



Perspectives on the Epidemic: Women and Teenage Girls At Risk for HIV

Insights from Focus Groups

FULL REPORT OF FINDINGS

Prepared by Lake Snell Perry & Associates, Inc.
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INTRODUCTION

The HIV/AIDS epidemic has had an increasing impact on women. Women account for a growing proportion of new AIDS cases, rising from 7 percent of AIDS cases reported in 1986 to approximately one quarter (26 percent) of cases reported in 2001.¹ Moreover, women of color are disproportionately affected by the epidemic – African American women account for 63 percent of new AIDS cases reported among women and Latinas account for 17 percent.² The majority of HIV infections among women are in women of reproductive age.³ Younger women are also at particular risk, with teen girls accounting for more than half of all new HIV infections reported among people ages 13 to 19 in 2001.⁴

To understand more about those women at risk for HIV, the Kaiser Family Foundation commissioned this focus group study of women and teenage girls. During January and February of 2002, Lake Snell Perry & Associates (LSPA) conducted six focus groups with women and teenage girls who are at higher risk for HIV to understand their attitudes, knowledge, and behavior about HIV. Participants included in the focus groups were heterosexual, unmarried, have had one or more sexual partners in the last year, and do not regularly practice safer sex. Focus groups were held in Philadelphia, Los Angeles, Miami and Savannah with lower-income African American, Latina, and Non-Hispanic white women and girls.

The purpose of this project was to learn about at-risk women and girls' knowledge and concern about HIV/AIDS, and to probe whether and how the risk of HIV affects their sexual behavior. Specifically, the study explored what participants know – and do not know – about HIV/AIDS in terms of transmission, incidence and prevention. Participants also discussed whether and to what extent they feel that they themselves are at risk for HIV, as well as whether those around them are at risk. The groups also discussed if and how HIV/AIDS affects their interactions with sexual partners and potential sexual partners around issues like condom use and HIV testing. Lastly, the focus group participants evaluated a number of prevention and awareness messages in order to inform the efforts of those who create such messages.

Detailed findings are presented in four sections. Section one explores participants' level of concern and knowledge about HIV/AIDS. The second section explores their sexual behavior in relation to HIV/AIDS. The third section looks at messages around HIV/AIDS awareness and prevention, as well as what messengers might effectively deliver these messages. The final section examines the implications of this study for those seeking to communicate with women and girls at risk for HIV.

¹ Centers for Disease Control and Prevention (CDC), HIV/AIDS Surveillance Report, Year-End Editions, 1986 - 2001.

² CDC, HIV/AIDS Surveillance Report, Year-End Edition, Vol. 13, No.2.

³ Ibid.

⁴ CDC, HIV/AIDS Surveillance in Adolescents, L265 Slide Series, Through 2001.

Research Methods

Fifty-five women and girls, ages 15-40, participated in the focus groups, conducted between January and February 2002. To be included in the focus groups, potential participants had to be from lower-income households – defined in this study as at or below 300% of the Federal poverty level. Table 1 shows the schedule of the focus groups and a profile of the participants.

Table 1

	Group Description	Number of Participants	Date	Site
1	African American women ages 20 to 40	10	1.23.02	Philadelphia
2	White teen girls ages 15 to 19	6	2.19.02	Los Angeles
3	White women ages 20 to 40	10	2.20.02	
4	Latina teens ages 15 to 19 (in Spanish)	10	2.25.02	Miami
5	Latinas ages 20 to 40 (in Spanish)	9	2.26.02	
6	African American teen girls ages 15 to 19	10	2.28.02	Savannah

Potential participants also had to be unmarried and at risk for HIV. While married women certainly can be at risk for HIV, the focus groups were limited to include women who are unmarried in order to maximize the potential of reaching women who would be more likely to have more than one partner.

Determining whether individuals are at risk is, needless to say, a challenge. We relied on their answers to several questions about their sexual behavior. Participants were considered at risk if they said they had sex – including oral sex – within the last year; priority was given to those who had sex within the last six months. Participants were also asked how many sexual partners they had had within the last year. In each group we accepted only one or two participants who said they had had only one partner; the remainder must have had two or more. Participants were also asked how frequently they and their partner(s) use condoms. Priority was given to those who said they do not use condoms every time they have sex. However, there were one or two participants in each of the groups who said they use condoms consistently.

The focus group facilities recruited participants using both their databases and community outreach methods. We obtained parental permission as well as household income information from the parents of teenage participants.

In interpreting these results it is important to remember that focus groups are a qualitative research tool. Therefore, these results cannot be statistically projected to the larger population of women and girls at risk for HIV. Rather, this type of research provides subtle insights into individuals' experiences, attitudes, and opinions. By giving these individuals the opportunity to share their feelings and experiences in their own words, the focus groups allow more vivid, detailed findings than quantitative research methods can achieve.

DETAILED FINDINGS

I. Context: Concern, Knowledge and Sources of Information

Level of Concern and Perception of Risk

Most participants are concerned about HIV/AIDS, but for many the concern is for others rather than themselves.

Women and teens vary as to how concerned they are about HIV/AIDS, and how personal their concern is. A handful of women express very little concern. For these women the threat seems very remote. As one white woman says, "I'm 36 years old. I've lived through a number of years and ...I don't have one boyfriend that's ever [had HIV], and I don't have any girlfriends who have had a boyfriend who have had AIDS. ...I don't know a girlfriend who has a girlfriend who has a girlfriend who has had AIDS."

Me, personally, I [am not] concerned for myself, but, I am concerned for other relatives that I know that are having intercourse, sex – teenage cousins that are coming up that are not really knowledgeable.

African American Woman

Some women are concerned about HIV/AIDS but their concern is abstract and societal rather than personal. As one African American woman explains, "I'm concerned on behalf of a lot of females having children and they are infected with it and their child coming out infected with it." Others are not concerned for themselves, but are concerned for friends or family members. Some have specific friends about whom they worry. For example, another African American woman explains, "I have a friend who hasn't been in a relationship in a long time, but she has a male friend that she has known for a long time. Every time he comes in town there is a sexual encounter and I'm not sure how safe that is. That's a worry."

The majority of participants say that they are not too concerned about HIV/AIDS on a personal level. When asked why they are not personally concerned, some women say it is because they "practice safe sex." As an African American teen explains, "[I am not concerned because] I would never do stuff without using protection." Others say they are not too concerned because they have had only a limited number of partners or are in long-term, monogamous relationships. An African American woman explains that she is not concerned because, "I have one partner and I've been involved with this partner for eight years. I have been tested and it's just been going good so far for the eight years we've been together."

[I am not concerned] because I haven't had that many partners. Also, I've been with my boyfriend a long time.

Latina Teen

Some participants are personally concerned.

A handful admit that they are concerned because they do sometimes take risks. Others are concerned because, as they put it, "you never know." For some of these women, lack of trust in their partners and in men generally underlies this concern. A handful mention the fact that a man could be HIV positive and not know that he is. As a Latina teen explains, "You are sexually intimate with him. You don't know if he's cheating on you or sleeping with somebody else. And, he already has a past history and you don't know if he has something in his body." An African American woman,

echoing the uncertainty and ambivalence of many women, explains, "I'm slightly concerned only because, regardless of [having only] one partner, you are still at risk. So, I mean, I'm still slightly concerned I guess."

It is worth noting that, in the course of the focus groups, some women began to express more concern. Often they become increasingly concerned when they learn new information about transmission or are reminded of facts they might already know. For example, concern seems to grow when certain facts – such as that HIV can be transmitted through oral sex and that people might be HIV positive without their knowledge – are mentioned.

