

HIV PREVENTION NEEDS IN AFRICAN AMERICAN WOMEN 50 YEARS AND OLDER

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In the United States between 1991 and 2001, there was an increase of over 848% in new AIDS cases in African American women fifty and older. This increase is due in part to changes in reporting. Because of the startling statistics and scarcity of studies in this population, this study examines the HIV prevention needs of two groups of African American women over fifty, injection drug users and non injection drug users. Focus groups were used to collect data on general HIV knowledge, experience with HIV prevention, psychosocial factors, drug involvement, and risks and barriers to HIV infection and prevention. Data was also collected through a survey that gathered information on demographics, sources of HIV information, HIV testing and risks including knowledge of risk, belief of risk and risk behaviors. This study found that lack of education and misconceptions regarding disease transmission act as a barrier for prevention efforts; a need for inclusive HIV prevention efforts such as multi-generational in-home programs, multi-family programs and the incorporation of prevention messages with existing health services; a need for skills building, condom negotiation skills and self-empowerment. Effective methods suggested were techniques that align with African American culture and heritage such as storytelling, inclusion of family and community. In order to generalize findings from this study, future research must include a representative sample of African American women 50 years and older such as churchgoers, sorority women, health conscious women, ex offenders, past injection drug users, infected or affected women and newly single women. The findings of this study are significant to public health research because they

add to a growing body of knowledge regarding the HIV prevention needs of this group, can be used to design prevention messages for the population from which they were gathered, and most importantly provide insight to what a subpopulation of this group views as effective prevention methods. Recommendations for future research are also provided for federal government agencies, state public health agencies, community organizations, the family structure, HIV service groups, physicians, universities and researchers.

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PREFACE

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1. INTRODUCTION

Since the beginning of the epidemic of HIV/AIDS, African Americans have been disproportionately affected by the disease. More recently this has spread to include African American women. In 2003, African American women accounted for 67% of new AIDS cases among women while comprising only 13% of the total female population in the US (KFF, 2004). In 2001, HIV was one of the top four causes of death for African American women ages 25 to 54 (CDC, 2004). While the number of women infected continues to grow, the number of older adults does also. Over a ten year period, the number of AIDS cases in older adults 50 years and older grew from 21,049 in December 1991 to 90,513 in December 2001, an increase of over 330% (CDC, 1991; 2001). In African American women 50 years and older the number increased went from 790 in December 1991 to 7488 in December 2001, an increase of over 848% (CDC, 1991; 2001). These increases are due in part to changes in reporting.

In the state of Pennsylvania, women made up 20% and African Americans made up 50% of the cumulative AIDS cases through 2003 (KFF, 2003). Of the new AIDS cases through 2003, women made up 28% and African Americans made up 53% (KFF, 2003). In Allegheny County, Pennsylvania, African Americans made up 58% of the AIDS cases in 2003 and non-white females accounted for 70% of total female cases while representing only 8% of the female population. Of the 298 total female AIDS cases reported in the county, in 2003, 212 were non-White with women 50 years and older representing 36 cases and non-White women comprising 19 of those (AGHD, 2003). Because of these startling trends and the sparse amount of research in this segment of the population, it is imperative that issues related to HIV/AIDS be addressed within this subgroup. Therefore, this study will focus on identifying the HIV prevention needs of heterosexual African American women 50 years and older. Since the major transmission

routes for African American women nationally in 2002 were heterosexual sex (70%) and injection drug use (28%) (KFF, 2005), the needs of two populations will be explored: injection drug users (IDUs) 50 years and older; and non injection drug users (non-IDUs) 50 years and older. Given that women 50 years and older are influential with the African American community, it is hoped that they will serve as a bridge for providing information to women like themselves as well as to the other generations for whom they provide care.

2. REVIEW OF RELEVANT LITERATURE

Because of the immense increase in AIDS rates among older adults, research in this area is on the rise. Topics reviewed in this section include AIDS and aging, risk factors for older adults and prevention/interventions/education. However, due to the scarcity of studies with older adults and HIV prevention in general, this review is very limited. Studies are sorely needed within the 50 years and older population across many demographic characteristics.

2.1.1. Aging

When considering AIDS and aging, it is important to remember that there are two separate and distinct groups of people: 1) those infected at age 50 years and older, and 2) those infected at younger ages who are living longer due to advances in AIDS medications (Mack & Ory, 2003). In the case of individuals infected after age 50, many physicians are less likely to have discussed sexual behaviors or HIV infection with them and the older patients are less likely to talk about their risk behaviors (Fowler, 2003; Mack & Ory, 2003). Another aging issue is the similarity of HIV/AIDS infection symptoms to those of general aging. Symptoms such as physical fatigue, depression and night sweats, common among older adults with chronic diseases, can mimic or mask signs of HIV/AIDS (Justice et al., 2001; Kwiatkowski & Booth, 2003; Levy, Holmes & Smith, 2003; Sormanti, Wu & El-Bassel, 2004). Another aspect of aging is the increased life span of healthy people. As people live longer lives the chances of divorce or widowhood increase, which creates new opportunities to meet new sexual partners (Auerbach, 2003). Older persons who find themselves back on the dating scene are often unaware of the sexual risks people are facing today (Auerbach, 2003; Levy, Ory & Crystal, 2003).

2.1.2. Risk Factors

Older adults have been found to have many of the same risk factors as their younger counterparts such as unprotected heterosexual sex and drug use. A study conducted by the National Council on Aging found that 61% of men and 37% of women 60 years and older reported being sexually active on a regular basis (Strombeck, 2003). Many older adults are engaging in more sexual activity later in life due to an influx of drugs such as Viagra, Levitra and Cialis (Marcus, 2002; Orel et al., 2004). Schensul et al. (2003) studied low-income senior housing to see what effect building location and characteristics, and social networks had on HIV prevalence and risk behavior among residents 50 years and older. Buildings were selected because of high residential risks for HIV exposure such as impoverished neighborhoods, high crime rates, commercial sex trade, and drug activity. Their sample (n = 398) of residents was 71% African American with a mean age of 67.4 across six buildings. While many of the residents were misinformed about HIV transmission rates, for instance 35% believed they were at risk if someone coughed on them and 55% believed they were at some risk for HIV, 60% of the men reported being sexually active versus 25% of the women. Schensul et al. also found that 28% of the older men reported having more than one sexual partner and being involved in casual sex (sexual services provided by women for financial or other gain) whereas only 1% of the older women reported having multiple partners.

Regarding male condoms, only 9% of women reported regular use stating it was not necessary for birth control purposes and 25% of men reported regular use stating it interfered with sexual pleasure and made erections difficult. Twenty nine percent of residents reported alcohol use in the past 30 days, 23% reported ever using marijuana and 16% ever using hard drugs (i.e., heroin, cocaine). Their study concluded that special efforts need to be made to limit

drug and alcohol use as well as to increase condom use. Although buildings in the study differed on the level of security and the types of activities that were allowed (i.e. commercial sex, drugs), there were no differences found in levels of sex or drug related HIV risks. Similar findings were reported in a study by Radda, Schensul, Disch, Levy and Reyes (2003).

