

POWER
HIV+ Gay Men's Focus Group
October 1, 2001
Facilitated by
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Introduction:

APLA's Research and Evaluation Core and POWER program staff (Dr. Matt G. Mutchler and Buddy Akin) facilitated a formative focus group with gay male clients of APLA on October 1, 2001. The purpose of the group was to gain information to help POWER staff plan and develop POWER programs and activities. The group lasted for 2 hours and the following issues were discussed: disclosure of HIV, relationships, substance use, treatment side effects and sexual dysfunction, mental health and depression, sexual risk activities, recruitment and retention of POWER participants, and program recommendations. Seven gay-identified male clients participated in the group. These are highlights from the findings of the focus group.

Highlights:

- Participants want to be able to talk about sex, HIV disclosure, depression, responsibility for safer sex decisions, relationships, sexual dysfunction and treatment side effects, and broader life coping issues.

- Learning of the HIV diagnoses affected participants differently in terms of sexual careers. For instance, some reacted by having less sex, moving away from gay enclaves, and withdrawal. While others reacted by increasing risk-taking including unprotected sex, moving closer to gay communities, and having more sex as well as more varied sexual practices.

- Disclosure of HIV strategies varied from not telling anyone, to making decisions on a case-by-case basis, and to telling everybody regardless of relationship status (casual or primary) or HIV status. Participants were surprised at how few male partners ask about HIV or seem to care about practicing safer sex. Some said they don't use condoms, but are careful not to share bodily fluids. Others said that their partners should be responsible to protect themselves. Still other participants were clearly struggling with the question of when to disclose their HIV status. A few participants said that their solution is not to have any sex. Reasons for not disclosing include: fear of rejection. However, there was also the sense that many gay male sexual partners are out there 'living dangerously'.

- Strong emotions were attached to many sexual issues that were expressed. For instance, men shared that they felt 'emasculated' when they turned positive because they thought they were sexually defective. Others felt emasculated because they experienced impotency and other sexual dysfunction problems associated with HIV treatments. One participant shared that turning HIV opened new doors for him to seek social support and

sexual freedom. The extent of fluidity and diversity among reactions to becoming HIV positive cannot be over-emphasized.

- Individuation was also very present in stories about sex with primary versus casual sexual partners. Some participants worried more about disclosing HIV with primary partners, while others told all partners. Still others didn't say anything to anyone, assuming that their sexual partners were making their own informed decisions. A few men were not having any sex because they did not want to take the chance to infect anyone, while another individual increased his sexual activities and shared that he and his partner were free to explore whatever instincts aroused them (with or without condoms). Another participant said that he saves some sexual acts for his partner and limits what he will do with casual sexual partners. While most men stated that they had made decisions about unsafe sex with primary and casual partners, the tone of conversations connoted a sense of struggle with those decisions and many underlying uncomfortable emotions.

- Participants made some important suggestions for sexual health programs. First, they said they wanted to talk about HIV disclosure issues, sex, treatment side effects, substance use and sex, and mental health issues. Many did not know that APLA had a sexual health program and stated that APLA should recruit in gay magazines, via personal invitation, and also phone calls to get the word out. In addition, they said that once POWER staff had helped some people, the word would get out. On a general level, participants said that there is a greater need for coordination and communication among APLA staff in general. POWER staff may wish to enhance communication with other APLA program managers to make sure that POWER is being advertised effectively and correctly.

Notes from Focus Group Discussion

Participants – Tim, Zak, Larry, John, Jorge, Pedro, Chris (Pseudonyms)

Demographics – 7 men, 4 Caucasian, 2 Hispanic, 1 African American, ages ranged from 35 to 61.

