

PROGRAM SUGGESTIONS FROM WOMEN'S FOCUS GROUP

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A focus group for HIV-positive female clients was moderated by Ann Sells, on May 15, 2001 (N=8). The age range was 32 to 64, with a mean of 46.4. Eight participants identified themselves as female. Eight participants identified themselves as heterosexual. Two participants identified themselves as white/ Caucasian; 4 were black/ African American; 1 was Latino/ Hispanic; and 1 identified herself as Native American/ Alaskan.

The participants were very enthusiastic to participate and share their ideas. They would like many new programs at APLA. Their ideas center around educating the general public and the HIV+ community, but especially, the HIV+ and HIV- heterosexual community. They would also like to see more programs in the form of support groups, with topics including self-esteem, medications' side effects and how they affect their mental and physical health. They feel a genuine need to support each other and seem very willing to do outreach themselves, while representing APLA.

Women feel a definite gender bias, not only in the HIV community, but in society as well. The participants felt that many of their needs are ignored due to this gender bias, and for that reason would like to see more programs involving their peers and leaders, women easy to relate to and from all different backgrounds. In general, women are able to create special, close bonds/ relationships with other women. They feel their needs to be very different from men's, yet they do not see such a separation between women with different sexual orientations. Therefore, new programs should be women specific.

Women feel very discriminated against in society. They believe that APLA continues to improve with its Women's Services, but much is still needed. The female clients find their needs to be very different from men. They react differently to the medications, their mental state is more vulnerable, and research geared towards women with HIV is scarce compared with men's. Also, they feel that many of the women's needs are universal and not separated by sexual orientation.

Representative comments:

P: ...All the research is about men. I think they should put more money into research for women. Not so much research for me. I don't think...It came up, issues about do you have any question about the way you transfer it...They don't agree on it. We're not women, we're just second-hands, men come first. They get the research and why should we take the same medication as men do. Our bodies are different. We are not, not getting research from the doctors...

I: How if at all, are the sexual health needs of HIV positive women different from those of HIV positive men?

P: ... [women are] more vulnerable than men

P: Being a women, I can't live that free. They have the acceptance, but I'm kind of like stuck.

I: How, if at all, do you think the sexual health needs of HIV positive bisexual or lesbian women, different from those of HIV positive heterosexual women?

P: I think it would be the same.

P: If you're bisexual...issues are same.

EDUCATION FOR THE PARTICIPANTS

Many issues came up that involve health education. The most commonly discussed topics in the focus group centered around mental health. The participants would attend discussion groups or workshops on how to deal with no longer identifying themselves as “sexual beings,” self-esteem workshops in terms of coping with the disease, and how to deal with the fear of the possibility of re-infection/ super-infection.

Representative comments:

I: ... So what other factors do you note among HIV positive women which may affect their sexual risk behaviors? What are the obstacles to sexual health and safer sex for women?

I: How does it affect self-esteem?

P: It is necessary for women to have some place to go so they can learn about these things.

Other educational programs include discussions/ workshops on the effects of medications, whether one is being affected by the virus or is going through menopause, more information about re-infection/ super-infection.

Representative comments:

P: Everyday...sometimes my husband, I don't want to touch him, and I don't know if it's him, or the meds...

P: I have been to lectures where they sat down and explained about infections. And meeting people from all over the world who have HIV, and learned about different strains from different nations. Like in Africa, they don't have the same strand that we do.

P: Or the same agent.

P: The same agent. Or other countries or even other parts of the United States. You know their HIV is not the same as ours. You know she said she got infected in Mexico. Mexico is different than us. Africa is different than us because of who we are as people. We're just different. If we go to Africa, we got to get all these shots. We gotta get all this...We can't eat the food, we can't drink the water...

P: You know what I'm saying. Because our bodies are different; we have processed...

P: Our bodies are different than our own.

P: There are different strands of HIV...You feel ...your whole family isn't safe.

I: Do y'all have any more thoughts on re-infection?

P: In a way, it makes you more cautious because you have to think about being re-infected...

P: I'm not going to let another one ruin it for me. They're going to question me and I don't ... I should have taken more precautions.

The women felt that the best means for learning would be through forums and discussion groups, or from each other. They are quite eager to learn more about HIV, and education seems to be the most desired method in order to calm many of our clients anxiety's.

Representative comments:

I: ... What kinds of sexual health educational activities might help you cope in positive ways with the issues we have discussed?

P: Forums.

P: ...there is this duty for us to constantly keep us up to date...

I: At APLA, would you be more likely to go to educational forums, social events, or case managers to with your problems?

P: Somebody that knows... She has a Ph.D. She gave us a class on disclosure, which was really good because now I know how...

P: I didn't know what I thought I was, but I know I had to go to room shelters and everybody there had HIV.

P: That's right.

P: I had no knowledge. I mean what is that...Some people there were sick... They were worrying, so now I worried. I had a chance to look at it, be touched by it you know.

P: I lived in a shelter 2 years ago, and I thought I was going to die. But instead, I learned how to live...

P: Well I firmly believe...without education you are blind, you know. You don't know what you are dealing with. But once you find out what your dealing with, it's easier with any disease. It could be Diabetes, Cancer, HIV. You have some type of education behind you and knowing what your dealing with, the fear is less, for me anyway. My fear level is less because I know...