For some participants, it seems it is the seriousness of the disease and its possible consequences, rather than their subjective risk, that is of concern. As one Latina teen explains, "HIV is also something that determines the status of your life. Once you conceive [sic] that disease that determines the outcome of your life. You want to live a good and healthy life. You don't want to infect your body with a disease that's going to kill you." Those who have seen someone suffer with AIDS are especially likely to think about the disease in terms of its deleterious effects.

About half the women in the focus groups knew of people who are HIV positive or who have died of HIV. A handful of participants in each group say people close to them – family members or friends – have HIV or have died of AIDS. Latinas in the focus groups were the most likely to have had this kind of first-hand experience. Those with first-hand experience view the disease somewhat differently than others. As noted above, seeing someone suffer and die from the disease can be an instructive, if painful, experience. Moreover, simply knowing someone who is HIV positive also brings home that anyone can get the virus. As one Latina teen explains, "My brother's uncle [got AIDS]...I think that nothing really affects you until it comes so close to home. If it happened to him it could happen to anyone."

Which Groups Are Most at Risk

Most women have a fairly accurate notion of who is most at risk, at least in terms of behavior and "lifestyle."

When group participants were asked who or what groups are at risk for HIV/AIDS, their most frequent responses have to do with behavior, often framed in terms of "lifestyle". They mention intravenous drugs users and prostitutes. Beyond that, they talk about women who "sleep around" or "don't protect themselves." In the words of a white woman, "I think it's lifestyle....People that have an irresponsible lifestyle go out to the bars, take home different people every week [are the most at risk]." A few point out that anyone having sex – or sex without a condom – is, by definition, at risk.

You don't know who has it. You can meet somebody, fall in love and not know.

Latina Woman

[If you know someone who has HIV/AIDS,] you take it more seriously. We hear about it and a lot of times a lot of us don't have friends or family that [are] affected by. Then when someone close to us that might have it, we will take it seriously.

African American Woman

Some know about racial and ethnic disparities, but there is also resistance to the idea that certain groups are at increased risk.

[HIV rates have grown faster among] black and Hispanic girls in their 20s, from what I understand.

White Teen

There is some awareness that certain groups of women are at higher risk than others. Between a quarter and a half of the participants seem to know that African American women have been more affected than white women. Slightly fewer seem aware that Latinas too have been more affected than whites. According to one Latina teen, she knows that African American women are more at risk “because that’s all you ever hear about on TV.” The only group that appeared to be totally unaware of this was the African American teenagers. A handful of women in the groups know – or assume – that less educated women, and women with lower socio-economic status, are at greater risk. As one Latina woman explains, “I think the poor, low income people have a higher possibility of having AIDS spread than somebody who is educated.”

It is worth noting that some women are resistant to the idea that some groups are more at risk than others. They are especially uncomfortable seeing it as a racial or economic issue. They argue that a person cannot be at risk because of the color of their skin or their income. As a white women said “Why is it because of race... This doesn’t make sense to me. People are people, they have sex whether you are Asian or Black or whatever.” Some are also uncomfortable with the idea of anyone being excluded from a risk; they feel no one is truly safe. In the words of one white woman, “I think anybody who has ever had sex in their life even just once [is at risk].”

Most feel single women and those who engage in casual sex are at greater risk, but some point out that married women and those in long-term relationships are susceptible too.

Everyone has the same risk, no matter who you are, where you’re from, how old you are, what nationality you are. You’re having sex and you are at risk and that’s it, simple as that.

Latina Teen

Most participants feel that married women are at reduced risk of contracting HIV as compared to their single counterparts. However, some women say that married women – and women in ostensibly monogamous relationships – may be at greater risk because of a false sense of security. As a white teen explains,

I guess I think that people who are married can contract it a lot easier because [people] who are being promiscuous, they know that they are sleeping with multiple people so they should protect themselves. People who are married and trust their husbands think, ‘I don’t need to use protection, I’ve been married for ten years and we trust each other’

Similarly, an African American woman warns that married women are at risk because “everything that glitters isn’t gold.” She goes on to explain, “You being in a marriage and thinking that everything is fine. Your husband. . . might be out there doing something.”

Participants are also somewhat divided about whether more unmarried woman contract HIV from casual sexual encounters or from long-term partners. The majority seem to feel that those in casual relationships are at greater risk than those who are in long-term relationships. However, a few women, such as the African American quoted above, see this as a fallacy. Or, at the very least they note that women in long-term relationships are certainly not free of risk.

Knowledge

Most participants are fairly well-informed about HIV transmission, but there are some important gaps in their knowledge. A handful appear ill-informed.

Most of the focus group participants know that HIV is transmitted via bodily fluids most often through sexual contact and intravenous drug use. Most know that, barring abstinence, condoms are the best way to protect oneself from HIV.

While most participants are informed about transmission in general, a fair number are not *fully* informed. A handful of participants seem to feel that withdrawal provides adequate protection against HIV transmission. For example, one Latina woman, in discussing prevention methods, said one method her friends use is “not letting him cum into the vagina.” A few other participants – especially among Latinas – also make comments suggesting that pulling out prior to ejaculation prevents the spread of HIV.

Most of focus group participants appear to know that HIV can be transmitted through oral sex. However, there were a few participants who were surprised by this information. Some even question whether there truly is an appreciable risk; one white woman said, “I think they say you can [transmit HIV through oral sex], but I don’t think [you really can].” Participants’ conversations around this topic, particularly those of teens, suggest that many of their peers behave as though oral sex is risk-free. For example, a Latina teen explains, “A lot of people say, ‘Oh yeah I’m going to get oral sex.’ And they don’t think they can get the disease. In my school almost everybody does that and they just think, ‘Oh that’s nothing, you can’t get a disease by that.’”

Most participants know that using condoms can help prevent HIV transmission when performing oral sex. However, a few participants, particularly in the teen groups, were unsure about how to prevent HIV transmission during oral sex. For example, one teen Latina said, “There’s no way – or maybe there is – but as far as I know there is no way of protecting yourself from [HIV during] oral sex.” Other women express displeasure and even disbelief at the thought of using condoms during oral sex. One white woman says, “using the condom orally, it tastes bad. They have spermicide on them.” Another asked incredulously, “People do that? They have oral sex with a condom on?” (Most talk about oral sex in the groups was about giving rather than receiving oral sex. Thus, we cannot say much about women’s beliefs and experience with HIV prevention and receiving oral sex.)

There was at least one participant – an African American teen – who did not understand the most basic facts about HIV/AIDS. Specifically, she did not know that a person can only get HIV from an infected partner. Rather, she was under the impression that just having multiple partners put a person at risk, regardless of their partners’ HIV status. As she explained, “I thought you just had to get yourself mixed up, and that’s how you get [HIV/AIDS]

I guess a big problem is that since people see sex as [a way of] getting a disease, [they think they] might as well have oral sex. Nobody sees anything wrong with that.

Latina Teen

While most women know that you cannot determine a person's HIV status by looking at them, a handful of women still appear to believe that there are signs. For example, one Latina woman told others in her focus group, "There are signs to look for." Another adds, "If somebody has HIV or AIDS, skin sores, they get things on their tongue. You need to be checking these things. It all depends how advanced it is, if they have it." Likewise, while most participants know that you cannot contract HIV from casual contact, a few make comments that reveal a different feeling. One African American teen said about a person she knows who is HIV positive, "Whenever I used to see her, we used to hug and stuff like that, but I don't hug her no more." Even more troubling is that some appear to hold some ill-informed, severe attitudes about people with HIV/AIDS. For example, one African American teen, much to the dismay of others in her focus group, said, "I don't understand how you can go get tested for it and have it, and they still let you walk around."

