. That's from… [?]

(00:40:25) DC: So it has to be some good intentions, there has to be a little assertiveness there, a feeling like you want to protect yourself, and so you're willing to have some conversation…. [W8 says something] but it's certainly not easy. Do you feel that/ I think we covered this a little bit, that it's easy, that married women can actually go home and have this conversation? I think it comes with some stuff. You know, on your way home you're thinking about some stuff. Like what? Like what he's gonna say/ [women agreeing]

(00:40:55) W1: Right, because originally you say "I think we need to start using condoms." I'm gonna think like, "what you been doing?" You know?

(00:41:03) DC: Even if I've been doing stuff I want to know/

[Women agreeing, start talking]

(00:41:06) W1: You know, just mentioning like/ as the husband, I would think like, "why's she want me to/"
DC: "Well did she catch me?" [Laughter] I mean, a lot of things go in/
W1: And he might be thinking "I've been meaning to say that for a long time myself" [Laughter] "I'm glad you brought it up"

(00:41:30) DC: And so we have to learn how to say it. And just like anything else, this may not be what we're doing, but we're thinking about that, so maybe we'll learn from all the information you guys are sharing from us that we need to have a married women's, five women in a thing, and we're role playing how to introduce condoms. And I don't know, but that's why we tape this because we're/ because people need skills, and if someone hasn't role played that, and know that they can say it in different ways, they may not know how to do that. And we can't assume. And maybe a lot of us may be having these conversations because we're dealing in a world where closed relationships don't stay closed that long, they open up periodically, and it may be conversations that we need to begin to figure out how to have, or once again having community places/ which she has this program and this free session [Laughter] it's about how to do that. It's about how to have that conversation, and how to reclose your relationship, and how to have a conversation with a couple of sessions as to what's going on in your relationship, why things are broken, and what are we gonna do. Are we always gonna use condoms, are we gonna recommit? All those kinds of things. Well I think you said that. If you have that conversation, does it mean that you were cheating? I think we think that initially [Women agreeing.] We think that they think that, or/
(00:42:56) W2: We think it. [Laughter]

(00:42:58) W1: And them too until they come into this session and hear all that we've heard, they're gonna think that *you're* cheating. Because they don't have the information to know why you would ask for this. They don't have the information that you now have.

(00:43:15) DC: And what if you're not in one of those safe relationships? A lot of relationships we don't see that because it's behind closed doors. But it's a power thing, when someone's physically more powerful than you, if someone has more resources than you do, they control the relationship. [Women agreeing] So if you don't have equality in the relationship because of physical abuse, mental abuse, economic issues/ can you really have this conversation? [Women mumbling. Mostly saying no, even though it is obvious they don't want that to be the answer.] So you/ can you imagine being silently at risk and knowing that you're at risk and not being able to have any power to reduce your risk and then suddenly showing up with HIV? [Women are silent.] And we see this every day in our practice… because this is where live, your/ the people are coming in already infected from 13 to 70 years old/ So you know, it's not always that easy. These other things, do you think we impact them? So we can't judge, right? [Women agreeing] That's the purpose of that question, to say you never know what's going on with someone else, and so part of this is just having lots of empathy, lots of understanding, and be able to say what do you need? How can I help you? And they may not be able to give you the story, but there's lots of other things that go on, and we just need to be able/ and people just need to know that because then maybe they want to talk with you. [Women agreeing] If they hear you talking in a certain way about other topics, and I've got this serious thing going on, I might not feel that you're a safe person to talk to. But if you have empathy, you show these things in other ways that you talk, someone might feel safe talking with you or asking you to counsel them for a few minutes. How do you think I may want to do this? This is going on, they know you can't give them a good/ well not a good answer, but they still may need a friend's advice, well I'll be with you, I'll stay with you, whatever you want to say however you want to do, and I'm always gonna say, "I know Dr. … [?] she'll take you, let's go to her." Because my counseling when I went through a lot of things I had to go through some counseling, and mainly my counseling was just so I didn't kill anybody. [Women agreeing] And to deal with my stuff that someone had violated me

and disrespected me, and my anger toward them/ So counseling is two ways. You have to get over all that, before you can deal with stuff. It's not easy. But you know, it's helpful.

(00:45:50) [DC then asks how the women would promote testing in their communities. People say: get one as part of your annual gynecology exam; and have HIV testing days and offer food. DC goes on to talk about picking up HIV early and getting treatment early, and how that can allow them to have a normal life expectancy.]

[00:55:51 END RECORDING]

DC = Dr. Campbell [ ] = side notes/commentary of what is happening
W# = woman/participant # “” = paraphrasing
… = unintelligible
/ = pause or break in the sentence/ interruption/ sudden change in topic direction

[DC says she wants to find out the opinions of the women, and is going to pose some scenarios.]

[DC starts SCENARIO 1]

(00:00:30) DC: As a gynecologist I see this a lot – we have a married woman, or a woman in a long-term relationship/ she comes to my office for the third time, she has a sexually-transmitted infection and she’s married. [A few women laughing, shaking their heads] Exactly. And I make this real clear to her that this is sexually transmitted. Didn’t get it from the toilet seat, you didn’t just jam it up there, it’s sexually transmitted, you know. How do you get these sexually transmitted infections? If you’re married or in a relationship?

(00:01:00) W7: Your husband’s walking out on you, or she’s doing it/

(00:01:04) DC: There you go, you or he. It’s not closed. So we’re going to establish that as not closed. And if you’re sitting there as a female, and you know *you* didn’t step out/ what does that immediately mean? [Woman mumbling something to her friends] What did you say?

(00:01:19) W11: Jodie did it.

(00:01:25) DC: But certainly it’s a hard thing because you can’t put the denial stuff up, because something’s going on, right? [Women agreeing] Now this is a problem. Because if you didn’t have HIV yet, that could be on your plate shortly, right? We already talked about why this woman’s exposed. She’s exposed because/

(00:01:47) W7: Her husband/
DC: Because somebody’s stepping out? [Women saying yes] And?

(00:01:51) W7: The girl’s stepping out ... or the man’s stepping out too.
DC: And she got this. [Meaning the STI]
W7: They’re stepping out, and stepping out, stepping out/ [Laughter]

[DC moves on to SCENARIO 2]

(00:02:05) DC: You become aware that your sister’s husband is having an affair. What you gonna do? [Many women saying: tell her] You’re gonna just tell her? [Women: yeah] How you gonna tell her?

(00:02:14) W11: Hey girl come here, let me show you something. [Laughter]
DC: You’d show her pictures? What would you show her?
W11: Nine times out of ten he’s gonna leave a path, he’s gonna leave a trail, he’s gonna keep some doors something already over [?] again.

(00:02:27) DC: So how/ why would she believe you?
W11: That's why you're gonna show her.
DC: So you would have followed him, and now you're taking her, or you're gonna take some pictures? What you gonna do?
W11: I mean somebody's gonna tell you, and eventually you'd go and follow the trail, see for yourself.

(00:02:44) DC: Would anybody else/
W7: There's got to be an intuition or something that deep down intuitional that a woman has, she knows/ when the behavior changes slightly, something's going on. And we as women on our part need to be strong and not be bothered [?] and get a vibrator. [Laughter] We've got to take care of ourselves/

(00:03:09) DC: So you would cut sex out? If you gonna go get a vibrator you're not gonna have sex anymore?/
W7: Or go to the store and get some condoms, and make sure I've got 'em/

(00:03:17) DC: So about your sister/ she's gonna go get some pictures and she's gonna show 'em. What are the rest of ya'll gonna do? What would ya'll do?

(00:03:25) W7: I would confront him, say "look, I've seen this here," and then I'd see what he's gonna do first. I'll let him know that I know/
DC: So you'd give him an opportunity to respond? You're gonna let him know you know, and then give him an opportunity to respond?
W7: Yeah

(00:03:42) DC: That's a good one. Any discussions over there? What would any of you guys do?/ You got electric phones [???] ya'll are young folks, ya'll are not taking no pictures. I see ya'll over there with your phones out, what's up with that? Would you do that? I mean, would you tell your sister?

(00:04:01) W3: I would tell my sister/
DC: She's 25, she's a young woman, so you would tell her?
W3: I would tell her.
DC: You think she'd believe you?
W3: She'd probably be upset at first but, it's my sister, so that's a risk I'll take. I know she would come back to me.

(00:04:14) DC: So you're gonna take that risk? [W3: mmhmm] And I think that that's the point I want to point out that/ it's gonna be some upsets. But now that you have this information are you going to risk that upset? [Many women saying yes]
W4: I would, I mean, now/
DC: Now that you have this/ more information/
W4: It's a lot going on in those monogamous or married relationships. You know, sometimes it depends on the relationship you may have with your sister, in my case my sister would believe me, but/ you know, if you have sister friends that you might tell something to me because of that level of love for that person, wanna allow them to believe you, they may be in denial about it, and that could be kind of a sticky situation.

(00:05:05) DC: But that's more their response to the information as opposed to what you feel about providing the information/
W4: Right, I would provide it to make sure my conscience was clear.

(00:05:14) DC: So sometimes it is the intent/ that other person might be questioning your intent for why you provided the information? [W4: yeah] But it's not an easy thing, it seems kind of easy at first. But suppose this sister has four kids?
W11: Still tell 'em. [Many women start talking at once]
DC: …she has four kids and now you're gonna say some information that may cause some disruption in the relationship, what happens to that woman and her four kids?

(00:05:42) W11: Well that depends on how strong she is in her … [?] if she's working/ I mean there might still be two incomes coming in, but if she's working she still might be able to survive … [someone cuts in for a second] she's gonna collect something from the judge/ when they go in front of the judge/ [Laughter, many women talking]
W4: See that's what I was thinking/
W11: Maybe in divorce court, but he's gonna pay/
DC: Child support?
W11: Child support or whatever else he got/
W4: And they may be able to resolve it. [Women agreeing] Get an HIV test and go to counseling/

(00:06:19) DC: So it's a potentially resolvable situation, and it's important for us to share that information with them. But how would any of us feel if we didn't share the information and they were negative today, and then in a year or two you have a conversation with your sister and she tells you she's positive. [Women agreeing] So I mean, now that we gain information, talking through these kinds of things help us to potentially have maybe a conversation that may really occur. How we and other women feel about it, just kind of rehearsing that other than you and your own … [?] We just talked about how common HIV is in our community, so/ and we've talked about ways that its transmitted and we know that this is one of the common ways, and so we may be dealing with these types of situations with relatives as to what we personally are going to do./ [Women whispering, mumbling] And I think we've already shared what we think other women are gonna do. What do you think a 70 year old woman will do? And I'm almost that age, and I can tell you what a woman my age would think/ I came up in the age of "mind your own business."

(00:07:23) W10 or 11: If it's a 70 year old woman she … [too quiet]/
DC: No, no, no, I mean/ [Laughter] I mean a woman at my age, how would I deal with it as opposed to how a younger woman would deal with it? Because I come from the era where, women really felt you should mind your business. And you really shouldn't meddle. And so, you know, certainly I've changed because I've grown but, when I see other women my age, 60 or 70, you're gonna hear "that's not my business." But once again, that was gonorrhea and syphilis. And so/
W7: This is your life here, this is different…. If my sister had an affair with a man that's not married, I wouldn't have any problem confronting them. Let them make the decision what they're gonna do… wailt until they're together and then talk to him [them?], this is what I told you.

(00:08:32) DC: So it's good that you're thinking about how you're gonna have these conversations. Because you're right, you made the point this is different. [W7: yeah] And so it's a different response.