Illicit drug use is a risk factor for older adults, which includes alcohol abuse and prescription drug abuse. When combining drug use with sexual behaviors, the risk for HIV rises (Kwiatkowski & Booth, 2003; Schensul, Levy and Williams, 2003). Kwiatkowski & Booth (2003) conducted a study with IDU users to assess their risk behaviors. Their sample of people 50 years and older (n = 1508) had a mean age of 55 years, was 86% male and 70% African American with 97% identifying as heterosexual. Although those who were 50 years and older were more likely to be IDU users (71%), they were less likely to use a previously used, unclean needle (16%) and injected less frequently than their younger counterparts. The 50 years and older group was just as likely as the younger group to have had multiple sex partners (36%), to have exchanged sex for money or drugs (33%), and to have had sex with an IDU (34%). Regarding condom use among those 50 years and older, 63% reported never using condoms and only 16% reported always using condoms. Kwiatkowski & Booth found that older IDU users practiced safer behaviors regarding needle sharing. However, their sex-related behaviors still put them at increased risk for HIV infection.

Older women have become increasingly more at risk for HIV infection because of behaviors and physical changes. With pregnancy no longer being an issue, many do not use condoms, which are often thought of as a birth control method (Patel, Gillespie & Foxman, 2003; Schensul, Levy and Williams, 2003). Physical changes in a woman's body, such as thinning of the vaginal walls and decreased lubrication, increase susceptibility to STDs and HIV infection

(Patel, Gillespie & Foxman, 2003; Sormanti, Wu & El-Bassel, 2004). Older women's sexual activity and condom use have both been found to decrease with age but older married women have been found to be more sexually active than their non-married counterparts (Patel, Gillespie & Foxman, 2003; Sormanti, Wu & El-Bassel, 2004; Zablotsky & Kennedy, 2003). Marriage also plays a role in not using condoms, with women in longtime marriages feeling that suggesting condom use would infer infidelity on their part (Patel, Gillespie & Foxman, 2003).

Older women of color have been found to be less likely to use condoms due to cultural and/or relationship norms (Montoya & Whitsett, 2003; Zablotsky & Kennedy, 2003). Many African American women may have negative attitudes about condom use and/or feel unable to negotiate condom use with their partners while Hispanic women may be uncomfortable discussing sexuality (Montoya & Whitsett, 2003). In some instances the discussion of sexual behaviors, which contradicts cultural and/or relationship norms, has led to intimate partner violence. For example, Hispanic women are generally expected to be submissive to male partners and raising sexual issues, including condom use, is in opposition to this expectation. Similar to their younger counterparts, older women have been found to be the victims of marital rape as well as unwanted sex in marital and long-term relationships, as a result of wanting to avoid physical abuse (Sormanti, Wu & El-Bassel, 2004). Physical abuse or threat of violence has also been found to significantly decrease women's readiness to engage in HIV protective behaviors such as condom use.

2.1.3. Prevention, Interventions and Education

Several organizations exist with the purpose of increasing older adults' awareness of HIV prevention and making efforts to meet their care and services needs. The National Association

on HIV Over Fifty, formed in 1996, includes affiliates in New York, California, Florida, Chicago, Boston, and has contact points in Washington, D.C., Phoenix, Arizona, and Austin, Texas (Linsk, Fowler, & Klein, 2003). Other programs include the Area Agency on Aging in Phoenix, The New York (State) Association on HIV Over Fifty and the Senior HIV Intervention Project and Senior HIV/AIDS Prevention and Education in Florida. Organizations such as these are a vital part of providing education, information, case management, advocacy, and service providers for the older population around HIV/AIDS (Linsk, Fowler, & Klein, 2003). The development of interventions geared specifically for older adults is important in slowing the progression of HIV in this population.

Maes and Louis (2003) conducted a study with older adults to examine knowledge, perception of risk and at-risk behaviors around AIDS. Their study found that the older adults who participated were less knowledgeable about the transmission of HIV and medical aspects of AIDS compared to findings in other studies. The older adults also had lower levels of perceived susceptibility to AIDS and the majority displayed low at-risk behaviors for HIV transmission as well as a low use of condoms to prevent HIV transmission. The findings of their study were very limited and ungeneralizable because the majority of the participants were married Caucasian women. Older adults of different ethnicity/race and/or those in nonmonogamous relationships may provide very different responses. A study of older women in an urban setting by Henderson, Bernstein, St. George, et al. (2004) found that the majority of women scored poorly on questions regarding knowledge about sexual transmission and prevention of HIV; the effectiveness of condoms; and the role of abstinence in prevention of HIV. These women also reported that their primary care physicians rarely or never discussed HIV/AIDS with them, indicating a need for adequate education about HIV transmission by physicians.

Klein, Nokes, Devore, Holmes, Wheeler and St. Hilaire (2001) conducted focus groups with older adults in New York to determine their HIV prevention needs. A focus group was also conducted with health care providers of older adults. Four major themes were found:

1) Sexuality and aging

- People 50 years and older were putting themselves at risk for HIV infection through unprotected sex, especially during life transitions;
- People 50 years and older are having sex with people younger than themselves;
- People 50 years and older were concerned with how Viagra would impact HIV transmission;
- People 50 years and older may be more reluctant to openly discuss their sexual practices.

2) Interpersonal issues/fear and loss

- People 50 years and older remember family and friends who were diagnosed with HIV or who had died.

3) Tailoring and marketing prevention and treatment messages

- People 50 years and older access health related information through a variety of sources with print media such as local newspapers) being identified as the most valuable;
- People 50 years and older did not feel HIV messages were targeted at their age group;
- People 50 years and older believed HIV messages could be integrated into other health related messages.

4) Provider concerns (provider group)

- Providers of services to people 50 years and older realize that the older adults have distinct needs;
- Providers confirmed that sexuality is still important to people 50 years and older;
- Providers recognized their own information and training needs regarding HIV prevention for people 50 years and older.

Information gathered from these focus groups was disseminated at professional meetings and through publications, and was shared with HIV/AIDS service providers in New York State. It was also used in the development of an informational brochure and used to support the allocation of additional funds towards prevention and intervention efforts specifically for the 50 years and older population.

In designing effective intervention/prevention messages, it is essential to assess where older adults currently receive their information. A study conducted by Altschuler, Katz and Tynan (2004) found that females were more likely to attend HIV/AIDS educational programs than males; older age was related to lower attendance at HIV/AIDS educational programs; and moderately or very religious participants were more likely to attend HIV/AIDS educational programs.