Beyond transmission, while most participants are familiar with the basics about HIV/AIDS, some lack essential information.

Most participants appear to be fairly well-informed about other aspects of HIV/AIDS. Many appear to understand the relationship between HIV and AIDS and many know that a person can have HIV and remain symptom free for some time. Most realize that there is no cure for HIV/AIDS but that treatments – generally involving a host of medications – can help people live with HIV/AIDS for a long time. A few also note that these medications are very expensive. Lastly, most know there is no vaccine to prevent HIV/AIDS.

Here again, however, there are some participants who appear to know less than their peers. This comment from an African American woman illustrates the confusion some participants have over issues like the relationship between HIV and AIDS, how and when a person can be tested for HIV/AIDS, and when and how symptoms appear:

I wanted to know -- some people say you won't know until after four years after you've have stopped dealing with that partner if you have AIDS or HIV. Some people say it takes up to 10 years. That's what I want to know. How long does it take because I know it doesn't take six months unless they are full blown. You would know that. I don't think nobody is going to lay down with nobody that is full blown.

Likewise, some did not know that HIV can be passed from mother to child. For example, one African American teen wonders, "A person can be born with it. I don't know how they got it."

Many know the phenomenon of "men on the down low", though only a handful are familiar with the term. Few consider this a serious risk.

I've never heard the expression [men on the down low], but I've heard of people that do that.

White Woman

"Men on the down low" is a term that has been used to describe men who have sex with men but do not necessarily identify as gay or bisexual, and are generally not open about their relationships with men; they may also have relationships with women. However, there is no single, accepted definition for the term. Focus group participants were asked about their familiarity with this phenomenon.

First, participants were simply asked if they had heard of the term “men on the down low.” Most say they had not heard the term. Several said they had heard the term, but were unsure what it meant. Some suggest vague definitions, most of which have to do with men lying to the women in their lives. In the words of a white teen, “[W]hat I’ve gotten from that term is guys who are just cheating on the person that they’re with – like on the down low, they’re seeing a person or other people.”

Only a handful of participants are familiar with the term and have a variety of ideas about the behavior it describes. Most often these women believe it refers to a man who is secretly bisexual. Says one African American teen, “I think it means they are gay, but they aren’t out.” A Latina woman guesses, “Maybe you mean men that are married and they are really gay?” In defining the term, none of the women specifically state that these men do not identify as gay or bisexual.

About half the women say they know about or have heard of this phenomenon. A handful know men who fit this profile. For example, an African American woman says the following about a male friend:

We used to have [this] conversation. One time I seen him sleeping with his girl and the next minute I see a guy at his house... He used to say, “I’m not gay because they are not penetrating and I just like being the dominant one.” I thought, “Baby, you need to talk to somebody.” So he is still in denial about his sexual way.

Others have heard indirectly of men who do this, through word of mouth or gay male friends.

Whether they have heard of it or not, , participants differ as to whether they see this as a personal threat. Some women do see it as a real and relevant threat. For example, one Latina explains, “It’s scary, especially here in Miami because it’s very fashionable and very cool to be bisexual. That’s like the latest craze. If you’re bisexual, you’re cool.” Another Latina adds, “It’s scary...you’re thinking that the guy you’ve been with for years is straight and maybe he had a secret thing with another guy.”

Others seem to find this threat abstract or far fetched. For example, an African American woman, in reacting to tested messages on this theme⁵ explains, “It didn’t really hit me the way some of the other ones did. I guess because maybe I’m in denial about men having sex with other men and they have a wife. It didn’t hit me like, ‘Whoa, that’s me.’”

Many participants appear open to new information, but few actively seek it out.

Even those who feel they are – and seem to be – fairly well-informed about HIV transmission and how to protect themselves admit that there is always more to know. As one African American teen says, “I think I know enough, but it wouldn’t hurt for me to know more.” Participants seem open to new information, though few seem to actively seek it out. This comment, from an African American woman, illustrates this attitude:

All my gay friends, they meet people and they go, ‘I just slept with a guy who’s married and has two kids.’ And that’s scary. That’s very scary, because I see it all the time.

White Teen

I was always taught that you can only get AIDS through sex and needles. I wanted to know if there other ways also.

African American Woman

⁵ See Message 8 in Section III.

[I'd like more information on...] different ways that you can catch it, the phases of it, what is the signs. My girlfriend is always on the Internet looking up information. Sometimes I don't ask her about it, but if I was to ask her, "Can you look me up a specific thing?", she would do it for me. She is always out there. I would like more information because I really don't know everything about it. I'm like a lot of people. I don't think it is going to hit home.

Some note that they can never have enough information because things change quickly and new developments are always around the corner.

In short, it seems that while participants are not actively looking for information about HIV/AIDS they are open to new information. As one African American teen explains when asked where she gets information, "I just listen to people talk about it...Just everywhere. Whenever the subject of AIDS comes up, I listen to people talk about it." It is also important to keep in mind that many participants feel they are well-informed about the basics of HIV/AIDS and how to protect themselves from contracting it. Therefore, they may tune out messages that seem familiar.

Sources of Information: Talking about HIV/AIDS with Friends, Family and Health Care Providers

Focus group participants were asked whether and to what extent they discuss HIV/AIDS with friends, family, health care providers and others. Their answers shed some light on the relevance of HIV/AIDS in their daily lives. Participants were also asked where they have learned what they know about HIV/AIDS.

Participants vary as to whether and to what extent they discuss HIV/AIDS with friends. Some rarely talk about it, others remind their friends to protect themselves.

It's taboo. It's something that I think everyone knows it's out there, but you're hesitant to talk about it.

Latina Woman

Many participants say their friends rarely if ever discuss HIV/AIDS. A Latina teen explains, "I don't think a lot of people are open about their sexuality...They don't talk about what they do." As an African American woman explains when asked if she has ever discussed HIV testing with her friends, "I feel as though that is something private. I wouldn't go up to them [and ask,] 'Did you get tested for HIV?...' [You] could be my best friend in the whole wide world, [but] I'd just feel as though I'm invading your space or your privacy." Others explain that their conversations about HIV/AIDS, to the extent they have them, are not personal. As an African American teen explains, "At school we might talk about it, like, 'This person has it and this person has it.'"

For those who do talk about HIV/AIDS with their friends, conversations are often about checking up on each other to make sure they are protecting themselves. As one white woman explains, "I think there is a lot more pressure for my girlfriends to make sure that – not pressure, but you check with each other and kind of try to make sure that we are all trying to be safe."

Some participants discuss HIV/AIDS with family members. Others do not.

Participants also vary as to whether and to what extent they discuss HIV/AIDS with their families. Some say HIV/AIDS is something they have never and would never discuss with family members. One African American woman explains, "I've discussed it with my doctor, but never with my friends or family. I had someone in my family die from AIDS, but it was never something like we talked about."

Some participants – in the teen groups in particular – say HIV/AIDS has come up in conversations with their mothers. One Latina teen explains, "[My mom will ask] what I did over the weekend, trying to find out about me... She kind of says, 'Well if you ever decide to, you know [have sex], use protection, because you're young and have a future.'" Some say their parents are indirect. One Latina says "[My mother] doesn't go directly to HIV/AIDS, but just, [tells me] 'you better be careful.'" Others say their mothers are more direct; another Latina teen explains, "My mom says getting pregnant is the least of the problems, the biggest is AIDS."

Many say their health care providers talk about HIV/AIDS.