[DC moves on to SCENARIO 3]

(00:08:42) DC: Alright, here's your kids. Your daughter or your niece says/ she's talking in the third person, right? "You know, all my friends got boyfriends and they're sexually active." What do you think is going on with your daughter? [All the women say "same thing" or "she's having sex"] She's doing the same thing? So she's seeking for information, and as she's doing the same thing what is she at risk for? [Women: HIV] And everything else, right? [Women agree] Does she know how to protect herself you think? [Women saying no] Do you think most of these young people/
W11: I mean 9 times out of 10 she [they?] probably do but the way it's going they do it…. [??]

(00:09:18) DC: And when you say they do where does she/ where do you think most young people get their information? [Women mumbling, one says "from their friends"] From their friends? And you think their young friends are giving them good information? [Women: no]

(00:09:30) W7: It came but went like that [Laughter]

(00:09:32) DC: So even if they're gathering good information, it came and went like that, huh? [Women agreeing] But are they giving good information? Do we think as a group here that young people who are gonna start being sexually active between the ages of 13 and 17 are getting enough information to be safe? [Women: no]

(00:09:48) W4: Not from their friends, they should get it from their parents.
DC: They should get it from their parents?
W4: Yeah, I got a 15 and 16 year old.
DC: And I like that, but the thing I'd like to ask, as a group, do we think most parents have enough information so that they can give them information? [One woman says something] Yeah I know you do, but we're now talking/
(00:10:10) W4: Now/ then you go back to economics and social systems where people are in poverty, and so you have another generation leading into another generation. When I was in school we had sex education, and I don't think they have it, now I'm not sure.

(00:10:30) DC: We've got some young people here, do we have that now? What do they cover in your sex education?

(00:10:36) W2: What you talked about.
DC: Okay, so you hear these conversations. Do they teach you how to put on condoms? [W2: Mmhmm] [Other women mumbling. MK asks W3 if they taught her that in school.]

(00:10:50) W3: Me? No, not how to/ no, we didn't when I was in school. I mean we had general anatomy of the female and male, but it wasn't never/ you get this, this, and this from doing this. It was never/ when I was in school.

(00:11:08) DC: Was this part of your curriculum, or was this an after school program?
W2: No, it was part of it. Like you had to take it.
DC: Okay, so we're moving because I would say Marissa and I are out in the school systems, even most of the schools that we go to sex education in any comprehensive way is not taught. So when I say you don't/ and it really is driven by the community board, the superintendent, in a particular school. So you

may have gold schools or red schools [?] but as a community it is an abstinence based program. The schools are just like our religious programs, it's abstinence based, and when that's said that they want you to be abstinent, they're not teaching you how to handle the other side. Because you shouldn't be active anyway. As if people are not active. Given that, where are the children/ and yes, parents should do that, but do we feel that just looking in on all communities and families, that our nieces and nephews and those are getting that, and do parents have that information to give? I mean, so, if they don't, they're not getting it in schools, they don't get it in our religious organizations, we know that parents are having struggles with passing that information on, so I would say to the group then where does that occur other than peers. And if we think another 15 year old can teach another 15 year old, do we think that they're getting information to protect themselves? So, this is not for an answer today, but as a community, what is our feelings about that when we look around and we've got 15 year olds all in our families. How are they gonna learn to be responsible? Because there's 2 decisions here: you should not be active, not really. But if you're gonna make that decision, you need to be responsible. So there's 2 separate decisions, and we need to be able to separate them. You know, I'm still never gonna be okay with you being active, but I'm not okay with you not being responsible, especially if I have provided that information. And in many ways/ because you know, even as adults you can have …… [?] so you may be able to say it, you may still be able to get on a community group, you may be able to advocate for their schools, but you're providing as a parent or a leader multiple ways for someone to get the information …[?] so they can't say "I don't know," like Bill Cosby said, "I don't know." So but as a community, are we doing that effectively? Because behavior at that age, do we think that it carries over to adulthood? [Women say yes] Right. We're the mothers, we're the women who are responsible for our families. We have to think through these things, not just for me, but as a community.

(00:13:55) DC: And we already answered that, how can the community respond to this? So it may mean providing information. Do you agree with that? [Women say yes] Where would you recommend that some of these education programs occur?

(00:14:06) W12: In the church?
DC: In the church? …. Do you have sex education in your church here?
W12: No.
DC: So we don't have it here, but it should occur in the church. But if it's not occurring in your church, your church represents all the churches, for the most part. We have a hard time getting into churches, so where's it going to occur? We have a hard time getting you guys in here to teach you. Where's it gonna occur?

(00:14:36) W4: I would say you. One way would be/ I mean I know she said that she gets it at the school, but you would have to find a way to get it into the neighborhoods where they're impoverished. You'd probably have to be creative, what could you do to pull in a lot of the young people in that area to empower them with this knowledge. Because if you go to the school, then you lose a lot of people that are dropped out/ So you know like, maybe some of the community centers in the areas/

(00:15:14) DC: Who would help us get into them?
W4: Community leaders, because they still exist in those communities. You have people that work with/ in those communities. I have a friend like that serves lunches in the summer time in a certain

impoverished area, so you would have to get together with some of the community leaders from that area, and then see how maybe you could pull them/

(00:15:41) DC: I like that idea. Maybe you can offer that as getting back in touch with us, and it only starts one place, one person says well this person may be able to help you get into that one's schools, or that one group, so part of this is to say that I need your help to do these out of the box kinds of things, because we're pretty much out of the box. We're at community forums like this trying to find ways to impart education as well as to protect ourselves.

(00:16:09) W7: Networking is very good because just going back/ we're becoming educators, so just going back to whatever things we're involved in, like I do a lot of things to rebuild a proper place for children [??], I could go to the program director and say listen, I was educated with something this past weekend and it was very informative. Why don't you go and talk with this lady and see what we could do/ …[multiple people start talking at the same time]

(00:16:38) DC: … write those suggestions down because we'll take those suggestions and try to build on them, and also in your flyers my name and my contact information, and you need to shoot me these kinds of things because this is what we're here to do as a team, each one of us step on a should and keep infiltrating information into our communities to increase the educational level.

[DC moves on to SCENARIO 4]

(00:17:00) DC: Alright, here's the next one and then we're finished. A woman is married and she finds out her husband's on the down low, [A few women laugh] do we think that this is common?
[All women saying yes]
W11 & W1: Yes, it's common.
[Multiple women talking]

(00:17:19) DC: … and this is … because it's a relationship with another man versus another woman, so it's different values for extra-marital affairs with another man versus a woman. [Laughter] But you feel strongly that it's different?

(00:17:34) W4: … it's politically incorrect and all of that, but it would just/ I could not bear that/

(00:17:43) DC: And that's okay. This is our feelings about it. But we think that these things are happening in our community. So it means that some of our sisters might be dealing with this, right?
[Women agree] Yeah.
W6: Yeah, they are.
DC: Right. And it increases their risk of infection. More than even vaginal intercourse, so I think/ are we all aware of this in our community? Do we all know someone who's potentially/ and it's ok to be that but are they doing other behaviors that are putting people at risk? Are they? You think? [Women saying yes] It's a tough topic, huh? It's tough/ What are the barriers of telling women about MSM behavior? What barriers do men have telling women "I also like having sex with men?"

(00:18:39) W11: It's embarrassing [?], I don't think he would tell her.
DC: So you think he's just not gonna tell her? That's a barrier, not telling her. Why?
W3: They don't want them to think that they're gay.

DC: They don't want them to think that they're gay. [Women agreeing] So they're just not gonna tell them?
W4: Maybe it's homophobic, I think/
DC: A lot of women are?
W4: No, our community/
DC: Our communities are homophobic/
W4: Yeah, and it's probably/ and then you know we have these rumors going around, a brother's on the down low/ they're not like that, but in an incarcerated situation they are and then they come back home and, you know, that's there life there, but when they come back home it's not like that and so/ you know, you don't what's true and what the media is sensationalizing. And you hear about different guys that come home and start to spread rumors about being gay/ you really don't know if it's true, or if somebody's just hatin' on them, but I mean that's a big topic in our community now. "Oh such and such just got home, he did 10 years and you can't stay in there 10 years and not do something."

(00:19:47) DC: So women are beginning to sense that and talk about that in your community?
W4: Oh yeah, that's a big time topic
DC: Does that stop them from getting in relationships?
W4: I mean, somebody will take them in [Laughter]
DC: So they're getting busy with somebody.

(00:20:06) W7: That's not just incarceration/ that's not restricted to incarceration, I've heard about the down low from college campuses. That was the first I'd heard of the "down low" was on college campuses.

(00:20:18) DC: Can you expand on that, what do you mean by that?

(00:20:22) W7: That men were being with each other/ In those sororities [she means fraternities] and they were keeping it/ that was one of their initiation processes, and it started in colleges where it was called "down low."

(00:20:38) DC: Interesting. So it's everywhere, I mean it's not uncommon/ [W10,11,12 whispering among them] We got some whispering over there, share with the group, tell us what you're thinking. Anything you want to share? [Women shaking their heads no] So how does gender affect exposure to HIV? Do you feel that women can really talk to their partners about condoms? And is it a difference between married women and single women in being able to do this?

(00:21:12) W11: A married woman, if she talks to her husband about it then there's the feeling that one of them's creeping. One of them's out, one of them's stepping out. And with the singles, it wouldn't matter because if they're single they probably would use protection more quickly than the married couple would. [W10, 5, 6, nodding and agreeing]

(00:21:35) DC: So you're saying that bringing this up in a marital relationship, it implies creeping?
W11: To a point, yeah. When you get married you're supposed to be as one, not 1 plus 2 plus 3 plus 4 [Laughter] But then again to a point there's some marriages where there is/ the virus is already there, so they use protection anyway.

(00:22:00) DC: So people/ and it is true, it is our recommendation that if you're positive, even if your mate is positive, you should always use protection, because you can get another strand of it. So it's always/ even within that. But for married women, do you think it's a/ I mean, is it an easy discussion to go have/ because now you're not/ now you know it's not about creeping. Now it's that you don't know what everyone else is doing and you want to use them. Or, you're checking that box because you didn't act on that intuition before, it goes and comes periodically but you didn't act on it. But now you're sitting here saying "hmm. If I'm negative today, I don't want to be positive tomorrow." [Women agreeing] How do we have that conversation when we go home? Do you think that that's a conversation that's gonna happen when you go home?/
W11: No.
DC: Right. I mean, I don't know if you're right, but/ [Laughter] It's a hard conversation. So can married women introduce condoms in their relationships?

(00:22:58) W7: Yeah.
DC: How are they gonna do that? What you gonna/
W7: I'm single! [Laughter] I would just, you know, if I wanted/ and I'm older years now, I was so pissed at one time, but/ now there's a knowledge and understanding of life and general, I don't want to catch any disease, and I always think somebody/ sometimes I've got an intuition that somebody's doing something, so I want to … somebody/ you touch me [?] [Laughter] That's how I feel now because I don't want to catch anything, because people say they're not doing anything and deep down inside you know, you can see that something's not clicking quite right, because you know you're not doing it. So he's got to be going somewhere else and getting it, you know. [Laughter]

(00:23:52) DC: Well the sister here implies that women have intuition, do you think that most women know when their mates are stepping out?
[Women at the back 2 tables, W7-12, are saying yes. Then jumbled discussion erupts as some people are unsure if they agree, followed by laughter. Some women are saying "you just know."]

(00:24:28) DC: So everybody's stepping out at night so their behavior's changing? Do you know where most of your affairs occur? Where do most people start their affairs?
W1&7: Work.
DC: At jobs. So do you think that 2 people can get busy from 5 to 6 and then come on home? [Women agreeing] So how do you know?
W1: You never know/
W7: You just never know…/
DC: Oh! What did you just say?/
W7: You never know/
DC: Right, you never know.