Questions posed (as paraphrased from agenda and notes), and responses given (as taken from hand written notes):

1. What issues/topics should sexual health and wellness programs address for HIV-positive male clients?

Zak – disclosing status, types of sex, self-esteem issues
Larry – non-disclosure, unleashed sexual activity
Pedro – drugs
Tim - sex, coping, dealing with life
John – the lack of relationships
Jorge - HIV treatment/reactions

2. How has your sexual life changed as a result of learning that you are HIV+?

Zak – diagnosed in 1992, less sex, moved away from city initially, then moved back recently, he reacted with “Thank God, I don’t have to live 40 more years”, stopped having sex
Larry - diagnosed in 2000, says we should assume we’re taking a risk, he discloses if asked, HIV has freed him sexually, believes his lower viral load reduces risk of transmission, avoids sharing sexual fluids with others
Pedro - diagnosed in 1991, says some people want to get it
Tim - diagnosed in 2001, posed question “With risk taking, do you disclose?” Says rejection happens, some like Russian Roulette, asked how long others had known of their status (answers documented as dates herein)
John - diagnosed in 1989, more risk taking, more sex risk after diagnosis, less fear of infection, initially withdrew, meditated, moved to the city, handles disclosure differently each time, sometimes early, sometimes later, no one talks about it, on one asks, it can’t happen to them, asked Mel about his diagnosis
Jorge - diagnosed 17 yrs. ago, people may reject you when they hear your status
Chris - less sex, stayed in city, stopped sex after diagnosis

Facilitator asked about feelings associated with diagnosis.

Zak - stopped sex, feel defective
John - something wrong with me, identity shaken without use of penis (no sex)
Tim - seeing others depressed didn’t bother me (in reference to support groups), saw others in the same boat, knew he was not alone

Larry - Didn't want to be around sad people, went to support groups, one at Alive & Well was very helpful, feels he must move forward

3. Sexual behaviors with primary partners vs. casual partners

John – HIV occurs to me if I'm interested in a relationship, less so if it's just sex
Chris - discloses in both cases, feels many people don't read the information available on HIV transmission

Tim - asked Michael for clarification, has had no sex in 2 yrs, has experienced depression, observed that some people use the term HIV rather than AIDS, feels that many people don't have access to HIV transmission information

Larry - partner is negative, both enjoy sex with others, usually "play" together, no rules, follow their instincts, says it has been a difficult journey, agrees with Enrique

Pedro – doesn't disclose to casual partners, believes everyone should assume that their partners are HIV+, says it's their responsibility, says using a condom or not is fine, poses question "Who doesn't know about HIV?"

Jorge - Does everything with his primary partner (Enrique), but only limited activities with casual partners

Facilitator asked about feelings associated with this topic.

Chris - feeling inadequate

John - is on & off his meds, had testicular cancer which resulted in the removal of one of his testicles, found it difficult to resume sex, says he goes for an opportunity for sex when it arises, says that his HIV meds have now become a way of life

Larry - is not on meds yet, feels that's part of his current freedom, asks "Is life over once you're on medications?" (met with a general "No")

Tim - says you get used to side effects of meds, they ease over time, says he doesn't get horny when he's sick, but does as he gets better again

4. Non-prescribed drugs & alcohol

Larry - no changes since diagnosis, Crystal is a bad drug, robs energy eventually, says he is into experimenting with drugs, does them whenever he has a "sex-a-thon", warns that marijuana is often laced with Crystal, mentions cocaine, mushrooms, acid, ecstasy (at circuit parties), GHB, poppers as drugs still in use in the community, says Viagra is a miracle drug, says drugs in general help release feelings people have trouble expressing such as sadness, horniness, etc.

Tim - says Crystal is a great high in the beginning, says there are regular and casual users, says the latter can fool themselves, says he doesn't go out much, depression keeps him in, mentions that there are natural alternatives to Viagra like Chinese herbs.

Pedro - says Crystal leads to depression, mentions poppers

- Jorge - says he did poppers in the past, but the use led to sinus infections, so he quit
- John - says in the first year he was back in the city he had a lover who was a Crystal user, Michael is not a Crystal user, so he had to differentiate between the support and the drug.
- Zak - does no drugs currently, says marijuana is good for sex, intensifies things, he works in bars as a DJ, is often offered drugs/alcohol but he refuses, sometimes feels like a sober outcast.
- Chris - pot makes him lethargic, speed facilitates anal receptive sex.