Rose (1996) conducted a study to examine the effect of an AIDS education program on older adults. A pretest-posttest survey was used to measure knowledge and perceived susceptibility of HIV/AIDS. Prior to the development of the education program, the pretest survey was conducted with 458 older adults to explore HIV knowledge, beliefs and behaviors in older adults. Findings were used to design and implement an age-specific education program as well as to develop a pamphlet, "What Everyone Over 50 Needs to Know About AIDS" prepared

by local doctoral student at Allegheny University of the Health Sciences. After the educational program was conducted, 318 older adults completed the posttest survey. Results indicated a significant increase in knowledge scores, perceived susceptibility and perceived seriousness of AIDS after the educational session. Participants were also asked to evaluate the education session and reported learning that most that older people can get AIDS too, ways to keep from getting AIDS and the window period between HIV and AIDS. The findings from this study indicate the importance and effectiveness of education programs specifically for older adults.

In efforts to assess the availability of HIV/AIDS risk-reduction materials targeting older adults, Orel et al. (2004) solicited information on HIV/AIDS from public health departments in each of the 50 states. All 50 states responded to the request for information. The vast majority of materials which included brochures, pamphlets, posters, fact sheets, web pages were geared towards young adults with only 15 states providing information specifically for older adults. The most frequently submitted publications for older adults were a pamphlet “What People Over 50 Need to Know About HIV and AIDS” (Channing L. Bete Co., 1995) and a brochure, “HIV & STD Prevention After 50” (ETR Associates, 2001), which included basic facts, prevention strategies and myths and stereotypes about HIV/AIDS and STDs. The scarcity of literature specifically for older adults was thought to be due in part to:

- Lack of public health funding causing agencies to prioritize HIV intervention efforts towards ‘high-risk’ populations,
- Societal attitudes and biases toward adults,
- Myths that older adults are not sexual active or do not put themselves at risk,
- Perception by older adults of low or no risk for HIV infection,
- Low priority of older adults by the CDC.

3. METHODOLOGY

3.1.1. Focus Groups

Community focus groups were conducted with African American women 50 years and older to assess the HIV prevention needs of this subpopulation. An IRB protocol was submitted and approved providing a description of the study. The protocol detailed risks and benefits, cost and payments, anonymity and the right to withdraw from the study. (See APPENDIX A) Each focus group was facilitated by Karen L. Reddick, M.A. who has over ten years experience in the field of HIV. She has extensive experience with focus groups and falls within the demographic age range of the target population. As facilitator, she was given facilitator protocol which provided a format for the focus groups. (See APPENDIX B) The recorder for the focus groups Monica Fisher, who has experience in focus groups and has worked in the HIV field for over seven years, was provided with a recorder protocol that detailed her responsibilities. (See APPENDIX C) The use of each protocol (IRB, facilitator, recorder) was instrumental in ensuring that the focus groups adhered to state of the art technology.

3.1.2. Community Involvement

In efforts to involve community members before conducting the actual research, a Community Advisory Board (CAB) was formed through the Pennsylvania Prevention Project. CABs are believed to have protective benefits to the community of interest as well as contribute to building meaningful research relationships (Quinn, 2004). The African American women 50 years and older who were invited to join the CAB all had connection to HIV through various means such as being active in their communities, work in the HIV field, service providers and being HIV positive. This CAB, which consisted of six African American women 50 years and

older, convened monthly three times prior to the data collection and provided insight on what questions should be asked, what groups of women should be included, and how the women should be recruited.

3.1.3. Recruitment

To be eligible for the study, women had to be African American aged 50 years and older. African American injection drug users 50 years and older were recruited by an outreach worker for the Pittsburgh AIDS Task Force (PATF), a former IDU, via Narcotics Anonymous and drug & alcohol referral facilities. African American non injection drug users 50 years and older were recruited by a senior citizen high-rise complex through a resident. The recruiters did not participate in the data collection. Each recruiter was provided with a recruiter protocol. The protocol stressed in importance of anonymity and gave detailed information including participants to be included, and compensation for participation. (See APPENDIX D) Each recruiter used had access to the target population and were viewed as credible and trustworthy.

3.1.4. Data Collection

There were two groups, one with injection drug users (IDUs, n = 6) and one non injection drug users (non-IDUs, n = 10). The IDU group was conducted in a conference room of a downtown Pittsburgh office building and the non-IDU group was conducted in the community room of a Southside senior housing residence. At the start of each group the purpose of the study was explained, the consent form was reviewed and compensation was discussed. Each group was asked questions in the following areas which followed a focus group outline: (See APPENDIX E)

- 1) General knowledge of HIV: the relationship between HIV and AIDS, risk behaviors, safe behaviors, transmission routes, and transmission from mother to child.
- 2) Experience with HIV prevention: information sources, prevention messages, prevention services, seeking services, special prevention needs.
- 3) Psychosocial factors: HIV issues, knowledge of protection from HIV infection, community role in prevention, community interference.
- 4) Drug involvement: drug or alcohol problems or use.
- 5) Risks and barriers: knowledge of personal HIV risk, barriers to condom use, negotiating condom use, willingness to use condoms, ways to increase condom use.

Participants also completed a survey that gathered demographic information including zip code, age, race, education level and marital status. Also collected were women's sources for HIV/AIDS information; whether they had been tested, and if so, where; knowledge of personal risk; risk belief assessment and risk behaviors. (See APPENDIX F)

3.1.5. Data Analysis

Focus groups were tape recorded and transcribed. The analysis was descriptive and interpretative in order to provide recommendations for effective prevention methods for African American women 50 years and older. Tapes were transcribed and coded by three members of the research team in order to provide a reliability check of the findings. Surveys were analyzed using the Statistical Package for the Social Sciences (SPSS).

3.1.6. Limitations

There are several limitations in this present study. The results of the study are not generalizable to all African American women because there were only two groups conducted an IDU and non-IDU group. There is a need to look at other sub-groups of African American women such as church women, sorority women and HIV positive women. Another limitation is the lack of data collection on socioeconomic status in collecting demographic information. Other limitations include only two focus groups were conducted, low numbers and all the women participating lived in Pittsburgh.

4. RESULTS

4.1.1. Sample

The IDU group consisted of six women with ages ranging between 50 and 59. All of the women had attended some college beyond high school and 88.3% reported they were single. The non-IDU group consisted of ten women with an age range from 50 to over 75 years old with the majority being 60-64 (33.3%). The majority of women had completed high school or some college and 88.8% reported they were single. Table 1 provides the complete demographics of each group.

Table 1: Focus Group Demographics

Variable	AA IDU (n = 6)	AA non-IDU (n = 10)
Age Group		
50-54	50	22.2
55-59	50	0
60-64	0	33.3
65-69	0	11.1
70-74	0	22.2
75->	0	11.1
Education		
Less than 9 th grade	0	11.1
High school graduate	0	44.4
Some college/beyond high school	100	44.4
Marital Status		
Married	16.7	11.1
Widowed	0	44.4
Divorced	33.3	11.1
Separated	16.7	11.1
Never married	33.3	22.2

*All numbers are percentages.

4.1.2. General Knowledge

The IDU group was very knowledgeable about the relationship between HIV and AIDS and ways by which HIV is transmitted. They were also well-informed of the differences between safe and unsafe behaviors. One participant stated, “Users may not share needles but they also use other people’s cotton and cookers”. Another described safe behaviors as “one sex partner, using a “raincoat” or protection and a clean needle every time”.