(00:24:59) DC: Because I'm wondering whether it's truly intuition, or do we just never know? Because I think if people want to deceive you, can they? [?] [Women agree/say yes] So do you know if someone's intention is to deceive you, how do you know?
W7: You don't.
DC: Right. So at first you think you have intuition and you know, but when you start talking it through,

the reality is, for periods of time, you may never know. Even/
W7: They're gonna ask you, "did you see me?" [Laughter]

(00:25:28) DC: But you just never know, so how are women going to deal with this, and especially, how are married women going to deal with this? And when you peel it away, it's a hard thing to know. I mean, because there's someone wants to just do that from like, from … 3 to 5, because it's at that location, and nothing else is changing, you never know. And women are okay with this stuff/
W?: I'm not.

(00:25:51) DC: Okay, I'm almost finished, I just have two more questions. And I think you answered this, and do you think that talking about these condoms is an accusation to your partner that he's creeping or cheating? And I think one of your sister's here said that she thought that that's the case. Is that what most women feel here? Do you think if you have that conversation that's what it means?/
W5: I don't.
DC: You don't? What do you think?

(00:26:15) W5: I think that it could just be for a health discussion, it doesn't have to be an accusation that he's cheating but, just so that we can get on the same page.
DC: So it's how you say it?
W5: Right.

(00:26:29) DC: Do you think that men having this information would make it an easy conversation for women? Easier? [W5: mmhmm]

(00:26:35) W4: If they were a part of this discussion, say the women who are married here/ then that could be their Segway into having that conversation, because you'd be like the mediator [Laughter] …They would have the same information and they would know why the conversation's coming up. And he wouldn't have to feel like it was an accusation, so it probably would work in that sense/

(00:27:05) DC: So how're we gonna get men to the table? That's a challenge/
W7: They should be here too…
DC: Well you know, in order to bring our men, we also/ we're gonna talk about this in the next session after we take a break, in order to get men here, we/ especially if we're bringing them to something that they don't want to do, we first have to have the information, and then use our powers to get them to a discussion that's gonna be useful. So it depends on how we ask. You can say "you better show up at that meeting!" Or, "I learned some very important information at this conference and I would really like for you to come to this meeting next week, I would really feel supported if you did that. Can you do that for me?" Which one do you think is gonna get a yes?
W6: Last one/ [Laughter]
DC: Depends on how we ask. Passive, aggressive, or assertive.

(00:28:07) DC: Well ok, now I think he's/ I suspect he's stepping out, my intuition's kicked in. How am I gonna tell? What kind of conversation is that? [Silence] Nobody's gonna tell him?

(00:28:26) W7: Men like to tell everybody about … [?] how they don't like to use condoms/
W6: Yes/

DC: Why do they say that?
W12: Because it don't feel good.

(00:28:38) DC: We get that a lot, we're gonna talk about that after we take a break. But I think this is happening in our relationship. Feelings are coming up, I've been keeping it down, now I may need to have that conversation when I go home. How does that work? Seriously. Because you know you had some thoughts and now you're hearing this information, now you're kind of feeling like you need to have a conversation. It's difficult. Nobody's got/ you're quiet now, it's almost as if you don't know how that can hit the table.

(00:29:18) W11: It can. Fix him a nice meal/ [Laughter] Fix him a nice meal and tell him we need to talk.

(00:29:31) W4: Since we got all this information, I would be like I want you to get tested. Because [Laughter] Well I mean if he's already having an affair, and he has stopped using a condom/
DC: You've been exposed.
W4: Right. So I'd be like you need to go and get tested because I think something's going on/ [Multiple women start talking]

(00:30:00) DC: So in other words, it's/ you almost have to take a deep breath to figure out how to address these types of concerns in our personal lives, and have empathy for how is a woman going to address this stuff in her relationship. If she's your sister, you already told her. How is she/ now that's it. Now she has to have that conversation. How do you do that, what's important, and I think the sister right here said, one of the important things is, even without accusations, you just both need to get tested. [Women agreeing] Because we need to know where we are, and then you need to begin to figure out what's the next step. Because you don't always have to leave/ because remember sex is different from a relationship, and men go for a lot for sex, but they're not relationships. And as the mothers and the mature women, we have to see them differently in order to address the things on our plate. Because a lot of them will take some if they can get some.

(00:30:58) W11: Yeah, that's right.
DC: And it doesn't mean love. I mean, for the other woman it might be love, but that's not the same thing for men. They're just gettin' some. So a lot of the discussion's what it means for our relationships and our communities.

[DC asks, So how can we get women to get tested? Women say: go to the health department where it's free; at your annual gynecologist appointment; offer incentives.
DC then asks where else they can go with this program. One woman suggests making it part of the pre-marital counseling at churches, because many make you go through counseling as a couple before you can get married in the church. Another woman suggests her group "Innovative Approaches" and doing a presentation there and having them being a group partner/sponsor. She says this is in Wayne County in the Health Department.]

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W# = woman/participant # “” = paraphrasing
… = unintelligible
/ = pause or break in the sentence/ interruption/ sudden change in topic direction

[DC says she wants to find out the opinions of the women and how they deal with things, because this is really important. So she is going to ask them some questions.]

[DC starts SCENARIO 1]

(00:00:38) DC: For example, suppose your friend came home and you know that this is a person who is in a steady relationship, or thinks they’re in a steady relationship, or they’re married/ and they’re now telling you they’ve had a couple of sexually tran/ you know, gonorrhea, Chlamydia, two times, or trichomoniasis two times, and this person doesn’t seem like they understand what happened. How do you feel about that? I mean, do you think that this woman’s at risk for HIV? [A few women already saying yes] What would you say to her? You think she’s at risk? Why?

(00:01:11) W2: She’s having unprotected sex, first of all.
DC: But she’s married.
W2: She’s married? Well she’s getting/ or he’s having unprotected sex. *Somebody* is. Well *she* is, with him, and he is, and you keep getting this disease. It only comes through sex. And if you’re getting yourself cleared, and you get it again… [interrupted by an announcement over the loudspeaker] something’s going on/

(00:01:34) DC: But she’s your girlfriend. I mean, what kind of conversation are you gonna have? [Loudspeaker announcement still continuing]
W2: I’m gonna tell her that he’s cheating/
DC: So you would be talking with her like that, you think that somebody’s cheating?
W2: Yes. It’s either you or him. One of you are cheating. And that’s honest/

(00:01:55) DC: I mean, because it’s something that I deal with as a gynecologist. And people want to say that it’s coming from the toilet seats and stuff and I have to have this conversation two or three times. But how does that woman go home? I mean, is it all/ from all the things that you learned, can every woman go home and have that conversation with her mate? [Women saying no] Why not?

(00:02:15) W7: Someone might get beat

(00:02:17) DC: Right. She may get beat/ so some women are not in safe situations. And so some women who are getting this who may be your friend, are also not in safe situations. And so when you’re not in a safe situation you can’t protect yourself. So some of our sisters are getting infections because they are not safe in their situations physically. And even though you may be their friend, and you know what’s going on and you get a sense that they know what’s going on, they keep coming back with these infections because they can’t do anything about it. So for you as a group when you hear about this, you know, some people are becoming HIV infected because they don’t have any relationship power. That’s not a good

place to be. But once again, we're 70% of these HIV and other STI infections, and so our sisters and our cousins are having these types of problems, not really being able to protect themselves. Do you guys agree? [Women nodding and agreeing] (3:14)

(00:03:21) DC: Well this is as a review, how do you get an STI?
W2: Sex. Unprotected sex.
DC: And so why do you think she's exposed to HIV?
W4: Because HIV is also a sexually transmitted disease and if she's getting one, she's at a high risk of getting the other one.
W7: And if the husband is stepping out, and he messes with the right woman, he's going to bring her something that is incurable, like a virus.

(00:03:55) DC: When you said the right woman/ oh, you meant a person who's infected…/
W7: Right. *It.* The…

[Moves on to SCENARIO 2]
(00:04:10) DC: You become aware that your sister's husband is stepping out. What do you do with your sister?
W11: That's my sister. I'm gonna shoot him! [Laughter]

(00:04:35) W9: Me personally, I'm gonna go ahead and have evidence ready, so it's up to her to confront her husband or … other than that, I'm gonna leave it alone.

(00:04:46) DC: What kind of evidence would you give her?
W9: Um, we have cameras on our phones/ [Laughter]
DC: So you'd follow him and you'd take a picture?
W9: It would be right off … where I'd just see him with another woman. I'm not gonna say "well I just saw your husband with some other chic or whatever. I'm gonna make sure that if I see you again, or it just so happens that I see that lady, and I talk to her, you know/ it's a way to play it off, and … then just/

(00:05:15) DC: You're gonna talk?
W9: Well I'm gonna be real, because now, these days and times, you have to be honest and you have to be upfront. Because you don't want it to backfire on you. So you want to at least be and honest person and let your sister or whoever know something is probably going on that you should be aware of, and not just keep it to yourself, because you never know/ I mean, if your sister or whoever does end up with AIDS or HIV or whatever then you're gonna be like "oh my gosh, I could've told her." So once I tell it, or just kind of/
DC: Then it's up to her to respond.
W4: Yeah, I mean it's up to her.

(00:05:58) DC: What do you think a 70-year old, or 65-year old woman/ do you think older women would do the same thing as this young lady here? Would she tell her sister?
[Older women shaking their heads and saying "probably not."]
W4: Different culture.
DC: So/ because I don't have any older women that age/ just from your thoughts, do you think that they would tell? What is their opinion about this? Older women?

(00:06:23) W2: That's what a man's supposed to do.
DC: He's just being a man.
W2: Mmhmm.

(00:06:29) DC: So it seems that there's an age gap. Just something different that younger women will do and older women will do. But those older women were not in an age of HIV/
W4: Exactly.
DC: So their behaviors were in the age of gonorrhea and syphilis, and you just take your penicillin and you just deal with what you're feeling. But it's not the same. Would you/ well I was gonna say would you coach that older person to do something different. But I was thinking, would that older woman even share with you what she's going through? She probably wouldn't even talk to you/
W4: She probably wouldn't even talk to you.
DC: So it's just a difference in what younger women would do/ and how do you think your sister will take this? Do you think/ I mean, how do you think your sister's gonna react?

(00:07:17) W9: It could go either way. Like, she could be like, "you know what, thank you sister for telling me so I can at least handle my business" or whatever, or she could be like, "well how do you know? How do you know, I don't think/" and you know, you could start arguing. So it could go either way/

(00:07:31) W10: Or she could say "I know."
[Multiple women talking at once]

(00:07:45) DC: I think after this presentation you know that she is, do you think she's at risk? Is she at risk for HIV?

(00:07:52) W4: Definitely.
DC: Because people are not using what? When they step out?
W4: They're not using condoms.

(00:08:03) DC: And I think that was the other question, what do you think others would do? A lot of you are saying that you would tell, but would all women go and tell? [Someone mumbles something] You don't think they would? [Women shaking their heads "no"] Even some young women wouldn't tell?

(00:08:17) W9: Some of them might actually go to the man.
DC: That's interesting. Go to the man/ But at least you'd do something.

[Moving on to SCENARIO 3]

(00:08:30) DC: We've got some young people here. What would you do when you find out that your teen is talking in the third person: "All my friends are sexually active."
W2: Birds of a feather flock together.
DC: Yeah but what would you do as a parent or an aunt? When you're sitting here listening to this story? How are you going to respond?

(00:08:51) W4: It's time to start sexually/ you know, talking with your teenager. You should have talked to them earlier, but if they're telling you that all of their friends are doing this, and all of their/ you know,

then they're in their network/ [W2 says something at the same time]
W2: You need to start teaching them to keep them safe/
W4: …you need to keep them safe. Making sure that they're using safe sex and that they know how to protect themselves. Because if they talk about all their friends are doing it/ they're right down the corner.