Many participants – especially in the teen groups – report discussing HIV/AIDS and safer sex with health care providers. An African American woman explains "My gynecologist asked me whether or not I used condoms; he asked me how many sex partners I had." In most cases this seems to be their doctor or a gynecologist, and in a few other cases they have spoken with nurses, nurse hotlines or workers at clinics. An African American teen explains, "I called... the university hospital. They have this nursing line. You can call that and you can get a registered nurse, and you can ask them any kind of health-related problem. They will answer your questions. If I want to know something I always call that."

On the other hand, some participants appear not to have talked with doctors or other health care providers about HIV/AIDS. More troubling still, at least one participant told of a worrisome interaction with her doctor around HIV/AIDS in which the doctor downplayed the risk of HIV/AIDS. She explains, "A doctor does pretty much laugh at you when you want to have an AIDS test if you are not a hooker."

The main sources of information about HIV/AIDS are the classroom, health care providers and television.

Both women and teens recall learning about HIV/AIDS at school. For many, it was the first place they heard of the disease; for a few it appears to be the only source from which they have received in-depth information. Most often they say they learned about HIV/AIDS in health education classes. Some feel their education on the topic was adequate and others feel it was not. As one white teen complains, "I think that they should teach it more in schools, because I myself didn't get that much." A Latina teen explains, "I go to a private school and all they say is don't fornicate, it's bad for you. Don't have sex out of marriage. They don't say anything about viruses."

I asked the doctor when was a good time to get tested and that is when I started really knowing about [HIV/AIDS].

White Teen

I remember when I was in school, which was a couple years ago, I think it was in junior high school. I remember when I first heard of the disease AIDS. It was the little boy, Ryan. He had something... That is when I first heard [about HIV/AIDS].

African American Woman

Another significant source of information has been television. Participants point to a variety of television programs and public service announcements. A Latina teen notes that, "They have been putting a lot about African Americans [and AIDS] on TV." Many others in the Latina teen group report learning about HIV/AIDS through the MTV program "True Life". Says one teen, "They give you a day in the life [of someone] who has HIV. They show everything she has to go through."

As mentioned in a previous section, some participants also report learning about HIV/AIDS from talking to health care providers, mainly gynecologists. Other sources include the web, women's magazines and books.

II. HIV and Behavior: Sex, Condoms, Talk and Testing

While knowledge and awareness of HIV/AIDS are important, the central issue is whether and how these teen girls and women are protecting themselves from HIV/AIDS. It is clear that their behavior – that is, the degree to which these participants are protecting themselves – is inconsistent. Some women are protecting themselves; others are not.

This section explores what participants say about their behavior – and the behavior of their friends – specifically with regard to condom use, HIV testing, and communication with partners about these topics and about HIV status in particular. This section also looks at whether and to what extent they discuss HIV/AIDS with friends, family members and health care providers.

Condom Use

Though most participants pay lip service to condom use – and some say they always use condoms – many admit they do not always use them.

Most of the women and girls in the focus groups start with the premise that the best way to protect oneself from HIV is by using a condom. A few of the group participants insist they follow a strict “no glove no love” policy. However, many admit that they – and their friends – do not always follow their own best advice. As one white woman says, “I think they know [about safe sex], but I don’t think they necessarily practice it ...[My friends] don’t always practice it. I mean sometimes they do and sometimes they don’t.” Participants explain that there are many reasons they, and their female friends, do not use condoms, as well as situations in which condom use is less common.

Condom use is less common in long-term, ostensibly monogamous relationships.

Most participants explain that couples often use condoms at the beginning of the relationship but that condom usage usually drops off over time; once a relationship is considered long-term, condom use is much less likely. As a white woman explains, “I think in the beginning it starts out that you use the condoms. Then after awhile it’s like, ‘oh, you trust each other.’” A Latina teen explains, “[A]t first you do [use condoms] and after awhile that’s it. At least that’s the way it is for me. At first you don’t know the person as well and stuff like that, afterwards you just build up confidence and trust.” What constitutes a long-term relationship appears to differ from participant to participant. For some this is a matter of weeks or month, for others it is as long as a year.

Well, say it’s been like a long-term thing so [the girl] knows for sure that the guy isn’t infected [then she might not use a condom.]

White Teen

How condom usage stops and whether this is discussed or just happens as a matter of course also varies. On one extreme are women with long-term partners with whom they have discussed issues of fidelity and HIV/AIDS. Often these women and their partners have had HIV tests. For example, a Latina explains, “I have been in a relationship for six years so I don’t use condoms. I did the first two years. We got tested the first two years and after that ...” For some couples condom usage appears to be discontinued with little or no discussion.

Some women do not appear to question the wisdom of this arrangement. Others appear to acknowledge that there is some risk in discontinuing condom use but are willing to take a certain amount of risk. As one white teen explains, “Yeah, you just think that you can trust somebody enough. And you’re never sure, for sure.” A Latina teen explains, “Because you always have to trust your boyfriend or whoever your are with and you never you know if there is 100% complete trust all the time.”

There are also exceptions to this norm. Some women continue to use condoms despite their relationships being considered long-term. For example, an African American woman explains, “We’ve been together about a year and a half, but we live in separate houses. So we’re still – I still make him wear one because I don’t know what he is doing when he is not with me.” A Latina teen explains, “I really don’t trust anybody. To me it doesn’t really matter how long you have been with somebody.”

Trust and “knowing the guy” are also reasons women and teens forgo condom use.

More broadly, women’s decisions not to use condoms come down to an issue of trust; some women say they do not use condoms because they trust their partners. Some admit that this trust is sometimes not well-considered. One African American woman explains,

As women we sometimes put all our hearts into a man, and not really think with our head what the outcome may be with sleeping with this person. So we trust. We kind of psyche our own selves up that, “I just want [this] to be okay. This is one time.” Then afterwards you are scared and you are crying, “Oh my God, what did I do?”

Some women seem almost blind in their trust. For example, a Latina teen explains, “[If I am] sleeping with someone. I somehow just trust him a certain amount.”

Similarly some participants, especially teens, explain that if they know a partner well enough they may not use a condom. For example, one white teen explains, “It depends on me. If I know the guy, then sometimes I won’t use it. But if I don’t know the guy [or] I know him but I don’t trust him so much, then I refuse.” Another white teen described how her friends make decisions about using condoms saying, “if they’ve just known them for a really long time and they know their history and they know that maybe if they’ve never even had sex before or something like that, then they’re not putting themselves risk [by not using condoms]. But if they don’t know that person for sure, then they are [using condoms].”

Some women are just in denial or get carried away.

[There's] that gut feeling of invincibility, like it will never happen to you. It could happen to other people, but they don't believe that it will ever happen to them.

White Teen

"Most people don't think it will ever happen to them," says a Latina teen. Another Latina teen explains, "I have a cousin and she's very friendly with the guys and they tell her – [her] family members and friends – but she doesn't see it as it's going to happen to her."

Participants also explain that people sometimes get caught up in the moment. As one white woman explains, "I have friends that don't necessarily use protection all the time ... because they get caught in the heat of the moment." An African American teen admits, "I'll be honest, when you are [in the heat of the moment], you aren't thinking about no condoms." A Latina woman expresses a similar sentiment: "When it gets down to it we are going to do whatever we want, at that moment."

Men resist using condoms.

Especially heterosexual men don't think they can get the AIDS. And men love to say that too. [They say,] "It's harder for us because I'm not using drugs, and gay guys [are the ones at risk]."