The non-IDU group was unclear about the relationship between HIV and AIDS and misinformed regarding transmission routes with the majority believing that saliva transmitted HIV. Participants were well-informed about safe HIV behaviors, citing abstinence as the best way to avoid contracting the disease however; they expressed concerns about “not sitting on public toilet seats and not using toilets after others”.

4.1.3. HIV Prevention

The IDU group reported that HIV prevention included education, awareness, not being afraid and the distribution of condoms and dental dams. Places where women 50 years and older get information on HIV included churches, doctors and community centers. Places for putting prevention messages named were churches, brochures and fliers. This group also felt that fear and stigma had an impact on women 50 years and older not returning for test results. Women 50 years and older were thought to take things for granted regarding HIV prevention because “they made it this far and don’t think they need it”.

The non-IDU group reported getting educational information through media venues such as television, specifically PBS and the news. This group felt that very few HIV prevention programs were directed towards seniors and had little knowledge about AIDS service

organizations or where they could go with HIV concerns. Five of the women reported discussing sexual activity with their primary care providers and eight of them reported reading HIV brochures they saw in the doctor's offices. This group believed that concerns about stigma and religious or moral implications would keep women from using HIV prevention services.

4.1.4. Psychosocial Factors

The IDU group reported that women 50 years and older do not feel they need to be concerned about HIV/AIDS and that this belief is not being addressed in current prevention efforts. It was suggested that the Department of Aging support efforts to reach the 50 years and older population. One participant shared, "I attended a buddy training but HIV/AIDS still didn't hit home until a family member contracted HIV". Denial, stigma and image were cited as interfering with African American women trying to protect themselves. Group members spoke about the image of women who are pillars in the community yet "sleep around at night" and the fact that many African American women have been raised to keep secrets. Many of the women believed that the effect of stigma caused persons in the African American community 50 years and older who contract HIV/AIDS to blame their illness on other diseases, "don't tell, call it something else, like cancer, leukemia". Denial was cited as a basis for women their age not using condoms believing their partners only have sex with them., "no women don't wear condoms because they only having one partner".

The non-IDU group felt that most women 50 years and older do not think they are at risk for HIV infection. One participant shared, "the majority of older women think, "I'm past that age, that's not going to happen to me". They also felt there was no promotion of HIV prevention

for seniors. Stigma was discussed and cited as the cause of seniors who get HIV/AIDS but don't talk about dying from it, "they talk about dying from opportunistic diseases".

4.1.5. Drug Involvement

IDU group participants felt that drug and alcohol use is a big problem in the African American community among women their age. They acknowledged the association between drug and alcohol use and lowered inhibitions, stating "that women should use clean needles to focus on not transferring blood". Some women in the group discussed how "people had 'it' but didn't tell people . . . people started carrying their own works". Aside from illicit drug use, the impact of legal or prescribed drugs was also discussed and thought to cause a drug induced haze in persons who are sexually active. They also recognized that although women may not be involved in drug or alcohol use, their partners may be.

Non-IDU participants disagreed about the impact of drugs and alcohol on the 50 years and older age group. Some felt drugs were not an issue for this age group while others felt prescription drugs may have an impact on the risks seniors take.

4.1.6. Risks and Barriers

Table 2 describes how the participants rate their risk for HIV infection. The majority of the women in both groups (IDU – 66.6% and non-IDU 77.7%) considered themselves to be at no or minimal risk for HIV infection.

Table 2: Self-rated Risk for HIV infection

Risk of HIV Infection	AA IDU (n = 6)	AA non-IDU (n = 10)
No risk	33.3	44.4
Minimal risk	33.3	33.3
Some risk	33.3	22.2
At risk	0	0

*All numbers are percentages.

Table 3 reflects the number of participants who have had an HIV test in the past year as well as along with current knowledge of their HIV status. The majority of the IDU group (83%) had been tested in the past year with 100% of them being knowledgeable of their HIV status, whereas the majority of the non-IDU group (89%) had not been tested in the past year and only 44% were knowledgeable of their HIV status.

Table 3: HIV Testing and HIV Status

	AA IDU (n = 6)	AA non-IDU (n = 10)
HIV Testing (past year)		
Yes – HIV Testing	83.3	11.1
No – HIV Testing	16.7	88.9
HIV Status (known)		
No	0	55.6
Yes (Negative)	100	44.4

*All numbers are percentages.

The IDU group felt that the difficulty in negotiating condom use served as a barrier to protection due in part to low self-esteem, low self-worth, and loneliness as well as engaging in unwanted sex. There was consensus that male partners are very unwilling to use condoms and women must learn how to say no. One woman shared, “there are no adverse reactions from

partners regarding condom use” while four others shared, “there is a risk of violence, threats and accusations”.

The non-IDU group felt that older adults do not wear condoms because they do not believe they are at risk for HIV infection and there is no need for pregnancy prevention. They also cited loneliness and questions about fidelity as having direct effects on older women’s ability to introduce condoms: “Women may not protect themselves because they don’t want to be lonely”.

5. DISCUSSION

The African American women over fifty in these two groups displayed significant differences in general knowledge of HIV and AIDS as well as transmission routes. Both groups were very aware of safe behaviors. The IDU group was more aware of where to find HIV prevention information than the non-IDU group who felt there was very little age-specific HIV prevention materials for persons 50 years and older. Both groups cited stigma as a barrier to women using prevention services and that women in their age group feel they are not at risk for HIV infection. Stigma was discussed again by both groups as the reason that older individuals who contract HIV/AIDS blame the illness on another disease or opportunistic infections. Many African Americans still view the disease as one of gay men and are willing to hide infection status. Although members of both groups agreed that drug and alcohol use lowered inhibitions and increased risk behavior, it was at varying levels. While both groups considered themselves at minimal or no risk for HIV infection, the majority of the non-IDU group were unaware of their current HIV status. Though the two groups reported different experiences with condom negotiation, loneliness was cited as a barrier to condom use by both groups.

Despite the similarities and differences between the two groups, specific themes emerged that must be addressed in order to develop effective prevention efforts. In order to effectively reach African American women over fifty, the first change needed is in their perception of risk. Both of the groups in this study felt they were at no or minimal risk for HIV infection. While this may be true for some of the participating women, IDU use, lack of condom use and lack of knowledge regarding HIV status places most of them at increased risk. Efforts to address this perception barrier will need to reverse a 'school of thought' in this generation of women. African American women born prior to 1955 were typically raised not to talk about sex.

Because HIV prevention and sexual activity are directly related, it is very important to help women of this generation become comfortable discussing their sexuality. This is the first step towards changing perception, creating an open dialogue. Women from this generation were also reared in a time where condoms were used for pregnancy prevention. Since they are past the age of pregnancy, they do not see the need to use condoms. It is imperative to change this mindset also because as research has shown, these women are sexually active and next to abstinence condoms are the most effective way to prevent HIV infection.