(00:09:17) DC: How would you ensure that they get the information/ this information? Where would you/ how would you/ would you teach? Or do you take them somewhere to be taught? Where do you take them?
W2: Do it all. You teach them, take them/ like here, just over and over and over and over again, no matter what. So at least you got to keep it coming to them. So that they can hear it and then at least practice open safe sex/

(00:09:41) DC: So if we are going to say that young people need more of this education, where do you think they're gonna get this? Where do they get this? Somebody said their peers. Do you think that that's ok?
W2: No. False information.
DC: A 14-year old teaching a 14-year old? So where do they get as/ where do we want them to get it?

(00:10:00) W7: We want them to get it from home. Or like, I had a teacher that basically put her job at risk and scared her class straight. And I must have been in sixth grade, and she showed us what it looks like to have gonorrhea, chlamydia, and everything like that. That scared me straight from sixth grade. But what teachers you have in a society that's already/ we don't have enough jobs as it is, that's gonna put their job at risk and say, "you need to know this. You need to see this."

(00:10:40) DC: So schools are one place.
W7: Definitely.
DC: That *could* do it, that doesn't/
W7: But are not.
W4: The church could do it, but they don't/

(00:10:48) W12: I was about to say, I had a sexual ed class when I was in the eighth grade at … [name of the school] We had a lady that/ she came like for a week and then we had like a test about it. It was only like, that one time/
W4: What did she show you, this teacher? What did you learn?
W12: She tells us about like Gonorrhea, she talked about how to put on condoms, she talked to us about HIV and AIDS, she talked to us about like different ways that females and males react during sex and different things like that.

(00:11:22) W7: But in my opinion I don't agree that that's enough. That's the school that I taught at, I did my student teaching, so the one week out of however many days, that's not enough. It's just not enough. It needs to be realer [?] you know, like I heard students of mine whispering and talking amongst their friends about who they wanted to sleep with, and this and that, but they really didn't *know* know the consequences of doing what they were out there doing.

(00:12:04) W4: And you said that was in high school?
W12: That was in middle school.

(00:12:08) W1: We had that too in eighth grade but she didn't tell me all that. She was just like/ I don't know, it was just that she didn't really go in depth, she was just like, you know, you can be at risk if you don't use a condom, be abstinent, and stuff like that. That's all she basically told us.

(00:12:24) DC: It was the same week program?
W1: She did it like three days, and like one of the last days you'd get like a response… [Women start laughing, can't hear the rest of what she says]
W11: Well a week of school is hard to … [More laughter] But I think it's different in different states. Because I'm from Maryland, and my kids actually learn/ [Cut off by an announcement over the loudspeaker] They went in depth with them, with sex, and this was in third and fourth grade. To the point that I had to sign a permission slip. And it gave the outline of what they do. And the second part … answer. On certain questions they had to …. [Laughter]

(00:13:24) DC: So it varies from state to state/
W11: It does vary/
DC: And it varies from whether parents can do it or not, but would you guys agree that is there any place that people are getting *comprehensive* sex education? And then where should that occur? Because it isn't just a couple of days when you think of something as comprehensive it's a continuous learning process. So as our young people, where are they getting that? If we don't know if parents have been taught, how can they teach their children? If it's not consistently taught in schools, and it's not taught in churches/

(00:14:00) W5: My mother, she sent me/ took me to the clinic, and they had these programs where they give you the birth control and show you the videos, and/
DC: So she took you to a health care provider?
W5: Yeah, she took me to one/
W11: My parents took me to Planned Parenthood.

(00:14:22) DC: So once again, taking out to an organization [Women still talking in the background]
W2: See the problem is they should give it right back to the community, because that's where the community is sharing in. And I guess when I was growing up we had a lot of … community centers, and like this, people used to come in and have an involvement. Because that's what's going to happen, you're going to be close to whoever you are in those communities, and that's how they should give back by at least trying to share it that way, because it's the community who's doing it. So if we could give back/ but that's so hard.

[Move on to SCENARIO 4]
(00:15:03) DC: Here's the last scenario, I just want to talk/ we've probably talked a little bit about this. You know, you have a married person or a person who's a college student, and she just finds out that her mate is on the down-low. Do you think that that's common?
[All women shaking their heads and saying "yes"] We have a behavior that's very common, and down-low, when you're having anal sex, and there are women who like anal sex too, but anal sex increases your risk because the … in the anus is very thin, and that tissue can break, and once that breaks you get a port of entry. So just having anal sex just increases your risk in general/ [Women whispering something, start laughing] Because there are women who like anal sex too, but when you think about it you think of just men having sex with men, but there are women who participate in anal sex as well, so women can be

becoming at risk and it's also from the type of sexual activities that occur. Do you think that there are barriers for men who are on the down-low telling women?

(00:16:21) W4: Of course.
DC: And? / You think that that's why they don't tell or they tell?
W4: I think that's why they don't tell/
W2: Stigma/
W4: Because it's like you said, coming out and by coming out it may risk losing what they have and they'd rather not let people find out because they don't think it's an acceptable behavior. And so to come out and say that just puts you at risk of being ostracized.
W2: Which is a sad thing, it's how you think of it. [?]
DC: What do you mean?
W2: I hate to say it[?]/ because if they said like, they was the initiator when they was doing it, then they don't feel like they're gay.

(00:17:03) DC: So it depends on who's the initiator?
W2: Exactly/
DC: If they're the receiver they're gay, but if they're not the receiver and you're doing it, then you're not gay, you're just having sex.
W?: Which is a good point because even in that/ For Colored Girls, that's how he perceived it, he's not gay. Because he's the initiator.
DC: So he's the receiver.
W? (same): Right, so he don't think he's gay, and so they look at it as a different stigma. They just like it tight or whatever, so they have a different perception of being gay.

(00:17:33) DC: Right, right, right. So that's true. You know, from this point of view, do you think that you can talk to other women about using condoms and HIV?/

(00:18:00-END) [Session is stopped so that the women can fill out the Post-Test before leaving, since the Library where the session was being held was about to close.]

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… = unintelligible "" = paraphrasing
/ = pause or break in the sentence/ interruption/ sudden change in topic direction

(00:00- 00:01:45) [DC finishes talking about the complex social factors that increase HIV in Black communities, and especially for Black women. She then introduces the focus group section, explaining that she would like to hear from the women and get their perspectives, and also get them to talk to each other about these issues.]

[Starting SCENARIO 1]
(00:01:45) DC: These issues are more common than we think, and I'm a gynecologist so I see this all the time. What's going on with this married woman who happens to be your friend, she came to me and I have to tell her "no, you didn't get it from the toilet seat." You know, she's married and she's got her third sexually transmitted infection. You know, we're sitting here and/ because if you say that I got it from something, then what do you have to accept?

(00:02:11) W6: Her husband's cheating.
DC: Or you. So she's your girlfriend and she's trying to tell/ "well I got it and it must have been from a toilet seat or something." You come to this program, how do you feel about what she's saying?
[W8 mumbles something]
DC: You've got to speak up, I know you've got some comments.

(00:02:25) W8: Well, I'm too real. I'd be like/
DC: No, be real girl!
W8: Yeah I'd say "for real, you got it from the toilet seat? For real? For *real?* So it had two legs and a heartbeat?" [Laughter]

(00:02:45) DC: I mean, so you're talking to your friend because you're surprised she's saying it like that/
W8: You know I can use that line, "for real? For real?" If she's my friend she wouldn't tell me a lie, I hope.
DC: About whether she's stepping out?
W8: Well I mean if she is, that's your business. But I'm gonna need you to put something on that.
DC: Right, right.
W8: That's what I'll say, "I'm gonna need you to put something on that if that's what you choose to do, you need to put something on that, and you need to go to Walmart, they have condoms for women." [Laughter]

(00:03:13) DC: Right. So you know that she's at risk and you won't let her slide with telling you/
W8: No.
DC: that she don't think that happened. You gotta say something/
W8: Well I would just tell her you need your toilet to put a condom on. [Laughter]

(00:03:31) DC: And what if your friend is looking at you and she's saying, you know, "I'm not stepping out, I haven't stepped out since/ I really, honestly haven't stepped out. I wonder why I'm getting this?" [A few women laugh in disbelief, everyone starts talking at once]

(00:03:53) DC: …she's talking to you like that, saying that, what's going on with her?
[Many women: She's in denial!]
DC: Right. So we all have friends that go through something and are in denial about it, but she is trying to convince you, "I ain't stepped out, and the doctor said this but you know, I know my man and this definitely came from some toilet seat or something."
W2: That's crazy/
DC: She didn't come to this program/ No, really.

(00:04:19) W6: It's sexually transmitted. It doesn't say toilet seat, it's *sexually* transmitted. [Laughter] Somebody had sex in this situation/
DC: Right.
W6: And you got it.
DC: So you get it and you're gonna just say in different ways so that she tries to get it. You're not gonna let her weasel out on that.
W6: Oh no.

(00:04:39) DC: Because you remember that she's in my office, I'm telling her the facts. I'm not having a dialogue with her. I'm saying, "ok, this did not come from a toilet seat, this is sexually transmitted. You might need to consider that something is open in your relationship." And I'm not saying it's him, because it could be her. I'm just saying, "you get this from unprotected sex, whether in a relationship or not." And so, she's left without/ because I'm not in a psychology conference here. I'm not a counselor, I'm giving the facts. And so this is how I'm treating it, so you're probably the first person she's come to, to see if she could talk this through.
[W8 whispering something, sounds like "if you can't talk to your partner…"]
DC: I need you to stop whispering and speak up! [Laughter]

(00:05:24) W1: If it was me, he would be the first one/
W8: Who would be? [Hard to hear]
W1: Yes.
DC: You'd do what?
W1: If it was me/ yeah.
DC: So you'd be right on him, right/
W1: No, I'm not gonna be/ I'll be right on you.
[Women keep whispering; again, hard to hear]

(00:05:41) DC: So you're saying that/ If some of these women's are leaving the office going right to their men and getting ready to have a get down/
W1: Exactly. [Laughter, everyone talking at once]
DC: … "Let's go, because I know I didn't step out!" [Continued laughter]

(00:06:06) DC: So even if you didn't know the other way, because you know, when you want to hide stuff, you can hide it for a while. But meanwhile, someone could have gotten a sexually transmitted

infection. So you show up in my office and I tell you this, and you know you're not hanging out, so that means that I'm getting ready to go make a confrontation.
W1: Just like … said, "why did I get married? [Laughter]

(00:06:33) DC: But it leaves the confrontation.
W6: They'll get told you have an STI, and they'll tell they're partner, they'll get treated, and like, this is what he get/
DC: Say that again?
[Other women agreeing with W6. W5 helps clarify:]
W5: They think that/ they may be messing around, so they think "I did it." He'll think it came from just him, and they don't know, you know? They'd never know.
(00:06:57) W8: Oh, both of them could be doing it, but not know. [Women agreeing]

(00:07:03) DC: So she said that if the woman was messing around, she's not telling me, she's got the information. She just thinks that maybe it's *her* messing around. So she goes and gets treated, and didn't say anything, that's why she showed up the second time. So it is true that in relationships it's not just men. And you can have multiple people messing around, and everybody does whatever they want in a relationship, it's not for us to judge. But you're her friend or her sister, and suddenly after this program, what you're thinking is, "alright, it's gonorrhea and chlamydia this time, this is my sister, and she's on a roll she could get HIV. That's some chronic stuff. How am I gonna communicate with her? How am I gonna tell her how much I love her and she if she can break this cycle? Because she's your best friend because/ if she's having this conversation with you, she's a close friend. [Women agreeing, one woman says: yeah, she'd have to be.] So it tells you how close HIV is in our networks, of our friends being exposed to this.