5. What other issues are important?

- Tim - disclosure, choice of “coming out” – both HIV and sexual orientation, says do what’s good for you, don’t hold it in, many are afraid to have sex after HIV diagnosis, but sex is important, says it’s hard to change a sexual lifestyle.
- Chris - sex & disclosure, asks does the drug cloud your mind? mentions drug use & disclosure.
- Larry - everyone is responsible for themselves.
- Zak - address intimacy, falling in love has become “negative”, find a balance of sexual risk/guilt/health.
- Jorge - relationships & impotence
- John - sex brings up guilt, takes more to change, then let it be what it is

6. What is the best venue for advertising one on one sessions & workshops?

- Tim - here at APLA group therapy sessions you find common experiences, says he was against it for years, still goes to one on one sessions, says we need to let more people know about services, need more coordination between APLA programs, need to be more organized, says clients are often overloaded with information.
- John - some sex clubs have therapists occasionally, he has been interested in accessing their services when at a sex club, he never thinks of APLA as a place to talk about sex or to access therapy, has seen ads at sex clubs for APLA activities, didn’t know about all of the APLA services, mentions that bars carry many magazines.
- Larry - feels he makes too much money to access APLA services, says those who make more money have basic needs too, suggests getting a core group of clients who like the program and will spread the news word of mouth.
- Zak - says there is lots of confusion about the APLA system, says it’s a mess
- Jorge - mentions the constant repetition of the need to present proof of diagnosis within the APLA system (met with general agreement).
- Tim - says the best way to advertise is at the personal level, word of mouth.
- John - says when given a flyer he automatically drops it to the ground.j

- Zak - says personal calls help a lot, maybe flyers at health food stores, the Bodhi Tree, gyms.
- Larry - mentions William Schindler – tantric sex as a possible topic for a workshop.
- 7. Closing comments – once around the room – what would help most with wellness and sexual health?**
- Chris - disclosure to partners, depression
- Pedro - people need to protect themselves first, think of themselves first, HIV is not over, there's no cure.
- Jorge - says he had a fear of dying at first, accepted HIV with time, became confident, says we need to run people through this process step by step until they reach a comfort level.
- John - says that many unanswered questions & unaddressed issues in his life led to depression, says some issues are not health-related, never saw APLA as a place to address sexual issues, says he had given up at first, says there is a need to discuss the root causes.
- Larry - says he is always greeted with smile at APLA, says all types of people need help, people shouldn't be turned down for economic reasons, says that belonging is empowering.
- Zak - says the only way to succeed is to do one-on-one sessions or gather a group of like-minded people, mentions drugs, depression, disclosure, says everyone is different.
- Tim - recommends getting better internal and external communication going at APLA, says the only people in the building who know everyone's names are the security guards, says we need more internal cohesion, says money shouldn't be an issue.

Overall observations:

1. It may be significant to note that none of the participants mentioned sexually transmitted diseases other than HIV with regard to transmission and/or disclosure.
2. All of the participants are apparently sexually active, except Tim, who was diagnosed within the last 6 months.
3. All of the participants have apparently tried and/or used various drugs at one time or another.
4. The most openly experimental drug user (Larry) also identified as being in apparently the most open and adventurous relationship.
5. Recurring themes of concern to participants included:
 - disclosure in general and the perception that it happens less with casual partners,
 - the importance of sex in their lives (self esteem, self identity, etc.),
 - impotence,
 - relationships, intimacy, falling in love
 - depression, isolation
 - the perception that responsibility for disclosure/safer sex negotiation does not rest solely with them,

- the traumatic effects of being newly diagnosed and the ensuing effect on their sex lives (varying from little to no sex to an increase in sexual activity),
 - the value of support (one on one and group),
 - the perception that APLA's system is confusing, less organized than it could be and geared to serve those with low income,
 - the perception that advertising is best done through word of mouth, personal phone calls and strategic advertising in certain magazines/venues.
 - The perception that life is not over when on HAART medications, adaptations can be made.
6. In my opinion there were feelings of safety within the group, as evidenced by the openness with which participants spoke and the increase thereof as the session progressed.
 7. A good level of cohesion seemed to develop within the short time frame of the session, and I feel that this group could even have segued into some type of ongoing support and/or action group if that were the purpose.
 8. The focus group process appeared to be a somewhat empowering one for the participants.
 9. The participants appeared to have many HIV-related questions outside the scope of the focus group agenda.