Several African American women of this generation would move from their parents' home to their husband's home, not having the opportunity to date or live on their own. This presents a problem for women who find themselves single and dating again after a divorce or widowhood. Many of these women who are faced with dating again after a long time or for the first time are not aware of the pitfalls and dangers of unprotected sex. Some still have the mindset that if a person 'looks clean they are clean'; however this is not always the case. Support services are needed for newly single women that provide information about dating and ways to protect themselves if and when they are sexually active. Loneliness was cited as a barrier to unwanted or unprotected sex by women over fifty. Suggestions to combat this barrier were skills building focusing on self-worth, self-esteem and condom negotiation. Using women, especially African American women over fifty, to empower other women, helping them recognize their self-worth along with social support groups can be used to combat the issue of loneliness.

Stigma was also cited as a large problem in the African American community surrounding HIV/AIDS. People are often afraid of what they don't know about. Open dialogue and discussion about HIV/AIDS as well as providing accurate, culture specific education can

help to combat stigma. Also bringing the various subgroups together to talk and exchange information will help to remove stigma surrounding this disease such as an infected & church group of women and an affected and IDU group of women. Bringing people together to minimize their differences and build on their similarities helps to strengthen the community. Once people realize that they are all dealing with many of the same issues, it makes it easier to come together towards a common goal, increasing awareness and decreasing infection rates. In the end there is not 'one size fits all' solution to the problem of HIV in African American women over fifty. However vital recommendations have been made in previous studies as well as innovative suggestions from this current study.

5.1. Recommendations

5.1.1. Previous Studies

Effective interventions for older adults must use age-driven study designs that are culturally appropriate and sensitive to the combination of age with ethnic and racial diversity (Levy, Ory & Crystal, 2003). A shift in beliefs towards viewing older adults as an at-risk population needs to occur by older adults and their physicians (Coon, Lipman & Ory, 2003; Levy, Ory & Crystal, 2003). Efforts should also address individual behavioral change, social factors such as changing community and peer norms, and policy issues, such as guidelines for state-mandated educational programs (Coon, Lipman & Ory, 2003). Intervention efforts can also be combined with existing programs and services that older adults receive such as financial support, social support, housing support and health care. Community partnerships can provide

dissemination pathways through existing services facilitation, effective implementation of programs and normalizing HIV prevention efforts at later life (Coon, Lipman & Ory, 2003).

African American communities continue to be plagued with low levels of education, inadequate representation in health care and public health fields, low socioeconomic status and high levels of communication gaps including a lack of information as well as myths and misconceptions regarding HIV/AIDS (Williams, 2003). According to Williams (2003) some myths and misconceptions are due to the Tuskegee Syphilis Study and include the following ideas:

- 1) AIDS is a gay man's disease.
- 2) AIDS is punishment from God for sinful behavior.
- 3) HIV/AIDS is a genocidal plot by the government against African Americans.
- 4) Government run public health programs cannot be trusted.

These mounting inequities and mistrust have direct implications on the fight against HIV/AIDS within the community in general. Older adults face many of the same issues (lack of information, misconceptions) coupled with a large fear of stigma (Klein et al., 2001). Due to the diverse ethnic backgrounds of older adults who are considered at-risk, a variety of approaches must be employed to reach the various group methods, such as street and community outreach; workshops and presentations; peer HIV/AIDS prevention educators; risk reduction counseling; HIV prevention case management; and community level interventions (Williams, 2003).

5.1.2. Current Study

Focus group participants expressed the need for age and ethnic specific prevention programs. Programs targeting African American women 50 years and older should include skill

building around prevention, self-empowerment and condom negotiation. The groups suggested that women 50 years and older talking to other women 50 years and older about prevention efforts such as 12 step model about testing & risk behavior. Peer education would help them feel more comfortable. Offering information through speakeasies, after hours clubs and church will ensure reaching a variety of individuals. The participants also expressed a need for more printed information on HIV testing and retesting in doctor's offices as well as doctors talking more to patients about HIV. Other program topics suggested by the groups included:

- 'Senior Sex' (i.e. 50+ and Alive)
- Condoms, specifically where to buy them and how to use them
- Menopause
- Sexual relationships
- Feelings such as denial, free talk, and venting
- Loneliness
- Support groups

They also believed that visual learning, direct messages (i.e., 'short & sweet'), story telling that is part of African American heritage and personal perspectives presentations would be successful delivery methods. Another effective delivery tool was to use people they 'know' such as older adult minority women or community leaders, who could be trained as peer educators. The use of multi-generational prevention programs was suggested to increase the prevention dialogue between generations. In addition multi-family, in-home (confidential) prevention education and skills building programs were recommended. Other recommendations were the use of existing services for the dissemination of HIV prevention education such as nurses, therapists, home health aides maximizing existing relationships.

5.1.3. Comparison of Studies

When comparing the recommendations between the previous and current studies, several similarities can be found. Both suggested the need for ethnic and age appropriate interventions as well as combining HIV prevention efforts with existing services. Both studies also suggested physicians should talk more about HIV as well as sexual activity with their older patients. Also similar was the need to change the belief that persons 50 years and older are not at risk for HIV infection. Although the use of peer educators were identified in both studies, the current study found that peer educators who were demographically matched would increase their level of comfort around this topic area.

The current study identified many nontraditional approaches to reaching older adults, specifically African American women. The use of after hours clubs, speakeasies as well as multi-generational and multi-family were suggested as ways to reach not only the target population for this study but also others in the African American community. Also suggested were delivery techniques thought to be most effective for the African American community such as story telling, African American heritage, visual learning, direct messages and the use of community leaders and ‘people that look like them’.

Also important to note are recommendations from the community advisor board (CAB) because they were more representative of the African American female population over fifty in Pittsburgh. The CAB suggested including the following subgroups of women 50 years and older:

- Infected women
- Affected women
- Caregivers
- Newly single women (divorced or widowed)
- Churchgoing women
- Health conscious women
- Ex-offenders
- Past IDUs
- Current IDUs
- Sorority women
- Senior high rise apartments

The CAB believed that each of these groups would provide a variety of information that would allow the findings to be more generalizable to African American women in the Pittsburgh area.

6. CONCLUSIONS

6.1.1. Summary

While the number of HIV/AIDS cases in African American women 50 years and older is steadily increasing, lack of education and misconceptions regarding disease transmission act as a barrier for prevention efforts. Significant differences in knowledge between IDU and non-IDU women demonstrate the need for segmented prevention efforts within subpopulations. An emphasis was placed on the need for inclusive HIV prevention efforts such as multi-generational in-home programs, multi-family programs and the incorporation of prevention messages with existing health services. Skills building, condom negotiation skills and self-empowerment were viewed as essential techniques in removing barriers to prevention by this population. Effective prevention messages targeting older women of color should be personal and believable, as well as employ techniques that align with African American culture and heritage such as storytelling, including family and community. Also important were the use of community advisory boards and the use of other African American women over fifty throughout the data collection process.