[Move on to SCENARIO 2]
(00:08:05) DC: Here's the second one about your daughter. Oh no, this is your sister. You're aware that your sister's husband is having an affair/
W1: Blood is thicker than water, I would be telling her.
DC: You'd what?
W1: I'd tell.
DC: You'd just walk up and tell her?
[All women: Yes! It's my sister!]

(00:08:26) DC: And she tells her man, and he says, "wasn't me. Wasn't me."

(00:08:29) W2?: First of all, he would be touched, and then I would…/ [Other women cut her off]
DC: So you would… [Other women still talking]
W2: In case I'm mistaken or something, you know, I don't want to go at her with drama when it's not warranted. You don't just take something to somebody without/
W1: the facts. [Women agreeing]

(00:08:49) DC: So you go and talk with him?
W2: Yes.
DC: "Wasn't me."
W2: But if I saw it, it's a wrap [?]/

W8: I'm gonna call your name out/ [Cuts of W2]
W2: There is no 24 hours, if it's true and I know it I'm going straight to her after I leave you.

(00:09:03) DC: So she would know this is a real problem, she's been to this program, she knows that her sister is now at risk for a sexually transmitted infection, particularly HIV, and she decides she's confronting *him.* And after you confront him, then you go and confront her. What would the rest of you do? What are your thoughts? If I was 70 years old, what do you think I would do?
[Some women answer "same thing"]
W2: Same thing with the sister's husband. Same thing.

(00:09:36) DC: And do you all agree? Think about your mothers or your grandmothers.
W8: No, they'd have kept it a secret.
DC: Thank you. So you need to be aware that there's what they call an age difference, culture difference/ and what we do as young women may not be what older women would do. And you may be having a conversation with a grandmother or someone who's 60/65 and who's chose to share that with you. She's not going to tell them, but she's just saying, "yeah I caught [called?] such and such out," and suddenly your ears perk up. And you have to have a conversation with your grandmother, because she's not telling. Her culture says, "mind your own business. Keep it to yourself." How do you think your sister's going to handle stuff like this?

(00:10:20) W6: She's gonna be embarrassed. [Short silence]
DC: Any other reaction your sister might have? [Many women start talking]
W3: My sister would take my word over his. [Other women still talking]
DC: Your sister will take your word over his. Will all sisters take your word over/
[Women: no]
DC: So some sisters are what? [Many women start talking again]
(00:10:40) W8: "You're just mad because you don't got no man." [Women still talking]
DC: So the bearer of good information, and well-intended, may not always be received.

(00:10:52) W14: I've been in that situation before/ I've been in a situation like that, and all I'm gonna do is share what I know, and what you do with that is on you. You know, but you've got to say something you can't just sit on stuff and then she gets hurt anyway. [Women agreeing]

(00:11:06) DC: So you have to have good intentions when you go, and you have to be prepared that it may not be "oh, thank you for telling me." It may be what this sister said, you know, "you just jealous." [Women agreeing] And you know all sisters don't have good relationships. So if I don't have a good relationship with my sister, I may or may not tell her. But still, from this program, you walk away knowing that what we do impacts. Even whether someone gets infected or not, because maybe today they weren't, I didn't say anything to them. So it's a hard decision to do that, but having affairs is not uncommon we said in our communities. Is that right? [Women agreeing] So, these people are somebody's sisters/ so somebody's sister's getting stepped out on and increasing their risk, and especially when we saw that with the original statistics, that we're 15 times more likely, and we're 80% of the cases. So maybe a lot of us are not talking to our sisters. I mean, just being very real/ [Women agreeing, shaking their heads.] There may not be some conversations going on that need to go on. /

[Moves on to SCENARIO 3]
(00:12:15) DC: Ok, here's your kids/ She's not talking about/ she said all my friends are sexually active/
W8: Oh that's my cousin right there.
DC: What do you mean? What do you mean by that?
W8: She's having sex, she's sexually active/ [At the same time, W12: that could be true.]
DC: Okay, so/
W8: I say keep right on acting like your friends, you can wear my black dress. [?]

(00:12:39) DC: What else could we do?
W12: You know, but here's the thing/
DC: Because I won't be mad and disappointed with them, [?] so we're just/
W8: I was very upset.
DC: Yeah.

(00:12:45) W12: Well here's the thing, that I know in other cases, like, you do have friends/ here's my scenario: as a teenager, a long time ago, I had lots of friends and we had an open relationship with my mom, so we could tell her stuff about our friends and stuff being sexually active and having several boyfriends. So you're really/ is your person necessarily at risk? Not if your parents are talking to you about it and you have open and honest conversations. But I think it's something that was mentioned in a black community, that my parents are pastors/ that our churches tell us not to tell our parents/ I mean, the kids not to tell your parents that you're having sex, because you're not supposed to have sex. And we're not getting knowledge and imparting that knowledge to people. But, I mean the kid could not be, just because their friends are doing it. They could be more susceptible because their friends *are* doing it and be peer pressured, but you know, you can have different situations. I think that's where the open and honest communication comes in and as generations are going, people are starting/ more parents are starting to have these conversations with their daughters and things of that nature.

(00:14:08) W14: Well I was gonna say I think a huge problem, especially in our community is some of the music that is so popular with our young people. You know, back when I was a teenager my mom used to talk about all the stuff I used to listen to and I didn't really see the big deal. Now you can't turn on the radio without people talking about grinding down and all these sex moves, and it's just getting younger and younger, that it's so, like, kids are getting all this sex talk, and so no matter what you're telling them, it's not being reinforced by popular culture. [W12 agreeing]

(00:14:38) DC: I'm only smiling because I had that discussion with my son. [DC tells a story about how her son loves music, and pulled out all of her old music, and the lyrics have just as much sexual innuendo and/or sex talk in them. The music is slower, but it says the similar things.] [Other women start talking]

(00:15:25) DC: We tend to want to believe that things change in cultures/ not cultures, in ages. And sometimes we're only seeing it through different eyes, and I no longer say that because my music was doing the same thing from the 50's and 60's. And it didn't seem like that to me, but when he started to play the 60's and 70's, he was still grinding and touching/

(00:15:48) W14: Was it as explicit as it seems now?/
DC: Probably not.
W13: Look at the videos…/

DC: I wasn't saying I was convinced, but I was just saying that it was still there. I think this young lady was saying videos/
W13: Videos are tied with it, and Marvin Gaye singing and it's not gonna be the same thing as it would be out now, seeing girls/ and they're letting them be out in thongs and the pasties, and you can see this right on daytime TV.

(00:16:20) DC: Right. And, you know we grow up and the reality is having sex is good. Having an orgasm is great. You know, when you get one you wanna holler and scream. [Women start talking] So when you get one at 13 or 14 you're still hollering and screaming. So you know, we say don't do something and somebody do something and it's good/ Because it feels good, and so it's hard to tell someone not to do something that feels good. And so we send a message of guilt with something that does feel good in right situations, and therefore like anything, "I like the candy I'm gonna get some more." So we have it promoted, it's easily accessible, it feels good, and it continues.

(00:17:16) W4: I work at a health department, and I live in Washington County, third with HIV rates. And I do talk to the people, and … in the system, and we do talk to her a lot, and tell them about/ I can't lose ... [?] and I tell her, I said you know people out here, I can name them, but I would lose my job, to tell you people out here that have it. They don't look like it, and you will never know that they're out there and have this, and the school took the health educator out of the school, and they're fighting to put them back in the school and they won't even put it back in the school, so they won't even educate the young people about it. And when we try to fight for the health educators to put them in the schools and stuff, I don't understand why they won't educate the young people with this. So I mean, how can you educate the young people without it, and they're spreading it more and more. And the health department is going to their houses picking them up so they can come get their medicine and things like that/

(00:18:32) DC: Can we find other places to educate kids? I mean, you know, is there other places that we can do that as concerned citizens and mothers and fathers and aunts and uncles? Because you're sending us to a system that's set up, but most of us don't want to go to the health department. I mean, we go when we have to, I went when I was younger because I didn't have any money and I was in college, but that's usually not our preference, to get our health care there, because you feel like it's open, it's in the community, and everyone knows. So that's one thing when you're diagnosed, but as a group now that we're learning about this problem, we're learning that we're the increased number of new cases are going, and we see as a community of women here we're saying that, there's really no place for our kids to learn because they're taking it out of the school system. We say well parents can do this, and so I always say to this group is, let's not talk about individual/ I mean we can individually, but what do we think most families do? Do we think most families are having this conversation? [All women: no.] So if most families are not having this conversation, then that means that most of our communities the kids are debuting with no information. And maybe if / like my parents only finished the eighth grade, and my parents didn't talk with me. And my parents were probably like most parents in my community. You know just because they didn't and couldn't, we're those who have education and know, how do *we* help set these things up so that the kids are not impacted by the lack of parents ability to teach and information to teach. We still are responsible as a community to think of information, so where would you propose that it happen?

(00:20:18) W4: That's what I said, why are they taking it out of the schools? [Extremely hard to hear]
DC: But that's there, where would/ you propose that we put it back in the schools, then?
W4: We'll let the schools…
W5: Well that's true, but my take on it is, it's the generation now. Parents aren't able to spend as much time/ due to the economy, parents aren't able to spend as much time with their kids and have the discussions, which is/ it could be why they took it out, because they expect the parents to talk to their kids, but with parents having to work as much, they don't make time for it as they did in the past. So now it's not in school, *and* parents don't give it, so it's taking out their two main sources.

(00:21:02) DC: So where else?
W10: Church
DC: Uh oh, I heard a "Church." Do you think it can happen in church? [Some women say no]
W11: It may not be, but it needs to be/
W10: It needs to be.
DC: Oh you're saying it *needs* to happen. So my question is, that's a place we think maybe, but as a community of women in this room, do we think that that's happening in our churches?
W12: No! [Other women agreeing]
W2: Some churches are.

(00:21:28) W11: One thing that our society/ our society has a huge problem with not being honest with ourselves, and like you said, where do we do it? I talk about it anyway. I was just telling the committee we were on the other day that/ I was in a meeting, and we had just started talking and I was like "ya'll better wrap it up, because," you know, but I'll talk about it to anybody because there's a huge/ I don't want to see my friends die because they didn't do what they needed to do to keep their lives safe, so if I hear a teenage person talking about sex on the phone, I'll be like, "oh do you have some condoms? Do you want some condoms?" You know, but that's just my personality. So the average person is not very honest with theirself that that actual situation actually exists, so we don't get it out there to our kids. I mean, the undergrads/ I already told them what they can get, how they can get it, where they can get it from, and whether they want to hear it or not, it's something that's personal to me, because I did *not* want to hear that one of my sorority sisters, or anybody I know has done something that they could have prevented.

(00:22:46) W1: … I think a lot of parents are probably in disbelief or/
W11: They *are* in disbelief/
W1: And their children are having sex, so in their mind they're thinking/
W11: "Not my baby." [Women agreeing]

(00:23:00) DC: So NIMBY – Not In My Back Yard. [Women agreeing] "My kids are the 30% not the 70.

(00:23:05) W8: Or at the same time the one thing they are discussing is, "you'd better not do it." [Women agreeing] Instead of saying, "if you are, you make sure you protect yourself." [Women saying: that's true]

(00:23:18) W4: Because it's not like it was in *your* days and it's not like it was in *our* days. [Many women start talking at once] I mean it was bad in my days, but even worse now. [Women still talking]

(00:23:27) DC: How would you recommend that it happen? We're saying that it's out of schools, we're saying it *could* happen in churches and some churches are doing it/
W1: I think it should start at home, first of all. See that's the problem/
[Women start agreeing that it needs to start at home]

DC: It needs to start at home?
W1: Yeah it needs to start at home.
W8: And people need to stop having kids and expecting everybody else to raise them. [Women agreeing] Look who's having the kids now though/
All women: The kids.
W4: The kids are having kids!