White Woman

Many participants say their partners are resistant to using condoms. As one African American woman explains, "A lot of guys say they don't want to have sex with a condom. They use it as an excuse." Some men will actually talk their partners out of using condoms. Some men argue that, as straight men, and non-IV drug users, they are unlikely to be HIV-positive and so their potential partners need not worry about contracting HIV/AIDS. Others complain that sex with condoms does not feel as good. A Latina teen explains, "Some guys say it feels different. It feels better without [a condom]." A Latina woman says, "I think men really don't want to wear condoms. [They say,] 'It's so tight, I hate it.'"

It is worth noting that it is not just the men who feel condoms lessen the pleasure of sexual interaction. Some of the women and teens in the groups also say that sex is less pleasurable or "not the same" with condoms. A few also say that at times using a condom has caused their partner to lose his erection.

For some it is an issue of relative risks; if you insist on using a condom you risk other bad outcomes.

I think at some point some females would like to use condoms but they are scared to approach the guy with it.

African American Woman

It seems that some women and teens do a sort of "risk analysis" in making decisions about condom use. They weigh the risks of contracting HIV with the risks of upsetting or even losing a partner, ruining a moment, or creating an awkward situation. More simply put, they decide whether the risk is worth the pleasure. As one white teen explains, "It's kind of like with IV drug users, they want what they're going to get more than they care about a 5 percent chance [of contracting HIV], you know?"

On some occasions condom use is assumed and in other instances it is explicitly discussed.

Sometimes you don't even say it. Somebody take out the condom. You just may pull out the condom and you are looking at each other.

African American Woman

Some focus group participants explain that condoms are not always discussed; rather there is a tacit agreement that they will be used. A white teen explains, "I think that it's kind of assumed that they're going to use a condom unless something comes up otherwise." This is most often the case, it appears, in casual encounters. As a white woman explains, "If you are going to have casual sex I think it's pretty much assumed [that condoms will be used]."

Some say that they bring up the topic of condoms prior to sex. One African American woman describes the discussions she has had with partners this way: "Sometimes they will start talking about sex. 'What do you do? What do you like?' [And I'll say], 'What I like is for you to wear a condom.' 'If you do this, I'll do that.'" Some say this conversation often only occurs at the last minute, that is, once they are already "in bed" with a partner.

Discussing protection is very difficult for some women.

While some of the focus groups participants take discussing protection in stride, others find it disturbing. As one white woman explains, "I hate it. I hate having to do it..." Another adds that asking a man to wear a condom is "[just like saying,] 'you could have a disease, and so could you please put this thing on so I don't get anything.' It's just horrible, just horrible."

Discussing condom use with long-time partners may be especially difficult because it may raise issues of infidelity. As an African American woman explains, "If this is just a guy that you just meet for the first time, or you are talking to for a little bit, it may be different. But if this is your boyfriend...the conversation is totally different because he can throw it back in your face [and say], 'What do we need a condom for? What are you doing?'"

Women and teens sometimes carry their own condoms. Others cannot even imagine doing so.

Some women and teens alike provide their own condoms, either carrying them around or keeping them at home. As one African American woman jokes, "I carry it with me like a met card. I don't leave home without it." A Latina teen shares a similar philosophy, "I would always have them. If by any chance I didn't have or we were somewhere else or something like that and he would say let's do it, but I don't have one. 'Well then you aren't getting none...I will not have sex if I don't have a condom.'"

When I was with my boyfriend I was the one who always carried the condoms.

Latina Teen

However, a few women, like this white woman, balk at the idea of carrying and introducing condoms. She wonders, "Could you imagine the woman actually carrying [condoms]? She's got them in her purse. [People will wonder] how many men has she been with? That's really uncomfortable," she says. Others also feel that if they carried around condoms they would be viewed as promiscuous.

HIV Testing

In general, participants feel getting testing is wise. As one white women puts it, “I think it’s very wise to take an HIV test because if you sleep with one person, you have slept with everybody that they slept with and they have slept with everybody that you’ve slept with.”

About half of the participants say they have had HIV tests; some have been tested multiple times.

Testing across groups is uneven; overall about half of the participants report being tested. White women and African American teens are the most likely to report having been tested; almost all of the participants in these two groups report having been tested. By comparison only a two or three participants in the white teen and Latina teen groups report having done so.

The circumstances under which participants report getting tested vary. In several cases participants got tested due to suspicions or concerns about a former partner. For example, a white woman explains,

I was dating this guy and we broke up on bad terms and [as] one of his ways of getting back to me, he announced to everyone that he had HIV. So that prompted me to get tested. I was getting tested on a regular basis... I was concerned; I was scared and I just wanted to make sure. If I did have it, I didn’t want to wait until the last stage to hit me when I could avoid it and do something before then.

Other participants report cases where old boyfriends had had multiple partners before them. Some admit being so worried about their boyfriends sleeping around or having multiple partners that it drove them to get tested. A few others got tested after finding out an old partner had been doing drugs.

A fair number of participants say that they are tested regularly as part of their routine physicals or gynecological exams. A Latina teen, for example, explains, “I’ve been tested...every time I go for a check-up, which is like every six months. You just ask the doctor to test you for everything.” While some women may be tested without overt consent, generally, women have to explicitly agree to be tested for HIV. Hence, some of these women may be assuming mistakenly that they are being tested for HIV.

A few say they took – or were given HIV – tests for other reasons. One participant claims the college she applied to required an HIV test. A few others say their employers require regular urine and blood testing, including testing for HIV. Two African American teens say tests were done without their knowledge or permission, upon admission to a hospital. One says the hospital took a test prior to surgery and another had an HIV test when she found out she was pregnant, during her first prenatal exam.

I went when I was in college and I had one done because when I was with a certain partner the condom broke. I’m such a hypochondriac, I would think about it 24-7 if I didn’t get it off my mind.

White Woman

I had a [male] friend who [got] tested after getting out of a relationship... He found out that she was cheating on him a lot.

White Teen

The incidence of couples getting tested together seems low.

[My] roommate was dating this guy and before they went to bed together they went and got tested together. [They] made it kind of a romantic thing or whatever...It's smart, I mean they went together and did it.

White Woman

A few participants say that they have been tested together with their partners, often at the beginning of a sexual relationship. As one white teen explains, "[W]hen I go into a relationship I make sure before we do anything that we both get tested and that I see his results and he can see mine." Others explain that they and their long-term partners stopped using condoms after being tested together.

In general, however, getting tested together appears to be fairly rare. According to one Latina teen, who speaks for many of her fellow participants, "I only know of one couple who before they ever did anything went and got a test together. Those are the only people that I have heard who have done that." Many participants, when asked about couples being tested together, reacted as though this was a novel idea.

About half (can't say many have been tested and then say many have not been tested) have not been tested and some are reluctant to do so.

While most participants seem to feel that getting tested is important, roughly half have not done so. For some, they simply have not had time or have not felt that getting tested was a pressing need. As one white woman explains, "I'd like to, I guess I just haven't gotten around to it." Another says, "I've been with the same person for such a long time and we are so careful that I guess I'm allowing that to be an excuse."

Some are more active in their resistance to getting tested for HIV. A white woman explains,

I'm kind of scared to ask. What if we do get tested and I see something?... It's hard to go.

Latina Teen

I have thought about it, I just don't want to. It sounds so – I really don't want to. I mean I'm assuming I'm fine, I'm pretty healthy. I have the weird concept that I test my own immune system. And when I get sick I don't take medicine and if I get better I'm assuming everything is functioning well.

Similarly, one Latina explains, "Some people [would] rather not know...Because they are going to get hurt. It's going to affect your life."

Conversations about testing or status appear to be rare. Most say such talks are – or would be – uncomfortable.