6.1.2. Public Health Significance

Reducing the spread of HIV/AIDS in general is of great significance to the field of public health. Because African American women have been disproportionately affected by this disease, effective prevention efforts are needed for this group.

- Federal government agencies need to view older adults as ‘at-risk’, setting a precedent for local and state agencies and allowing an increased flow of funding to this subpopulation.
- State public health agencies need to provide targeted information for older adults and HIV prevention specific to condom use, age group differences and marital status.

- Department of Aging needs to step up and take key position in efforts.
- Community organizations should target nontraditional venues such as after hours clubs, speakeasies and not just churches reaching farther across subgroups.
- Family structure should be used as an advantage to promote multi-generational, multi-family education efforts educating several generations at once.
- HIV service groups need to increase their visibility in the community and provide specific information targeting older adults and their specific risk factors.
- Physicians need to discuss HIV prevention and sexual activity with patients over fifty as well as the role of prescription drugs on risk behaviors.
- Universities should recognize the important role of community advisory boards when conducting community based research and utilize them in developing appropriate activities as well as lasting relationships with communities.
- Researchers need to conduct further studies on subgroups within the African American female population over fifty such as churchgoers, sorority women, infected women, affected women and health conscious women.

Although the results of this study may not be generalizable to all African American women, it provides insight to what a subpopulation of this group views as effective prevention methods. The information gathered here can be used to design prevention messages that can be implemented in the population from which they were gathered. If effective, materials can then be disseminated to similar subgroups for further testing and proficiency. In the end, this study adds to a growing body of knowledge regarding the HIV prevention needs of African American women 50 years and older.

APPENDIX A: IRB APPROVAL

Description of Research Study

Approved: 10/29/04
Institutional Review Boards
University of Pittsburgh
IRB #: 0410088

DESCRIPTION OF RESEARCH STUDY

TITLE: HIV Prevention Needs Assessment for African American & Hispanic Adult Women (50 years of age and over)

INVESTIGATOR: Emilia Lombardi, Ph.D.
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Grace Kizzie, L.S.W.
Research Specialist
Pennsylvania Prevention Project
Graduate School of Public Health
3520 Fifth Avenue, Suite 400
Pittsburgh, PA 15213
(412) 383-1619

SOURCE OF SUPPORT: Pennsylvania Department of Health

The following information explains the objectives, procedures, risks, benefits, and requirements of this research study.

DESCRIPTION:

Thank you for coming to this interview. This interview is being conducted to better understand the needs and barriers of people at risk for HIV in Pennsylvania. The information you provide today can help to develop better HIV prevention plans in Pennsylvania.

This interview is being conducted by the Graduate School of Public Health at the University of Pittsburgh.

I want to tell you about what would be involved if you participate in this interview. The interview will last up to one-and-one-half hours. You will be asked questions about your knowledge of HIV/AIDS and what you think will prevent people like you from getting infected with HIV. The interview will be taped-recorded with your permission.

RISKS AND BENEFITS:

Participation in the interview has minimal risk. Things we talk about could cause you to become upset during or even after the interview. However, the interviewer can address any of your concerns during or after the interview. You will also be told where else you can go for advice and support.

COSTS AND PAYMENTS:

There are no costs for you to participate in the research study. You will receive \$20 for your participation at the end of the interview.

ANONYMITY:

We are requesting that you do not identify yourself by last name and that you do not identify others in the group by last name. This way, it will be impossible for anyone to know how you answered any question. Also, information from the interview will be kept in locked files and only the research team from the Graduate School of Public Health will have access to these files. The tape made of this interview will be erased after a written form of the tape is made. Your name and any other identifying information will be kept out of the written transcript. The tape, before it is erased, and the written transcript will be kept in locked computer and office files to which only the research team from the Graduate School of Public Health will have access.

If the researchers learn that you or someone with whom you are involved is in serious danger or harm, they will need to inform the appropriate agencies as required by Pennsylvania law.

RIGHT TO WITHDRAW:

Your participation in this study is completely voluntary. You may refuse to take part in it or you may stop participating at any time.

If you have any further questions about this research study, you can contact the Principal Investigator, Dr. Emilia Lombardi at (412) 383-2233.

VERIFICATION OF EXPLANATION:

I certify that I have carefully explained the purpose and nature of this research to the participant in age-appropriate language. He/she has had the opportunity to discuss it with me in detail. I have answered all of his/her questions, and he/she provided affirmative agreement (i.e., assent) to participate in this research.

Interviewer Signature

Date

Principal Investigator Signature

Date

APPENDIX B: FACILITATOR PROTOCOL

FOCUS GROUPS

Before beginning the focus group:

- 1) Are you rested and alert?
- 2) Have you tested the tape-recorder with the focus group members to ensure a clear reception?
- 3) Are you using the correct set of questions for this population?

Then:

- Introduce yourself. (Your goal at this point is to establish rapport with the participants and to help them feel comfortable.)
- Prior to reading the consent form, generally describe the purpose of this study. That the Pennsylvania Department of Health and other groups related to HIV prevention need information about people so that better HIV prevention programs can be developed.
- Prior to reading the consent form, explain to the group that it will be their choice whether or not to participate after they read the consent form. Say to the potential participants:

“It is perfectly okay for you to choose not to participate in the focus group if you are not comfortable with it after we read some information about the group process. Also, you will be paid the \$20 even if you choose not to participate.”
- Read the consent form out-loud. Have the potential participants read a copy of the consent form while you read it out-loud.
- After reading the consent form out-loud, ask the recruits if they want to participate.
- If they agree to participate, remind the participants not to state his or her name during the focus group. (If they do state their name during the focus group, rewind the tape and record over the place in the tape where their name was recorded.)
- Remind the participants as to what your role is. Explain that some issues may arise during the focus group that you would normally talk about as in a normal conversation. But in this interview, your role is to simply ask questions and that you will save things you may need to say for the end.
- Tell each participant that there are no right or wrong answers. “We need to know what they really believe. This is the only way to get the information we need to do good HIV prevention planning.

- And if they have any questions before beginning the interview. (These should not be related to interview content.)

Remember: **ASK THE QUESTIONS PRETTY MUCH AS THEY ARE WRITTEN**
DON'T PROVIDE FEEDBACK
PROBE A LOT

****Make sure tape recorder is on. You should have tested it before it before the interview. It is O.K. to start the tape recorder at this point. Just please don't forget to do so.*

After asking the Questions, Thank them!