(00:23:49) W6: You have doctors who want to teach the kids, but the schools won't let them, you have/ I mean one of the biggest questions we used to get asked was like, "why did I get put out of the room when my child came in?" at … [name of the place] and we'd have to tell the parents, we want them to have that time with us to ask us open questions about sexual relations so they know what's going on. And you can see the relief on parents faces that they don't have to have this conversation. I came home and told my mom, "hey I learned about sex today," and she was like, "thank you god I don't have to talk to you about it."
(00:24:21) W8: What?
W6: Yes/
W8: No, no, no/
W6: She'd tell me that she didn't have to do that discussion with me/

(00:24:25) DC: So it's a very/ you can see that we have no consensus in our room about what to do about those who are most at risk. Yes?

(00:24:36) W14: I have a question. I didn't go to school in North Carolina, I grew up on military bases, and I feel like this "safe sex" and "sexual transmitted diseases," and all of that stuff is always that I was kind of touched on, so I always felt that I grew up with that knowledge. Do they not mention *anything*?/
W8: They do. They do in PE, that's why every child/ in middle school, they have to have PE in health, they have to. And they have a small unit/ but I know like sometimes parents can opt to sign out that their kid does not have to take it. So they have to go somewhere else. Which it's still parents' choice, you know what I'm saying?

(00:25:10) W5: But they don't offer it/ they took health out, they just have PE now/
W8: They still have the PE/
W5: Not in Washington County/
W8: Ok, Washington County/ [Women start trying to talk at the same time]
W14: They don't mention condom use, or anything like that? [Someone says "no"]
W4: That's what I'm sayin'/

(00:25:26) DC: And so maybe they're mentioning it, so I think in some counties, or most counties, they have a 2 or 3 hour program, and so the kids in one program are introduced to condoms and this is how you use them. Not necessarily a demonstration/
W8: Abstinence/

DC: So if you only introduce something one time, and it's not part of a continuous growth problem, is that enough to motivate that person or to help that person understand how to do that? So we have lots of gaps in that, and that's why this discussion is, because how can we help solve the problems or promote a problem, or/
W8: They're everywhere. There's gaps when you go to Kindergarten and you don't know your name, you don't know how to spell it, but they still push you along. And then you move forward, there's gonna be another gap. So it's a continuous cycle, that no one has really found an answer to.

(00:26:15) DC: And that's if we could solve it as a community, that's where it should occur. I mean, because we have just as many teammates here that are saying the parents should do it. So maybe the schools shouldn't do it anyway, and even if the schools do it, they're doing it for 15 minutes or a half an hour, and is that enough for learning? I think many places it needs to happen/
W8: It needs to happen several places. It needs to be something that is repetitive.

(00:26:38) W11: And the other thing that I wanted to add is that I think it also needs to come from our leaders and those people who the teens or the young children look up to. Because they're not gonna necessarily listen to their parents, because of the average teenager thinks they know more than they do anyway/ [Laughter] They'll listen to someone/ if they see Beyoncé saying, "oh yeah, wrap it up hunny," or whatever. Or Jay-Z/ [Laughter]

(00:27:14) DC: So it needs to be a community process, and many people need to be involved, including asking leaders and rappers and that to help promote certain things.

(00:27:26) W5: And I think we try to get the population out to the programs. It falls on who's going to bring their kids to learn about it. Who's going to bring their parents to learn about it. Because even the parents don't know the naked truth. You know, so, it's getting people out to/

(00:27:47) DC: So it's a/ you can see that we've talked about this for 10 or 15 minutes because certainly as a community we know that that's where it's starting. We're all at risk for the other reasons, but that's one that/ it's very difficult to get a consensus, it's very difficult to know where to start, how to start approaching that/ But hopefully this kind of conversation and hearing these types of dialogue in the future we'll all have small opportunities to address that. Sitting on a board, being a parent, wherever we are, that we're gonna have a voice because we now know it's important, and always trying to get it in somewhere, even if it's not directly/ Because it's a problem.

[Move on to SCENARIO 4]
(00:28:26) DC: So here's the fourth scenario, and this happens, guys. What happens if you have a married person, or what we see is college students showing up to college having had a boyfriend in high school for 5 years, and now they find out that their mate is having sex with other men. Because maybe in high school they couldn't be who they wanted to be. They get to college and they start to explore, or a married man starts to act out some fantasies. Do we think this is happening? Do we think that there are relationships in which men are having sex with women and men.
[Women start agreeing]

(00:29:02) W8: It is, it is. I had a friend who died from AIDS/
DC: And think they got it from their mate?

W8: No, he was undercover. He was a homophobe/
DC: So he was against homosexuality/
W8: Yeah/
DC: But he was/
W8: He masked it/
DC: But he was. Ok/
W8: Like when we would talk about gays or whatever, he'd be like, "oh I can't stand them!" and this that and the other. But at the same time, Halloween, he'd dress up as a woman. It's just like, *we* knew, we wanted him to just say/ just tell us. But we didn't feel comfortable letting him know that we kinda knew/
(00:29:36) DC: But he had women friends?
W8: Oh yeah, oh yeah.
DC: So he was also putting other women at risk/
W8: Yeah.

(00:29:42) DC: So somebody said there's a lot of that/
[W8 and W2 having a side conversation about the gay man W8 was just talking about]

(00:30:02) DC: So the question is do we/ we're talking about a behavior that we hardly talk about/ [Women agreeing] and we're most impacted as black women, do we think that this is in our communities? [Women saying yes] Do we see this? [Still agreeing]

(00:30:15) W2: And we/ I have/ There's this young boy, and he has certain tendencies. And certain family members are always saying, "blah blah blah." You know, not to him, but about him. And I'm always saying, "don't say that. Because who is he gonna have if and when he comes out." You know what I'm saying? He's gonna have to hide it, because in his own immediate family he can't be who he is.

(00:30:49) DC: So we know of examples of which we see it setting up.
W2: Yeah, and I think he's in middle school now. And I'm like, "let him be who he's gonna be, and shut up." And I tell them, I don't want to hear it. As long as he's not hurting anybody, leave him alone/ you know? I just don't want to hear it.

(00:31:07) DC: What about more mature relationships? This person's getting out of college, and this other person's been married for 10 years. She's 30, 40 years old.

(00:31:17) W4: Honestly, I've been in a situation/ my older brother was actually gay, and he actually died with me disliking him. And I regret it now.

(00:31:28) DC: So we're learning, too, how to accept things and those things, because it's in our families. You know, ten percent/
W4: Because when he was in the hospital I did/ he was in the hospital, I *was* going to see him, but I didn't make it in time to go and see him/
DC: So he had relationships with men and women?
W4: Mmhmm. No, not/ I don't think/ towards the end he didn't have women/
DC: But he started out/
W4: He started out/ yeah. He just completely started dressing as a woman.

(00:32:01) W14: I mean, the biggest problem that I see with that is, I mean we've already touched on religion now/ I mean I know for people who are really into their faith and if they believe heavily in the Bible, no matter what kind of acceptance message you try to preach, certain people are never going to look past that. And so if I were gay, I know for a fact my parents would not accept it, no matter what. You could tell them all of this "who am I gonna have" and blah blah blah, it's just their belief system, know what I mean? And so for people who have that burden on them, I mean, what kind of incentive do they have to come out if they know that their family's going to change their mind or turn their back on them. It's harsh/

(00:32:50) DC: Yeah, yeah it is.

(00:32:53) W12: You know, I would say, because I'm a PK and I'm/
DC: What's a PK?
[All: "Preacher's Kid"]
DC: Okay [Laughter]
W12: And I'm really deep into my faith and having parents that are pastors and having people in my family that go to church that are openly gay/ that are my family and that go to church/ I'm not saying/ Okay, here's a difference I think in terminology that as society changes that people are changing/ It's not a matter of accepting the behavior that the person is exhibiting, like if somebody wants to come out and say they're gay, it's not a matter of that I'm gonna accept it, because I don't agree with it still. But it's the thing of, I'm not going to turn my back on my family, if they want to talk about it, I'm gonna talk to them with it. I don't have to agree with everything that you do in life for you to be family, and I think that's what/ the tide is turning in a lot of places, churches, slowly. But in the black community more so it's turning because we're de-sensitized now to things that we weren't before. When I first came to college, there were people that you thought were gay, but people still kept it hidden. But now, it's like/ Like my sister teaches high school in … [name of school] and people go through phases where it's cool to be gay at some point in time, and so it's one of those things that/
(00:34:32) W?: For females/
W12: For females. So it's one of these things that people are even in churches/ it's not an acceptance, and that's never gonna happen because that's a debate with your/ that would be like saying that your faith is wrong/ to you, then you're probably not gonna do that. But the thing is, the more we're going through the years and more black families are saying "I'm not going to get rid of my child just because the society tells me I should"/
DC: Or the church/
W12: Or the church. I don't agree, but they're still family. Like, if somebody has a baby out of wedlock, do you throw out their child just because they/

(00:35:11) DC: So you're saying that there's more acceptance now/
[W12 repeats "acceptance" while make quotation marks in the air]
DC: So it's beginning to be that/ and the reason that we're talking about this as black women is, we are disproportionately impacted, and you know, we can't get a handle on this behavior, because this behavior is done in secret. But if this is a component of what's going on in our risk, it's up to each of us to have our churches become more like this church. And that means that when you're sitting there here with all of the elders who don't want to talk about it, either you can be quiet, or you can begin to voice your opinion, to whatever happens over a period of time, they become more sensitive about it because of your argument,

because of your information. And so if we all will be responsible with those kinds of things/ Because there's no answer, but it's just something for us to recognize that these behaviors are in our networks, and therefore it's behaviors that we or our family of women are having sex with people that are having either/ they're ambivalent about who they are for a period of time, so that's why they're having bisexual behavior, they haven't learned proper sexual behavior which means condoms because we haven't taught them when they're young, and therefore they're putting us young women at risk, or older women at risk at different points, and this risk exists/ without having judgment, and just having an understanding of why things are moving in our communities.

[Moves to questions about Gender Roles]
(00:36:45) DC: Well okay, do you think that you or most women can come home and after you've left this program, and say okay, we're gonna talk about condoms. I'm married but hey, I don't know, I've learned that most married women are becoming infected, I may want to start using condoms in my relationship. Is that gonna/ can you do that? [Some women say yes]
W8: Yeah, I can.
DC: You can? Do you think all women can do that? [More women saying no] What will stop some women from doing that?

(00:37:11) W13: Trust/
W2: Being embarrassed/
DC: Being embarrassed/
W2: Or the feeling that he's gonna think that maybe I'm doing something inappropriate/
[Other women start talking at the same time. Some are saying trust issues]
W13: It might be the other way around, he might be thinking you're doing something.

(00:37:27) W14: Is that in the recommendations, that you're telling married women that they should start using condoms in their/
DC: Well I think I/ my job is to share information with you and tell you where the infections are occurring, and help you come to some thoughts/ [Laughter] I mean, and you may say "I can't do that," or you may say "I can," or maybe "I don't want to use condoms," or maybe "I'm gonna do this, maybe I am gonna get tested every year because I don't know." Maybe you haven't, maybe there is still some small thing you can do. I mean, all I can do is share the information with you, but maybe the only thing that you can do when you leave here is say, "I'm gonna get tested every year, I never thought about it. But I'm married and I'm gonna get tested." That's still a step. Everybody has a step, everyone has something that they can do to decrease their risk.