Participants were asked whether they ask partners or potential partners about their HIV status or if they discuss getting HIV tests with them. Most participants say they do not generally ask such questions of their partners. However, some participants do report having asked partners about HIV status or testing prior to sex. A white teen explains, "Whoever I go out with, that's when I talk it through. That's when the subject really comes up." Says one African American teen, "I might say something like, 'Why don't you get yourself checked out?'" While some participants suggest these conversations have not been problematic, others report that asking these questions has been

awkward and difficult. An African American teen explains that when she has asked men if they have been tested they have given her a “stupid look... [as if to say] ‘Do I look like I got it, or something.’”

Those who have not had conversations like these fear they would be difficult. Some feel it would make partners – especially long-term partners – angry or suspicious. As one Latina teen worries, “Let’s say you go up to him and say, ‘I want to go to get tested.’ He’s going to say ‘Why, did you go and sleep with somebody?’”

Participants were also asked if a partner had ever asked them about testing or their HIV status. These conversations appear even rarer than those initiated by women. Indeed, most women had not given much thought to this notion and had mixed reactions to the idea of being asked such questions by a man. Some – especially among the Latina groups – say, though they might be surprised initially, ultimately they would welcome being asked about these topics. They equate being asked with love, concern and caring on the part of their partners. As one Latina woman explains, “[It’s] like he’s worried and like he’s not sleeping around. He wants to know.” Another adds, “I would feel like he cares.”

However, just as many participants say they would be offended if asked about their HIV status or about testing. It would seem like an indictment of their sexual behavior or an assumption that they are HIV positive. A few African American teens believe it might be a man’s way of saying he himself has something to divulge. As one explains, “I think he was trying to tell me something if all of a sudden he says, ‘We need to go get tested for AIDS.’ I would be like, ‘What are you trying to tell me?’”

III. Messages and Messengers

One of the purposes of this study was to examine participants' feelings about, and reactions to, awareness and prevention messages, in order to inform the efforts of those who create such messages. Toward this end, focus group participants were first asked to create messages they think would resonate with people like them. Specifically, they were asked, "What would be the most effective argument you could use with your friends to make them more aware of the risk of HIV/AIDS?" In some groups participants wrote their messages and in others they shared them verbally with the group. Participants were also asked to react to nine messages the Kaiser Family Foundation and LSPA created beforehand. Participants discussed these messages and evaluated them as to how compelling they were.

This section reviews these findings. The first part details the common themes and elements that emerged from participants' independently created messages and their reactions to the Kaiser/LSPA messages. The second part looks at each of the Kaiser/LSPA messages individually and describes participants' reactions to them.

Message Elements and Characteristics

Five main themes emerge from participants' discussions and ratings of messages. These are the elements and characteristics participants appear to find most important and compelling.

1. Protect Yourself, Empowerment, "Looking out for Number One"

Participants, in creating their own messages, stress the importance of "looking out for number one." As an African American woman says, "You are your number one priority." A white woman puts it this way, "Love yourself, use a condom." Likewise, those Kaiser/LSPA messages that expressly encourage protecting oneself and one's health are among the most highly rated.

2. Realistic Looks at Risk and Trust

Participants, in creating their own messages, stress that sex is risky. As one African American teen's message read: "You are having sex and anything is possible." Putting ones trust in a partner is also a risk. In the words of one African American woman, "Do you know 100 percent that he is faithful to you, that he is only with you? Are you 100 percent sure? If not, you should be tested." Promiscuity is frequently a component in many of these risk-centered messages. Participants feel strongly that others should be warned about the dangers of "sleeping around."

Kaiser/LSPA's messages that specifically stress the potential danger of trusting one's partner resonate with many participants. Moreover, participants note, it is even riskier to trust someone you do not know well. As one Latina teen explains, "You can't really trust anybody else because even your best friend will have some secret from you. So you shouldn't trust a guy you just met, who all he really wants is to get you in bed. He could lie to you, say anything to get you in bed."

The findings suggest that issues of risk and trust should be examined in ways that reflect the variety of real situations and relationships in which these women and girls are involved. For example, messages should address the fact that women and girls sometimes make a decision to trust a partner and no longer use condoms without discussing this decision with the partner.

3. Facts and Figures

Some participants, especially older women, believe the most effective messages contain statistics about the epidemic's increasing impact on women. Or, as one white woman puts it, "that the statistics are going up and up and up for heterosexual women." Some prefer to focus on the death rate from HIV/AIDS, which they believe is a more effective way to get a prevention message across.

Participants also appreciate messages that stress risk factors about which people are unaware, or facts they might know but of which they need to be reminded. One such fact is that a person can be HIV positive and not exhibit symptoms, or even know their HIV status. As one African American woman says, "Just because you don't look like you've got AIDS doesn't mean you don't have it." Another fact that some people might not be fully aware of is that HIV can be spread through oral sex.

4. Action – What To Do To Protect Yourself

In creating their own messages, participants very often included action steps. Among the preventive measures that participants stress are: consistent condom use, HIV testing, monogamy, abstinence, increased communication with partners, and increasing self-esteem. In the tested messages, too, participants react positively to action steps. However, listing too many action steps in any one message seems to overwhelm the audience.

5. Clear and Concise

Lastly, participants are critical of messages they feel are confusing or wordy. They prefer clear, concise messages that get to the heart of the matter in as few words as possible.

Tested Messages

Participants were presented with a range of messages, which varied in content as well as style. In each focus group, participants were asked to rate six or seven of the nine messages tested.⁶ Each message was rated on a zero to ten scale where zero meant that the message “did not work” for them and ten meant the message “worked” for them. Participants were given handouts with the messages on them. Each message was read by the group together and then rated privately by individual participants. After each was read and privately rated, participants’ ratings of the message were collected and they shared their feelings about the message in question. Specifically, they were asked why they gave the message the rating they did as well as what they liked and did not like about the message.

1. **Sure You Trust Him, But Are You Willing to Bet Your Life On It?**

Many women are infected with HIV by partners they think are being faithful. Protect yourself. Use condoms. Talk with your partner. Get tested and insist he get tested too.

Mean Score 8.0. Tested in 5 of 6 groups

This message was the most highly rated with an average score of 8.0. It tested especially well among Latina teens (mean score 9.6) and African American women (9.3). This message touches on two important themes. First, it is a “look out for number one” message. Secondly, it hits on the theme of trust. As one white teenager explains, “...all these people are like, ‘Oh, I’m so in love and we’re going to be faithful for the rest of our lives.’ But it’s bulls**t.” Others point out that this message is clear cut and realistic.

On the downside, some feel overloaded by this message and believe it could be shortened and still be effective. A white woman explains, “There is too much information. I think the first line is great and maybe the second line but then it’s, protect yourself, use condoms, talk with your partner, get tested...”

⁶ The moderator and focus group observers determined which messages would be tested in each group based on what topics had been covered earlier in the focus group session.

2. He May Not Even Know...

Men can be infected with HIV for years without knowing it, and can pass on the virus to the woman they love. Get tested and protect yourself.

Mean Score 8.0. Tested in 2 of 6 groups

Although this message was only tested in two groups – African American women and white teens – it scored very well in both, getting an overall rating of 8.0. Participants appreciate being told (or reminded) that a person can be HIV positive and not even know that they are. One African American woman explains,

Men can definitely be infected for years and not know and they can pass it...They may have found the woman they definitely want to settle down with. They love her to death and come to find out they've got AIDS. That means everybody needs to get tested to protect yourself because that could happen.

Even the title, "He may not even know" gave some participants pause.

3. Concerned about Romance?

If you think using a condom ruins the moment -- imagine what having to tell your partner you have HIV/AIDS does.