- If anything was said that needs correction, (harmful or misleading information), this is the time to do it.
- Do they have any questions or concerns?
- Give them Dr. Emilia Lombardi's business card. Explain to the participants that she is the Principal Investigator of the study, the director of the study. Tell them that they should feel free to call Dr. Lombardi with any question or concern about this study that they may have in the coming days, weeks or even months. Reinforce that Dr. Lombardi really wants to speak to any participant who has a question or who experiences difficult feelings as a result of being interviewed.
- Tell them about getting help in the future. Give them the appropriate referral information sheet. Explain to them what the "A" stand for and what the "C" stands for. Explain to them why you are using these codes. Suggest that they hold on to this information for several weeks. Tell them that it is possible that they might experience difficult feelings as a result of being interviewed because of the topics they discussed. If this happens, they may want to call the "C" in the list to get counseling. If they feel that they want to or need to be tested and counseled for HIV, they should call the "A" which is a place that they can receive HIV testing.
- Have person fill out the Participant Questionnaire themselves or read it to them and you fill it out. After you walk away, write on the questionnaire the demographic (Heterosexual African-American Women, Heterosexual Latino Women, IDU African American Women, IDU Latino Women, etc.).
- Pay individuals. Have individuals fill out Participant Payment Certificate. Tell them that they should feel free to write down fake initials if this makes them more comfortable.

*****Debriefing: (TAPE-RECORD THIS!)**

Content:

- Discuss what each of you (facilitator & recorder) thought were the most important themes.
- How did these differ from what we expected?
- How did these differ from what occurred in earlier interviews.

Process:

- How would you describe the focus group dynamics?
- Strengths/weaknesses?
- What could have been done better?
- What was the comfort level of the participants?
- Did the participant match the prescribed characteristics?
- Did the participants have any concerns about confidentiality or tape recording?
- How important was the \$20 in terms of their motivation to participate?
- Was the location suitable?
- Did the tape recorder work well?
- Were there any problems? If yes, please describe and note impact on group process (e.g. noise, someone fainted)
- What was the length of the session.
- Note any variations that occurred on protocol. Note any changes made to the facilitator script, especially questions.
- Note your general feelings about the participants and the focus group.
- Note your general feelings about the participants and the focus group.
- Note any recommendations you have.

Please inform Grace Kizzie by phone (412) 383-1619 of any needed follow-up. Please remember to place the group name on both the Participant Payment Certificate and on the Participant Questionnaire.

APPENDIX C: RECORDER PROTOCOL

FOCUS GROUP

1. Arrive at focus group site at least one hour early to confer with moderator, help to arrange chairs, set out refreshments, test equipment., set out forms, get food ready, etc.
2. Please bring food. Don't bring food that makes a lot of noise (e.g. potato chips). Bring paper plates, napkins, ice, paper napkins, plastic utensils, and drinks. Have drinks with and without caffeine. \$100 is budgeted for each group. I'll give you cash. You must supply me with all **original** receipts.
3. Make a diagram of the room. Note by first name who is sitting where. Refer to people by first name in notes if it is relevant (i.e. someone is standing out in some way).
4. Do not participate in discussion. Control non-verbals.
5. Tape Recording: You should have two tape recorders. I will show you how to use these in great detail. It is crucial that we get the groups tape recorded.
 - **Test the tape recorders before the group begins.** Set up the microphones in the middle of the where the participants will sit. Begin to record, walk around and speak softly from different areas. Then play back to evaluate.
 - Don't place the microphones on a table where someone is seated. The vibration and/or kicking of a table make it difficult to hear. I'd place them on a chair in the middle of the square/rectangle.
 - **Please, please, please, make sure the recorders are on when the group begins.** Tape the debriefing after the group.
 - New batteries are in the tape recorders though you should use electrical cords instead.
 - During the focus group, remember to turn the cassettes and place new cassettes for both recorders **simultaneously** during the actual focus group. **Play close attention to when the side ends!**
 - Use the tapes as they are labeled (i.e. make sure you use side A before side B and tape 1 before tape 2 and large/small recorders as noted).
6. I am assuming that you will not need to place signs indicating how get to the focus group given that these are being held within agencies. If there is a need, please post signs to make it easy for everyone to find the group.
7. Recording:

Because the tapes are not being transcribed, we are depending on the recorders to take excellent notes. You do not need write down everything that is being said. Rather, it is important that you capture the following:

- All concepts/themes - Please do not interpret anything. Record themes objectively.
- Level of consensus – Do people agree?
- Intensity of what is being expressed
- Group process: cooperative, hostile, people are comfortable, group has not been listening to each for most of this group so far. etc.
- Individual actions/non-verbals:
 - Mike seems very excited.
 - Sally is dominating the discussion.
 - Cheryl and Harry keep talking to each other and aren't really involved.
 - Bernie left room, Bernie came back.
- Silences

Please write clearly and legibly. Please type up the notes and give to Mark Friedman on the disk he gives you within one week after the focus group.

APPENDIX D: RECRUITER PROTOCOL

FOCUS GROUPS

1. As a result of being trained by PPP staff, you should be aware of: 1) the need to maintain the anonymity of the potential participants (Note: The term “potential participants” is used because the individuals will agree or not agree to participate at the time of the focus group), 2) the characteristics of the individuals you are to recruit, 3) the need to report any problems or concerns to either Dr. Emilia Lombardi or Grace Kizzie, and, 4) the consequences of inappropriate behavior related to the recruitment process.

2. You will need to speak with the facilitator before recruiting participants. Please determine when the facilitator is available to do the focus group. This obviously does not apply if you are doing both the recruiting and the facilitating. In all cases, try to schedule the focus group for within 3 days of recruiting potential participants.

3. When you are recruiting potential participants, please say the following:
 - You are being asked to participate in a study that Dr. Emilia Lombardi is carrying out. Emilia is an assistant Professor in the Graduate School of Public Health.
 - You must be 50 years of age or older and (STATE THE PARTICULAR CATEGORY YOU ARE SEEKING, FOR EXAMPLE “HETEROSEXUAL AFRICAN AMERICAN / LATINO OLDER ADULT WOMEN.”) to participate.
 - The purpose of this study is to better understand the HIV prevention needs for this subpopulation.
 - There are about 80 people being interviewed via focus groups for this research study.
 - If you choose to participate, you would be interviewed in a focus group setting. This would take up to 45 minutes. Your name will not be recorded. I will not give your last name to the person facilitating the focus group. In this way, your participation is anonymous. No one could ever determine how you answered the questions.
 - The focus group will take place (STATE THE LOCATION). (Note: if the location is not known, identify an appropriate location).
 - You would receive \$20 for participating.
 - Tell the person that it is very important that she arrives on time for the focus group and not bring anyone else.

4. Ask the person if she would like to participate in the focus group. Explain that they are not agreeing to be interviewed by agreeing to come to the focus group. Instead, the facilitator will read a form giving much more information about the focus group process when they meet. After the person hears this information, they will decide whether or not to participate.

APPENDIX E: FOCUS GROUP OUTLINE

PENNSYLVANIA PREVENTION PROGRAM WOMEN'S HIV STUDY

INTRODUCTION (10 minutes)

FACILITATOR: REFER TO BOTH AFRICAN-AMERICAN AND HISPANIC WOMEN ONLY IN MIXED GROUPS, OTHERWISE JUST REFER TO AFRICAN-AMERICAN OR HISPANIC WOMEN.

KNOWLEDGE: (15 minutes)

(Say that we are going to spend only a few minutes on this first set of questions.)