(00:38:15) W11: I understand, but what I told my husband when I took this class the first time, I said I would rather/ and I laid some condoms down, and I said I would rather you approach me with a condom, and that means you care about me, because I know what can happen, and after taking the class, I just don't want to die because you wanted to go out and figure out somebody else's stuff, so if you brought it to me, that's your thing/

(00:38:48) DC: But even if that happens, just because you did that, do you think that that's gonna happen, because… [W11 and a few others start talking at the same time] the day he walks home and says, "I want to use a condom tonight," [Laughter]
W11: I'd be like/ right, okay/ That's true, I gave him the option/

DC: Just to know that you're thinking about it, he begins to know that my wife is up on this, and if I step out with a secondary partner and don't use condoms and catch something, she's gonna reprimand me [?]/ so the conversation puts people on the alert/ [Women talking and laughing in the background] And this is what we talk about, because it does imply *something*. Because the day that he does that or she does that, number 3 hits there. It implies that number 3 is there, and then you've got to go deal with other things in your relationship, not that you can't deal with them, but to have to deal with them.

[DC then asks about how to get women to test. Women say do it at the doctor when you're there, or doing it in the church. The women bring up that the biggest way to draw people is to offer incentives and/or free items.]

[DC asks if more women (and men) knew how to put on condoms, more people would use them. All of the women say no. One woman says: "it's not the issues of knowing how to do it, it's the fact that women want to please men, and most men do not want to wear condoms, and therefore the women don't make them." The rest of the women agree.]

[DC asks where else she can take this program. Women say health fairs, and other sororities.]

APPENDIX C: ANALYSIS CHARTS

Condom Use Analysis Chart

	Kids learning about condoms? How?	**Talk about in church?**	**What is being taught?**	**Can married women reintroduce condoms?**	**Other Comments**
FG 1	• No	• No	• Abstinence	• No • **Implies cheating (both ways)** • Women are supposed to trust men	• A lot of young people are getting pregnant
FG 2	• No	•	•	• If you can rely on yourself • **Implies cheating (both ways)** • If relationship unsafe, NO	• She says "we have to use a condom" and he says "well I'm not doing that" • People are having kids with different partners, so not protecting themselves
FG 3	• Certain schools • Rest = No	• No	• One school taught them how to put condoms on	• **Implies cheating (both)** • If single, not a problem • Convo = probably not • Could be a health convo	• Women should get a vibrator, or go to the store & get some condoms & make sure to have them. • Some relationships do use protection b/c already infected • Men say they don't like to use condoms o "It don't feel good"
FG 4	• Certain schools • Rest = No	•	•	• [Cut off]	• People aren't using condoms when they step out (cheat) • Need to make sure young people are having safe sex
FG 5	• Certain schools • Rest = No	• No, but they should	• Abstinence • Don't talk about condoms	• Some say yes • Barriers = o Trust issues o Embarrassed o **Implies cheating (both)**	• Tell your friend if she's cheating, that she need to protect herself o "Tell your toilet to put a condom on"

Sexual Education and Resources Analysis Chart

	Did women's parents talk to them?	Getting Comprehensive Sex-Ed?	Where do people get their Sex-Ed?	Problems [preventing good Sex-Ed]	Can women identify any place people can get good info?	Where should people get Sex-Ed? (Recommendations)
FG 1	• Majority = No	• No	• **Peers** • Home=No • School = No • Church = No	• Parents don't feel comfortable • Church & Bible = abstinence • Need parental permission	• No	• Talk at home • School • Church • Health Dept.
FG 2	• Majority = No	• No	• **Peers**	• Parents uncomfortable	• [Didn't mention any]	• At home
FG 3	•	• No	• **Peers**	• Parents don't have info to give	• 1 young girl says she got it at school • Most people said they didn't/still don't	• Home • Church • Community leaders • School (for those that don't)
FG 4	•	• No	• **Peers**	• Sex-ed in school isn't enough • Parents don't/might not have info	• Some schools • Clinics/ health care providers (if parents take them)	• Home • School • Church • Clinics
FG 5	•	• No	• **Peers** • TV/music	• Music/ music videos • Taking sex-ed out of school • Parents don't have time b/c of work, or they're uncomfortable • Parents are in denial/disbelief • Parents don't have info to give • Kids don't listen to parents • Abstinence • "Kids are having kids"	• Not consistently • Some schools, but they give very little info	• Home (start at home) • Church • School • Health care providers/clinics • Leaders/ role models

Gender Roles Analysis Chart

	Talk to man about cheating?	Q1 Who's cheating?	Stay w/ man if he's cheating?	Q2- What do you do about MSPB?	Reintroduce Condoms?	Tell men to get tested?	Other comments
FG 1	•	• Husband • Then say "either"	• If you're married, you stay married • Women are in denial	• W2/W3: keep mouth shut [older women] • Many people don't tell • Others say they will tell • [Disagreement]	• No • **Implies cheating (both ways)** • Women are supposed to trust men	•	• Only tell girls not to get pregnant • Tell boys nothing
FG 2	• Some say yes • Hard to do • Depending on poverty, NO • Nowhere to go	• Both	• Reality sets in and they stay • Can't leave b/c of poverty and kids	• Tell • Need to help [sister] • Won't tell if the person won't believe it • **Get evidence/ proof**	• If you can rely on yourself • **Implies cheating (both ways)** • If relationship unsafe, NO	• Yes	•
FG 3	• "Did you see me?" • When asked women were silent	• Both	• Might be able to resolve it • Some say get a divorce	• Tell b/c you could be saving her life • **Get evidence/ proof**	• **Implies cheating (both)** • If single, not a problem • Convo = probably not • Could be a health convo	• Yes	• Ask, "did you see me?" if accuse him of cheating • Men always say they don't like to use condoms (don't feel good)
FG 4	• Might get beat • Some would talk to him	• Both	• If relationship is unsafe yes, you don't do anything	• Some say tell • Older women wouldn't tell • **Get evidence/ proof**	• [Cut off]	•	• "That's what a man's supposed to do" [older women]
FG 5	• Some say yes	• Both	•	• Tell • Older women wouldn't tell • **Get evidence/ proof**	• Some say yes • Barriers = o Trust issues o Embarrassed o **Implies cheating (both)**	•	• Group was in disbelief that some women claim their STI came from a toilet seat

MSM/MSMW (Men who have sex with men/and women) Analysis Chart

	Religious Reference	MSM/MSMW in Communities?	Barriers for telling women	HIV-Risk	Other
FG 1	• Homosexuality is preached against in the Bible/Church	• Yes	• Not answered (interrupted)	• Having unprotected sex with multiple partners	•
FG 2	•	• Yes	• MSM isn't acceptable	• When you hear about MSMW, you don't always think about being at risk	• Different if it's a man he's cheating with • Less acceptable, harder for the woman
FG 3	•	• Yes → It's a big time topic • Bring up prisons and MSM • Bring up college and MSM	• Embarrassing • Homophobia in the community • Don't want to be seen as gay • Men won't tell	• Won't tell, so stay w/ women and still have unprotected sex w/ men	• Different if it's a man he's cheating with
FG 4	•	• Yes	• Men won't tell • MSM not acceptable • Fear of stigma/being ostracized • The men don't think of themselves as gay	•	•
FG 5	• Religious ppl see being gay as wrong • Changing – ppl aren't turning their backs on family	• Yes • Some know ppl personally (both died) • Both of these men started out on the down-low	• Afraid of being rejected/disowned • No incentive to tell	•	•

MSPB (Multiple sexual partnership behavior) Analysis Chart

	Q1 – who's cheating?	**Q2 – What do you do about MSPB?**	**Q3 – Young ppl and MSPB**	**Q4 – MSM & MSPB**	**Can you talk to man about cheating?**	**Do you know if someone's cheating?**	**Stay with man if he's cheating?**
FG 1	• Husband • Then say "either"	• W2/W3: keep mouth shut [older women] • Many people don't tell • Others say they will tell **[Disagreement]**	• If friends are doing it, she probably is too	• Common & in their communities • Engaging in risky behavior	•	• Disagreement • Some argue yes, some argue no • Women in denial	• If you're married, you stay married • Women are in denial
FG 2	• Both	• Tell • Need to help [sister] • Won't tell if the person won't believe it • **Get evidence/proof**	• If friends are doing it, she probably is too	• Common & in their communities • Engaging in risky behavior	• Some say yes • Hard to do • Depending on poverty, NO • Nowhere to go	•	• Reality sets in and they stay • Can't leave b/c of poverty and kids
FG 3	• Both	• Tell b/c you could be saving her life • **Get evidence/proof**	• If friends are doing it, she probably is too	• Common & in their communities • Engaging in risky behavior	• "Did you see me?" • When asked women were silent	• Say yes at first • "intuition" • DC → work • Then change to "you never know"	• Might be able to resolve it • Some say get a divorce
FG 4	• Both	• Some say tell • Older women wouldn't tell • **Get evidence/proof**	• If friends are doing it, she probably is too	• Common & in their communities • Engaging in risky behavior	• Might get beat • Some would talk to him	•	• If relationship is unsafe yes, you don't do anything
FG 5	• Both	• Tell • Older women wouldn't tell • **Get evidence/proof**	• If friends are doing it, she probably is too	• Common & in their communities • Engaging in risky behavior	• Some say yes	• Women in denial	•

APPENDIX D: PRE-AND POST-TESTS

(Written by Dr. Diane Campbell)

1) Study ID _ _ _ _/_ _ _ _
First two letters of first and last name/year of birth
For Example: **John Smith born 1946 would be: josm1946**

Circle the Best Answer(s)

2) What County do you live in?
1. Pitt
2. Lenoir
3. Other_____

3) What is your age range?
1. Less than 18
2. 18-24
3. 25-39
4. 40-64
5. 65 and over

4) What is your Race/Ethnicity?
1. Black (at least one parent who is Non-Hispanic Black {NHB})
2. White (Non-Hispanic White {NHW})
3. Latino (Hispanic)
4. Other (Asian, American Indian, etc)

5) What is your sex?
1. Female
2. Male
3. Transgender

6) What is the sex of your sexual partner?
1. Male
2. Female
3. Both

7) What is your relationship status?
1. Never married
2. Married/living with partner
3. Separated/divorced/widowed

8) Highest education level achieved?
1. High School/GED or less; other training
2. Some or completed college
3. Some or completed graduate school

9) Annual Household Income (including mates)?
1. less than $5K
2. >$5K to $20K
3. >$20K to $40K
4. >$40K to $60K
5. Not reported

10) Age you first had sex?
1. Less than 14
2. 15-18
3. 19-24
4. over 25
5. never had sex

11) Number of different sex partners in the past 3 months?
1. 0
2. 1
3. 2-4
4. 5 or more

12) Number of different sex partners in the past one (1) years?
1. 0
2. 1
3. 2-4
4. 5 or more

13) Have you ever had a sexually transmitted infection?
1. Yes
2. No

14) Where did you do this survey?
1. Church
2. Sorority
3. School/ College
4. Community Organization
5. Home
6. Other_____

Please rate these statements:	**Rating Scale**	
	High	**4**
	Moderate	**3**
	Low	**2**
	No	**1**

15. Evaluate your risk for HIV transmission _____

16. Multiple sexual partners is __?__ risk for HIV transmission _____

17. A married women has __?__risk for HIV transmission _____

18. Having unprotected sex has __?__ risk for HIV/AIDS _____

19. Sharing needles is considered __?__risk for HIV transmission _____

20. Being poor is __?__ risk factor for HIV transmission? _____

Rate these statements	**Rating Scale**	
	Strongly agree	**4**
	Agree	**3**
	Disagree	**2**
	Strongly disagree	**1**