P: For me, the most important issue is talking to other people about it, support of other women through...because I've learned so much. Almost 10 years I've known, but just in the past year I've learned more than anything else. Just being around people in Los Angeles and a support group. They know so much. They know more than my doctors knew back in New Jersey. But I think the support, women have to go to support groups because you learn so much and I just think that is helpful.

P: Education and discipline. You need to have somebody to talk about things, with the girls...you can talk about it and education is the only...we're not scared now because we know what's out there and we know what to expect. With education, you know the signs, you're not going to ever forget...Whatever I can give you from my education, I will.

EDUCATION FOR THE GENERAL PUBLIC

Our female clients would especially like to see more education geared towards the public. They feel HIV stereotypes are still prevalent, and are one of the major problems affecting their mental health.

Representative comments:

I: ... what kinds of sexual health educational activities might help you cope in positive ways with the issues we have discussed?

P: Education of them [general public]...

P: Education, but also with the outlook...with family members who don't know anything about it...communication...the whole community. And, I just don't think people really understand.

P: ...The fear level is down...and that's with everybody. If everybody was educated, the fear about HIV would be less. We would be on these lines of saying...I have a blood disease.

P: The big stereotype...raise children, have a real job. Why do we always have to be with the drugs and alcohol addiction, when everywhere we go it gets presented to us first or be street-workers.

P: Or several sex partners.

P: Even going to the emergency, I felt like a leper...

They expressed interest in having a hands-on role for outreach programs. Also, they suggested the formation of panels with women with HIV of different backgrounds in order to show how all women are susceptible to HIV.

Representative comments:

P: ...With education, you know the signs, you're not going to ever forget...Whatever I can give you from my education, I will.

P: They really don't and I don't know what we can do about it. I don't know. Maybe, there can be some outreach program that goes further out, because...and so many people out there don't even know that they are going to be confronted with this either with themselves, or personally on another level. So I think outreach...education.

P: I think the most important thing is to have a panel of maybe four people that are maybe HIV infected from different backgrounds, different age groups, and taking them to the schools, and having an assembly of these people speaking to the children in the schools. And the reason for the different people on the panel, is to show that it doesn't matter... and to get it out there that to stigmatize, to take the stigma out of it. And a panel where there could be a ...question time, question and answer.

P: All professional people.

P: Same thing...social workers and those kind of people. All professions don't know what this is. They don't understand what living with this is.

P: I think education is so important to everybody to HIV+ and those not infected....for HIV courses and learn about what HIV actually is and how important and all the diseases are.

Much of the heterosexual community is uneducated about HIV.

Representative comments:

P: I meet guys who just want to have sex and ... tell them I have HIV... and if you want to die... then go ahead but I am HIV+, if you want to do it. Oh well....welcome to the world of HIV.

P: They know I'm HIV, but I was like look, I'm not even thinking about you okay. I'm thinking about me, you know, I don't want whatever you got. You may not be HIV+....

P: You may have HIV, but what if he has crabs....

P: ...You know...Some men, who don't want children, they're...they don't give a rat's tail about what I tell them because they still want to have sex...

P: Street-workers, if I give you an extra \$5 or \$10, they don't use condoms...

P: My husband won't use a condom. He refuses to use a condom.

P: ...Every now and then, he will use a condom....

P: In the beginning he use one, and he was so unhappy. He was like I can't feel anything. Why should I use a condom when this other man gave it to you, didn't you know. Why should you know, it was like an either thing.

P: Not just for our positive outcome...Men picked up for soliciting a prostitute should have mandatory HIV education class, going through the course.

P: I think it is really important to educate the High School students.

P: Yeah.

OTHER ISSUES

The women also expressed an interest in workshops that did not directly involve education. They would like to participate in empowerment workshops, not just incorporating HIV, but how to assert oneself as a woman.

Representative comments:

P: ...My best friend makes herself her first priority. And it's hard for her to raise children, and put themselves first. A person cannot take care of everyone...you have to take great care of yourself. So I think we need to be more self-care...mentally and physically. Both.

Also, they would like to learn more on disclosure in regards to laws, as well as, workshops on how to better disclose to sexual partners, family, and friends.

Representative comments:

I: What are your concerns about disclosing your serostatus with your partner, whether he is HIV+, HIV-, primary or causal?

P: It's against the law...

P: Serve 3-5.

I: Would you use condoms as an excuse not to disclose?

P: Only if you use a conversation, you can be sued in California. There are laws here. You have to learn laws. Now if you ..a discussion with a person as a casual thing, as long as you say let's use a condom. You can not be faulted.

P: I just broke down and told my 23 and 24 year old children...and they are like I don't know anybody like that [someone with HIV]...that was my fear in the whole fifteen years that this would destroy my kids. I feel relieved...

I: We know that women value their relationships with sexual partners, family, friends, and their community. What other issues should be addressed regarding family relationships, or those with society in general?

P: With your family, whether or not to tell.

P: ...And I want to know like what a child should know, whether they are positive or should a parent tell a child if their positive....There so hard...