Mean Score 7.5. Tested in 4 of 6 groups

This message ranked third with a mean score of 7.5. According to many African American teens and women, who ranked this message most highly, it is effective because it is short and to the point. Many participants also appreciate that it focuses on the possible consequences of not using protection in a powerful way by asking people to imagine having to tell a partner they are HIV positive. Moreover, this message speaks to two important barriers to condom use: the awkwardness of the moment and the fear of partners' reactions to being asked to wear a condom. An African American teen, in reacting to the message said, "I wouldn't want to tell him that I got AIDS, but I mean, I think it is easier to have romance with a condom and not be worried about something."

4. That's Why They Call it Oral Sex

Everyone knows HIV can be spread through regular sex. But, did you know you can also be infected through oral sex? Protect yourself and your partner when you engage in oral sex.

Mean Score 7.3. Tested in 4 of 6 groups

This message ranked fourth with a mean score of 7.3. The mention of “oral sex” grabs people’s attention. As one white teen explains, “When people hear oral sex ...they start listening.” Participants also appreciate the straightforward nature of the message; it states clearly that HIV can be spread through oral sex. Many participants – especially in the teen groups – say their peers need to be told this simple fact. A Latina teen explains, “[b]ecause a lot of people say, ‘Oh yeah I’m going to get oral sex’ and they don’t think they can get the disease. In my school almost everybody does that and they just think, ‘Oh that’s nothing, you can’t get a disease by that.’ But they could get a disease.” An African American teen concurs saying, “A lot of people don’t know that. I have heard a lot of people, especially boys, say that you cannot get AIDS from oral sex. They will say, ‘You can’t get it like that.’ They really believe that you can’t get AIDS like that.”

On the downside, some feel this message is too long. Also, a few say it will not change behavior because it is unrealistic to expect people to use condoms during oral sex. As one white woman explains, “I think it’s a good message, but I have a really hard time [believing] that everybody out there is going to be putting on a condom before they have oral sex.”

5. Love Doesn't Protect Against HIV

Sure, you love him and he loves you. That's why you should protect yourself and him. Talk about HIV. Use condoms. Get tested.

Mean Score 7.2. Tested in 4 of 6 groups.

This message ranked fifth with a mean score of 7.2. The idea that if you love him, you should protect him resonates with some participants. Insists one African American teen, "I think it would make them start using protection. If you really love a person you will use protection." Others say this message "really makes them think."

However, participants have a lot of negative comments about this message too. Many white teens – who rated this message most poorly with a mean rating of 6.3 – say they find the focus on love "cheesy" and "irrelevant." Says one white teen, "It's kind of dumb. I mean, they're trying to make it all [about] to love. But it doesn't really matter. Love has nothing to do with it..." Similarly, some African American teens say they want messages to reflect other kinds of relationships – those that may be just purely sexual or simply too new to include love. Lastly, a few insist that they are unable to talk about HIV/AIDS with their partners and hence that component of the message does not resonate with them.

6. You Would Never Cross A Busy Street without Looking Both Ways...

When it comes to protecting yourself from HIV/AIDS, almost every time and every time are not the same thing. Protect yourself -- use a condom every time you have sex.

Mean Score 6.6. Tested in 5 of 6 groups.

This message ranked sixth with a mean score of 6.6 and received a fair amount of criticism. Some felt it was too long and drawn out. "It's not getting to the point fast," explains one African American woman. Some did not like the analogous title. "I get the analogy," says one white teen, "but a lot of people cross the street without looking both ways. I can cross the street without looking both ways all the time." A few participants did not make the connection between the title and message body.

Some participants did find this message convincing. They recognize that "one time" can destroy someone's life. Says one white teen, "I think that it's pretty good, because it does make a good point. I would look both ways before crossing the street because I think that it would be stupid not to. And, it would be stupid not to use protection. So I think that it's pretty good." This message also speaks to self protection, a consistently strong theme. According to one white woman, "Anything that has to do with protecting yourself, of course I'm going to give it a ten."

**7. HIV/AIDS: It's Not Who You Think
HIV Infection rates are growing fast among women. Women of
color are especially at risk. Protect yourself. Get tested.**

Mean Score 6.6. Tested in 5 of 6 groups.

This message had the most varied ratings and responses of any message tested. Some participants were turned off or confused by its focus on women of color. For their part, some African American women resist the stereotyping they find inherent in the message; they feel they are being targeted in a negative way. Some whites and Latinas feel the message is too narrowly focused. As one Latina woman explains, “[It says] ‘women of color are especially at risk.’ I don’t think that’s true. HIV is not only for black people, it knocks on every door. Here it’s just sending a message to black people, not to everybody in general.”⁷ A white woman concedes that it might be a good message for use “in African American neighborhoods”, but thinks “it will give Caucasian women an excuse to exclude themselves from it.”

Negative reactions to this message may also stem from the people’s discomfort with the idea that some groups – especially racial or ethnic minorities – are more at risk than others. Some participants balk at discussions about risk; however, if this message had explained that rates are growing particularly quickly among women of color, participants might have had different reactions.

There were some participants – including some African Americans – who were enthusiastic about this message. In fact, African American teens rated this message higher than any other group, with a mean score of 8.8. As one African American teen explains she gave this message a high score, “because I’m black and it says that it is high risk for colored people. So I don’t know who might have it, and I might catch it from somebody. So I don’t know.” Some participants say they are attracted to its focus on women, regardless of color. One white woman explains: “I wasn’t thinking about the color issue. I was just looking at [where it says] ‘growing fast among women’ and [I thought], ‘Oh my gosh, I’m a woman.’” Some appreciated the focus on women of color. In addition, many participants find the statistics and figures quoted in the message convincing. In short, the fact that women are become increasingly affected by HIV/AIDS, is a powerful and compelling fact .

⁷ It is worth noting that most Latina teens understand “women of color” to mean only African Americans, whereas their older counterparts were more likely to self-identify with the term. However, as this quote shows, even in the Latina women’s group not all participants felt “women of color” described them.

8. Men on the Down Low
Men – even “straight” men with wives and families – who have sex with men, can get HIV and pass it on to the women in their lives. I know, because that’s how I got infected.

Mean Score 5.9. Tested in 2 of 6 groups.

This message, which was tested in just two groups, received a mean score of just 5.9. As noted before, many participants seem to consider men on the down low a remote threat. Thus, few consider this message relevant to them. As one African American explains, “It didn’t really hit me the way some of the other ones did. I guess because maybe I’m in denial about men having sex with other men and they have a wife. It didn’t hit me like, ‘Whoa, that’s me.’”

A few participants did find this message very effective. Those who have first hand knowledge of situations like this are especially likely to be affected by this message. Recalls one Latina woman, “My cousin looked like a regular guy. He got married to make everyone believe he was completely straight. When he got sick, we thought he died from a pancreas disease. During the last days of his death we found out he was dying of AIDS.” Some participants, even among those who consider men on the down low a remote threat, found the personalization of the message – that is, the sentences where the narrator says “that’s how I got infected” – particularly effective.

9. Meet Monique
Gets her nails done once a week
Gets her hair done once a month
Gets an HIV test every 6 months

Mean Score 5.1. Tested in 4 of 6 groups.

This message rated the lowest of all the messages tested. Participants feel the references to nails and hair are frivolous and even insulting. As one white teen says, “They’re just trying to appeal to girls and they think being stereotypical with nails and hair. I don’t like that.” A few feel the message would be more powerful if instead of talking about hair and nails it compared HIV-testing to more important priorities like school or work. A few simply cannot relate to the message at all. “I just don’t get it. Nails? Hair? HIV? It’s odd,” says one Latina woman.