21. Married couples should use condoms (rubbers) _____

22. I should use condoms (rubbers) _____

23. Should teenage girls learn how to use condoms? _____

24. Should teenage boys learn how to use condoms? _____

25. Should adult women learn how to use condoms? _____

Directions: Check Yes or No	**Yes**	**No**
26. Have you ever suspected present partner was unfaithful? ('stepped out'/ 'had an affair')?	___	___
27. Have you ever suspected one of your past 3 partners was 'unfaithful' ('stepped out' 'had an affair')?	___	___
28. Have you ever been unfaithful in your present relationship?	___	___
29. Have you ever been unfaithful in your past 3 relationship?	___	___
30. Do you always use condoms?	___	___
31. Would you participate in condom skill training?	___	___
32. Have you ever been tested for HIV?	___	___
33. Would you get tested for HIV if it was available?	___	___
HIV is transmitted by?		
34. Vaginal sex	___	___
35. Anal sex	___	___
36. Oral sex `	___	___
37. Dirty needles	___	___
38. Childbirth	___	___
39. Breast feeding	___	___
40. Hugging and Kissing	___	___
41. Sharing Spoons and Forks	___	___
42. Touching and Playing Together	___	___

Please rate these statements:

Rating Scale

High	**4**
Moderate	**3**
Low	**2**
No	**1**

43/35 Evaluate your risk for HIV transmission _____

44/36 Multiple sexual partners is __?__ risk for HIV transmission _____

45/37 A married women has __?__risk for HIV transmission _____

46/38 Having unprotected sex has __?__ risk for HIV/AIDS _____

47/39 Sharing needles is considered __?__risk for HIV transmission _____

48/40 Being poor is __?__ risk factor for HIV transmission? _____

Rate these statements

Rating Scale

Strongly agree	**4**
Agree	**3**
Disagree	**2**
Strongly disagree	**1**

49/41 Married couples should use condoms (rubbers) _____

50/42 I should use condoms (rubbers) _____

51/43 Should teenage girls learn how to use condoms? _____

52/44 Should teenage boys learn how to use condoms? _____

53/45 Should adult women learn how to use condoms? _____

Directions: Answer Yes or No	**Yes**	**NO**
54/46 Have you ever suspected present partner was unfaithful? ('stepped out'/ 'had an affair')?	___	___
55/ 47 Have you ever suspected one of your past 3 partners was 'unfaithful' ('stepped out' 'had an affair')?	___	___
56/48 Have you ever been unfaithful ('stepped out' / 'had an affair') in your present relationship?	___	___
57/49 Have you ever been unfaithful ('stepped out' / 'had an affair') in your past 3 relationship?	___	___
58/50 Do you always use condoms?	___	___
59/51 Would you participate in Condom Skill Training?	___	___

60/52 Have you had HIV testing? ___ ___

61/53 Would you get HIV testing? ___ ___

HIV transmitted by?

62 Vaginal sex ___ ___

63 Anal sex ___ ___

64 Oral sex ___ ___

65 Dirty needles ___ ___

66 Childbirth ___ ___

67 Breast feeding ___ ___

68 Hugging and Kissing ___ ___

69 Sharing Spoons and Forks ___ ___

70 Touching and Playing Together ___ ___

Do not answer

71 Risk Score _____

Please rate the statements by the scale

Rating Scale	
Strongly agree	**4**
Agree	**3**
Disagree	**2**
Strongly disagree	**1**

72/56 The workshop helped you evaluate your HIV/AIDS risk _____

73/57 The workshop is a good way to learn about HIV/AIDS _____

74/58 I would you participate in condom skill training _____

75/59 I would participate in a HIV prevention program _____

76/60 I would you recommend a HIV/AIDS prevention program in my community _____

77/61 I was comfortable talking about HIV/AIDS and sexual behaviors in the workshop _____

78/62 The workshop helped me associate poverty with HIV/AIDS _____

79/63 The workshop helped me associate race with HIV/AIDS _____

80/64 The workshop helped me associate abuse with HIV/AIDS (sexual, physical, mental and substance) _____

81/65 The workshop helped me associate multiple sexual partnership behavior with HIV/AIDS _____

APPENDIX E: IRB APPROVAL

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board Office
1L-09 Brody Medical Sciences Building• 600 Moye Boulevard • Greenville, NC 27834
Office **252-744-2914** • Fax **252-744-2284** • **www.ecu.edu/irb**

TO: Diane Campbell, MD, MPH, Dept. of Internal Medicine—Infectious Diseases, ECU—Mailstop: 628

FROM: UMCIRB

DATE: June 2, 2011

RE: Expedited Category Research Study

TITLE: "Sister Talk Project"

UMCIRB #11-0356

This research study has undergone review and approval using expedited review on 5.31.11. This research study is eligible for review under an expedited category number 6 & 7. The Chairperson (or designee) deemed this **North Carolina Community AIDS Fund** sponsored study **no more than minimal risk** requiring a continuing review in **12 months**. Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The investigator must adhere to all reporting requirements for this study.

The above referenced research study has been given approval for the period of **5.31.11** to **5.30.12**. The approval includes the following items:

- Internal Processing Form (dated 5.12.11)
- Informed Consent (dated 5.26.11)
- Workshop Evaluation
- COI Disclosure Form (dated 4.29.11)
- Profile Survey
- Focus Group Protocol
- Abstract
- Flyer
- Letters to Eastern Carolina Partners & Program Coordinators

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

The UMCIRB applies 45 CFR 46, Subparts A-D, to all research reviewed by the UMCIRB regardless of the funding source. 21 CFR 50 and 21 CFR 56 are applied to all research studies under the Food and Drug Administration regulation. The UMCIRB follows applicable International Conference on Harmonisation Good Clinical Practice guidelines.

1907-2007 CENTENNIAL

East Carolina University

UNIVERSITY HEALTH SYSTEMS
of Eastern Carolina

Informed Consent to Participate in Research
Information to consider before taking part in research that has no more than minimal risk

Title of Research Study: SISTER TALK Project

Principal Investigator: Diane Campbell, MD, MPH, RN
Brody School of Medicine at East Carolina University; Division of Infectious Disease
2300 Beasley Dr, Doctor Park #6A, Greenville, NC, 27834; 252-744-4500

Researchers at East Carolina University (ECU) study problems in society, health problems, behavior problems and human condition. Our goal is to try to find ways to improve the lives of you and others. To do this, we need help of volunteers who are willing to take part in research.

Why is this research being done? The purpose of this research is to evaluate new ways of providing HIV community education. By doing this research, we hope to learn if a community-based workshop can increase HIV knowledge and skills to decrease HIV risk.

Why am I being invited to take part in this Research? Are there reasons I should not take part? What other choices do I have if I do not take part in this research? If you are an adult female you are being asked to volunteer to participate in the workshop and if you participate you will be one of about 500 women to do so. If you are under 18 years of age you should not participate in this research. You do not have to participate in this research. You will not be penalized or criticized for not participating.

Where is the research going to take place and how long will it last? The community-based educational workshops will be conducted in a variety of community settings (college, sorority houses, churches, home, etc.) in counties located in eastern North Carolina (ENC). The total amount of time you will be asked to volunteer for this study is four hours at one time or in two, two hour sessions.

What will I be asked to do? You are being asked to participate in two, two hour programs. The programs may be given on the same day or two separate days. In the first two hour session you will be asked to complete workshop demographic, pre- and post-test and program evaluation surveys, listen to a one hour presentation on HIV transmission, participate in a one hour focus groups discussion on HIV risk. In the focus group you will be asked a series of questions that relate behaviors with and HIV transmission. The focus group conversation will be audio taped. Only Diane Campbell, the Program Coordinator and her assistant will have access to the tapes. The surveys and tapes will not be accessible, and will be kept in a locked cabinet located in the principal investigator's office. The tapes will be transcribed word for word and then destroyed in six months. If you choose not to be audio taped then you will not be able to participate in the focus group. In the second two hour session role play will be used to teach assertive communication skills, condom negotiation and application and complete a program evaluation.

What are the possible benefits, harms or discomforts I might experience if I take part in the research? There may be no personal benefit but the information gained doing the research may increase your HIV knowledge. It has

UMCIRB APPROVED
FROM 5-31-11
TO 5-30-12

Participant's Initials

been determined that the risks associated with this research are no more than what you would experience in everyday life. It will not cost you any money to be part of the research.

Will I be paid for taking part in this research? What will it cost me to take part in this research? We will not be able to pay you for your time spent participating in the workshops. It will not cost you any money to be part of the research.

Who will know that I took part in this research and learn personal information about me? To do this research, ECU and the people and organizations listed below will have access to the data collected in this research. With your permission, these people may see data and any private information collected in this research: 1) North Carolina Community AIDS Fund (NCCAF), grantor funding this research, will not have access to any client identification information; and 2) The University & Medical Center Institutional Review Board (UMCIRB) and its staff, who have responsibility for overseeing your welfare during this research, and other ECU staff who oversee this research.

How will you keep the information you collect about me secure? How long will you keep it? All data will be kept separate from any identifying information in the principal investigator's office for the period of 3 years. All audio-recording information will be transcribed and destroyed in six months. Data may be used for other purposes than this research, e.g., teaching presentations, grant applications, and research articles. When used, all information will be stripped of identifiers without anyone knowing it is information from the participant.

What if I decide I do not want to continue in this research? If you decide you no longer want to be in this research after the workshop has been started, you may stop at any time. You will not be penalized or criticized for stopping.

Who should I contact if I have a question? The people conducting this study will be available to answers any questions concerning this research, not or in the future. You may contact the Principal Investigator at 252-744-4500 between 9:00am and 5:00pm. If you have question about your right as someone taking part in research, you may call the UMCIRB Office at phone number 252-744-2914 (days, 8:00am -5:00pm). If you would like to report a complaint or concern about this research study, you may call the Director of the UMCIRB, at 252-744-1971.

I have decided I want to take part in this research. What should I do now?
The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

Participant's Name (PRINT)	**Signature**	**Date**

Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

Person Obtaining Informed Consent (PRINT)	**Signature**	**Date**

UMCIRB
APPROVED
FROM 5.31.11
TO 5.30.12

**********IMPORTANT INFORMATION**********

Continuing and Final Review Obligations

As Principal Investigator, you are required to submit a continuing or final review form to the Office for Human Research Integrity for IRB review. This is a federal requirement to continue or close your research study before the date of expiration as noted on the attached approval letter. This information is required to summarize the research activities since it was last approved. The regulations do not permit any research activity outside of the IRB approval period. Additionally, the regulations do not permit the UMCIRB to provide a retrospective approval during a period of lapse.

You must submit this form even if there has been no activity, no participants enrolled or you do not wish to continue the activity any longer. Research studies that are allowed to be expired will be reported to the Vice Chancellor for Research and Graduate Studies, along with relevant other administration within the institution. The continuing or final review form is located on our website at http://www.ecu.edu/rgs/irb/ along with our meeting submission deadlines. Please contact the UMCIRB office at 252-744-2914 if you have any questions regarding your role or requirements with continuing review.

Required Approval for Any Changes to IRB-Approved Research

As Principal Investigator, you are required, prior to making any changes in your research study must have those changes reviewed and approved by the IRB. The only exception is when those changes are to eliminate an immediate apparent hazard to the participant. In the case when changes must be immediately undertaken to prevent a hazard to the participant and there is no opportunity to obtain prior IRB approval, the IRB must be informed of the changes as soon as possible via a protocol deviation form.

Reporting Unanticipated Problems to the IRB that Affect Participants or Others

As Principal Investigator, you are required to report to the IRB all unanticipated problems that have occurred in your research within the time frame specified in the UMCIRB rule for reporting Unanticipated Problems Involving Risks to Participants or Others.