1. If someone you knew (like a friend or grandchild) was interested in the information, how would you explain the relationship between HIV and AIDS to them?
2. What kind of things do you consider to be “unsafe” behaviors, or behaviors that would put you at greatest risk for getting HIV?
3. What kinds of things do you consider to be “safe” behaviors, or behaviors that would put you at the least risk for getting HIV?
4. What are the ways that HIV can be transmitted from one person to another?
5. If a woman is pregnant and HIV positive, what if anything, can she do to reduce the risk of giving HIV to her unborn child before or during delivery?

EXPERIENCE WITH HIV PREVENTION / NEEDS: (40 minutes)

1. The following questions are about HIV prevention services. Before answering the specific questions, could you tell me what you think HIV prevention is?

(Provide clarification if necessary: Prevention entails providing information about HIV/AIDS and risk behaviors related to HIV; helping individuals assess their personal risk behaviors; assisting individuals to acquire understanding and adopt attitudes and skills that would reduce risks of HIV transmission; and assisting individuals in developing a risk reduction plan for themselves.)

2. Where could women our/your age go to get information about HIV? If you needed assistance related to HIV where could they go?
3. Are HIV prevention messages reaching (African-American and/or Hispanic) women our/your age? If so, what have you seen?
4. Were any of these HIV prevention services specifically directed towards African-American and/or Hispanic women our/your age?
5. What would make African-American and/or Hispanic women our/your age comfortable enough to seek HIV prevention?
6. What kinds of things (people, money, hours, etc) would keep African-American and/or Hispanic women our/your age from using these services?
7. What will a program designed for women our/your age look like?
8. What kind of special needs will it address?
9. How will it reach African-American and/or Hispanic women our/your age?

PSYCHOSOCIAL: (20 minutes)

1. Do African-American and/or Hispanic women our/your age think HIV/AIDS are issues they need to be concerned about?
2. Do African-American and/or Hispanic women our/your age protect themselves from HIV/AIDS? If so, how? If not, why not?
3. What, if anything, in your community helps/promotes HIV prevention for African-American and/or Hispanic women our/your age?
4. Does anything in your community interfere with older African-American and/or Hispanic women trying to protect themselves from HIV/AIDS? (Are brochures available in Spanish, especially, for older Latino women?)
5. What happens to people in your community if they get HIV/AIDS?
(**Probe:** Do others fear people with HIV/AIDS? Is there a stigma attached to those with HIV/AIDS?)

DRUG INVOLVEMENT: (10 minutes)

(Explain to the participants that we are looking for the relationship between drug use, sex, and HIV prevention. Some participants may be very comfortable sharing drug usage history, while others may not. Remind participants of the anonymity on the interview and the option to pass on any question.)

How much of a problem is Drug or alcohol use for African-American and/or Hispanic women our/your age in regards to HIV prevention.

RISKS & BARRIERS: (20 minutes)

1. Do African-American and/or Hispanic women our/your age think they are at risk for getting HIV? If yes, why? If no, why not?
2. Do African-American and/or Hispanic women our/your age use condoms? Why or why not?
3. Do African-American and/or Hispanic women our/your age negotiate condom use when they have vaginal sex with men? Do they have any problems with this?
4. How willing or unwilling are male partners in using condoms?
(**Probe:** Are there any risks of adverse reactions--violence/threats/accusations--from male partners regarding condom use?)
5. What would help African-American and/or Hispanic women our/your age who have sex use condoms?
6. Is there any additional information you would like to provide?

APPENDIX F: SURVEY QUESTIONS

PENNSYLVANIA PREVENTION PROGRAM
Women's HIV Study

The success of this study depends on you giving us accurate information. So, please take your time and answer questions honestly and fully. This survey is **ANONYMOUS**. (No one will be able to identify you.) Please **DO NOT** put your name anywhere on this form.

1. County / Zip Code: _____ / _____

2. What is your age? _____

3. What is your race?
 African American or Black
 Latino/Hispanic/Puerto Rican
 Asian, Pacific Islander
 Native American
 Caucasian or European American
 Other (please describe) _____

4. What is your highest level of education?
 Less than 9th grade
 Some high school
 High school graduate
 Some college or other education beyond high school
 Graduate from college
 Graduate or professional education beyond college (i.e.:
Master's / Ph.D., M.D.)

5. What is your current marital or relationship Status?
 Married (How long? _____)
 Widowed (How long? _____)
 Common Law Married (How long? _____)
 Divorced (How long? _____)
 Separated (How long? _____)
 Never married

- 5a. Are you currently dating anyone?
 Yes (How long? _____)
 No

8. Rank top 3 choices (1, 2 & 3) - where you get most of your information about HIV/AIDS?

- Friends
- Radio
- TV
- Internet
- Health clinics
- Family
- Schools
- Books/Magazines
- Pamphlets
- Doctor or other health professionals
- Churches/Synagogues
- Other sources _____

9. In the last year, were you tested for HIV?

- NO
- YES If yes, where did you get tested?
- HIV testing site or clinic
- Health Department
- Research Study
- Doctors Office
- Other _____

10. Please tell us what you think the risk is of getting HIV (**the virus that causes AIDS**) for doing the following things

A. When a man and woman have vaginal sex, what do you think the risk is of getting the HIV virus?

- Low
- Medium
- High
- Don't know

B. When a man and woman kiss, what do you think the risk is of getting the HIV virus?

- Low
- Medium
- High
- Don't know

C. When a man and a woman have oral sex, what do you think the risk is of getting the HIV virus?

- Low
- Medium
- High
- Don't know

D. How effective do you think not having vaginal sex at all is at preventing someone from getting the HIV virus?

- Not effective
- Somewhat effective
- Very effective
- Don't know

E. How effective do you think using a condom during sex is at preventing someone from getting the HIV virus?

- Not effective
- Somewhat effective
- Very effective
- Don't know

F. How effective do you think using a spermicidal jelly, foam, or cream (without condom) is at preventing someone from getting the HIV virus?

- Not effective
- Somewhat effective
- Very effective
- Don't know

G. How effective do you think using a diaphragm during sex is at preventing someone from getting the HIV virus?

- Not effective
- Somewhat effective
- Very effective
- Don't know

H. How effective do you think a man having a vasectomy (being sterilized) is at preventing someone from getting the HIV virus?

- Not effective
- Somewhat effective
- Very effective
- Don't know

I. How effective do you think having sex with one single partner who does not have the AIDS virus is at preventing someone from getting the HIV virus?

- Not effective
- Somewhat effective
- Very effective
- Don't know

Please excuse our explicit language but we need to ask these kind of questions so that we can learn more about your risks.
Remember: This survey is anonymous and your answers are confidential.

13. In the last 6 months have you: Since _____ have you:	NO (✓)	YES (✓)	Number of Times (#)	Number of Partners (#)	Number of times With Condom (#)
Performed oral sex on a man: Place your mouth on a man's penis					
Received oral sex: Someone places their mouth on your Vagina					
Received vaginal sex: Someone put his penis in your vagina					
Received anal sex: Someone put his penis in your butt					

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