There were a few positive reactions to this message. Some African American teens point out the importance of the Monique character “feeling good about herself” by getting her hair and nails done as well as taking care of her health. And, a few participants detect an empowerment theme in this message and they like that she is proactive about her health.

Some doubt that any message will work.

[The ads say] “Protect yourself,” “Get tested.” I hear that every day. It doesn’t make me want to get into my car and get tested.

Latina Woman

Some participants, especially in the teen groups, doubt that any message will work because, as one white teen explains, “People are going to do what they’re going to do regardless of what anyone says.” A Latina teen explains, some people might say to those who offer them advice about protection, “If I want to do it, I’m going to do it. I will appreciate your advice, but regardless it’s my life and I will do what I want.”

Others point out that the barriers to some behaviors – and talking about HIV/AIDS in particular – are insurmountable. As one Latina teen explains, “I have a very good relationship with my boyfriend and I can talk to him about anything. Not everybody has that. Not everyone is going to go up to their boyfriend and talk about their past and getting tested.” More generally, those in long-term relationships with partners they trust might not open to messages about condom use and talking about risks. As another Latina teen explains,

It depends on what situation I’m in. If I’m in a relationship with a guy for a long time and I really like him a lot, I’m sexually active with him, then I probably wouldn’t want to listen to all of that because I wouldn’t want him to break up with me because of that. That’s probably why and that’s probably why most people don’t listen. Maybe if I were somebody who sleeps around I would pay attention and I would get scared.

Messengers

According to participants the best messengers are doctors, educators and the popular media.

When I got tested three years ago, the lady that tested us took us to her office and she asked why we were concerned and she gave us information. It's not like they just say, "Okay, you're negative, okay, bye."

Latina Woman

Most agree that health care providers are good messengers because they are knowledgeable, trustworthy and a regular point of contact. Beyond doctors, nurses, nurse hotlines and health centers are also mentioned as good sources. Some suggest having pamphlets on HIV/AIDS available in doctors' waiting rooms. One white woman explains, "Put the literature in [the waiting area]. When I'm there and I'm waiting for an hour I'll read every single thing in there just not to be bored out of my mind." Some note that having pamphlets in waiting rooms may be especially useful for those who are afraid to bring the topic up with the doctor or nurse.

Schools are also an important source. As noted above, for many participants health classes appear to be their main – even their only – source of information about HIV/AIDS. A few teens suggest that students might learn more from guest speakers with special expertise than from teachers. As a white teen explains, "Some [kids may be] too shy to ask it to the teacher, you know? Asking a different person, I think is better." One Latina teen notes that her school has a club called AIDS Awareness, but no other teens in the focus groups mentioned similar organizations.

Despite having learned a good deal about HIV/AIDS through television programs and ads, some participants feel the popular media could be doing much more to raise awareness. One Latina teen insists there, "needs to be much more on TV than [is] currently offered. More commercials, more TV shows and talking about it more." Some participants also mention spreading the word using flyers, billboards and the sides of buses.

Participants differ about who the ideal spokesperson about HIV/AIDS would be.

Participants have varied ideas about what kind of person would be a good spokesperson for HIV/AIDS awareness and prevention. Most feel that the best, most credible spokesperson would be a person with HIV/AIDS. Beyond that, however, people have different ideas about what type of person would best fill this role. Some people feel a celebrity would be good because people listen to famous people; Magic Johnson was mentioned by a number of participants. Others feel famous people are too different from most people and might, as one white teen put it, "bring home the thing like that can never happen to me."

Many point out that the most valuable spokesperson looks like the intended audience. So, for example, women in the African American group feel that a teenage spokesperson would be most effective for a teenage audience. As one African American woman explains, "A teenager is not going to listen to a 35 year old woman talking about how she is HIV infected, but if it is somebody 16 talking about she has full blown AIDS, that is going to hit them. 'Oh my God, that could be me.'"

IMPLICATIONS

Many women do not perceive themselves to be at risk for HIV infection, and need to be convinced they are at elevated risk.

Many of these participants do not believe that they, personally, are at risk for HIV/AIDS; or, if they are at risk, the risk is minimal. They feel only what they define as promiscuous women, IV drug users and other people who are “not like them” are truly at risk. Likewise, some participants – especially among the teens – feel the partners they are with are unlikely to be infected. These girls feel they know the histories of boys with whom they are involved, and thus feel safe. It is important these girls and women understand that women and teenage girls like them – just like them – are at risk, and so too are they.

The most powerful messages and ads are those that address the real situations that teens and women face in their interactions with partners.

Messages should be crafted which speak to those who stop using condoms in long-term, supposedly monogamous relationships and those who feel safe with a partner because they feel they know him and his history. Some messages should address those relationships that are not about love relationships. Messages should also tackle the issues of trust and risk that play into decisions about condom use.

Establishing safer sex practices into social norms is an important component of HIV prevention.

For some women, and in some situations, condom use has become the norm. Indeed, sometimes condom use is assumed without any conversation. This suggests that ads that portray or encourage situations in which condom use is the norm in a wider variety of situations could be effective. For example, messages could suggest that the norm of decreased condom usage in long-term relationships be questioned, or better yet be replaced with one where condom use is not discontinued, or is discontinued only in conjunction with conversations and testing. Messages could also support or encourage more behaviors – such as using protection in oral sex, talking about HIV/AIDS, and HIV testing – becoming norms as well. If these behaviors are seen as the norm, the risk of doing them may not seem as high to women and girls who currently forgo them for fear of upsetting or losing partners.

There is confusion among women about the concept of risk.

As noted above, some participants resist and are confused by the idea that certain groups are at increased risk for HIV infection. Given people’s confusion about this, it might be better to talk about groups that are experiencing increased risk while avoiding the use of the word risk in this comparative context.

While most participants know the basic facts about HIV transmission, there are gaps in their knowledge and facts that have not truly “sunk in.”

It seems people need to be told (or reminded) that HIV can be transmitted through oral sex. This may be especially true for teens who are using this as a replacement behavior. Likewise, people could use a reminder that a person with HIV/AIDS may be symptom-free for years and may not even know they have HIV. There was some evidence that some women think withdrawal is adequate protection against HIV transmission; this misunderstanding must be corrected. Of course women and teenage girls who do not know the basics of HIV transmission – and there were a handful of these people in our focus groups – need to be taught the basic facts.

Many women say that prevention messages need to be shocking.

Many of these women and girls feel like they have heard and seen it all before. They feel like they know the basic facts about protecting themselves from HIV/AIDS and are not looking for new information. The same old message may not speak to such a jaded audience. The best messages, then, might be ones that shock people into paying attention. Indeed, ads have to be somewhat shocking anyway if they are going to talk about issues like oral sex and withdrawal.

Women also seem to respond to messages that are brief and directive.

Messages should be simple. Participants criticized message with too many sentences. Participants also praised message with action steps – such as, “get tested,” “protect yourself” or “use condoms.” However, some also point out that too many directives can be overwhelming.

Messages can be delivered by a variety of messengers.

Doctors and other health care providers, the media and educators all have a role to play in spreading the word about HIV/AIDS. Different messengers will work with different audiences.

An executive summary of these findings (Pub# 3381) is available on the Kaiser Family Foundation’s website at www.kff.org.



Additional copies of this report (#3382) are available on the Kaiser Family Foundation's website at www.kff.org.

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The Henry J. Kaiser Family Foundation
2400 Sand Hill Road
Menlo Park, CA 94025
Phone: 650.854.9400
Fax: 650.854.4800

Washington Office:
1330 G Street N.W.,
Washington, DC 20005
Phone: 202.347.5270
Fax: 202.347.5274

www.kff.org