

Designing online prevention programs for HIV+ MSM: An interactive workshop (for real)

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Workshop overview

- **Brief summary of background and research**
- **“Hot topics” that arose in our online interviews with HIV+ MSM**
 - Likes and dislikes about the Internet
 - Hooking up online
 - Disclosure
 - Serosorting
 - Condom use
 - Barebacking
 - Drug Use
- **Attitudes and recommendations about online HIV prevention**
- **Current approaches to online HIV prevention**
- **Examples of model programs**
- **Discussion:**
 - Reactions to the topics presented
 - Ideas for online programs
 - Challenges to online prevention
 - Other issues

Research on MSM & the Internet

- Internet is a popular tool for MSM to meet partners
- High rates of UAI w/non-primary partners
- Venue to find “barebacking” partners
- Internet using men more likely to report UAI & STDs
- Vector in syphilis outbreaks
- Widely used and effective communication technology
- Great potential to enhance HIV prevention efforts



Research on the Internet & people living with HIV/AIDS

- **Internet use by HIV+ men and women**
 - Search for AIDS-specific information, learn about clinical trials, and communicate with health providers (Kalichman 2006)
- **HIV+ youth frequently use the Internet** (Reeves 2000)
- **Internet can help:**
 - Promote empowerment, increase social support, facilitate helping others, and increase HIV-knowledge and treatment adherence (Flicker 2004)
- **HIV+ men who seek sex online are more likely to have HIV- sex partners and report UAI with serodiscordant/unknown partners than HIV+ men who don't seek sex online** (Kalichman 2005)
- **Most (84%) of HIV+ gay men recruited online (n=112) reported recent barebacking and 43% reported it with partners of unknown HIV status** (Halkitis 2003)

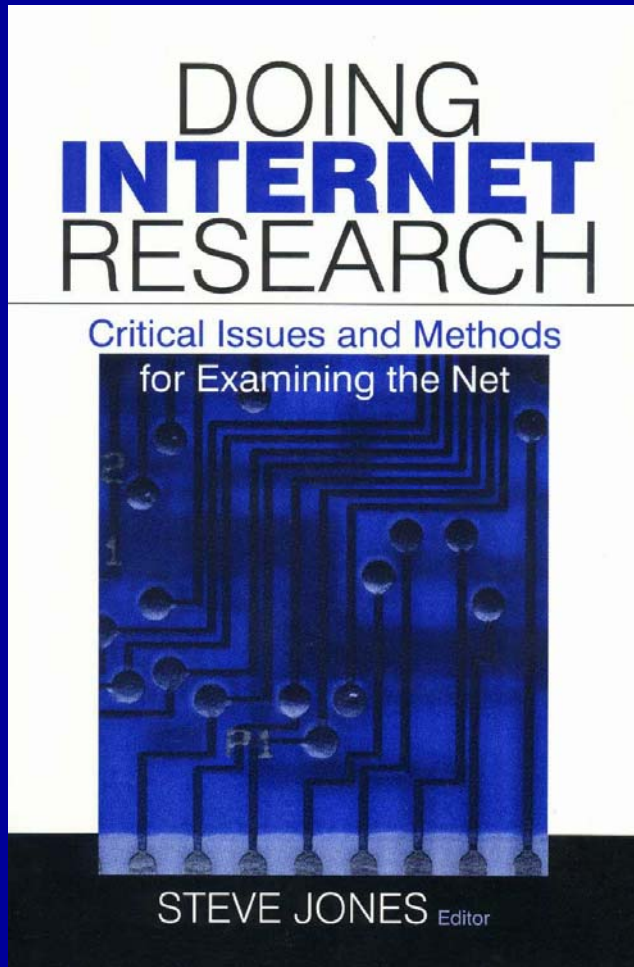


Qualitative research with chatroom using MSM

- Achieve a greater understanding of chatroom using MSM's personal characteristics, Internet use, and sexual risk behavior
- Funded by UARP Grant #R00-SF-062 & CAPS innovative grant
- Project Researchers:
 - Alberto Curotto, Ph.D.
 - Susan Kegeles, Ph.D.



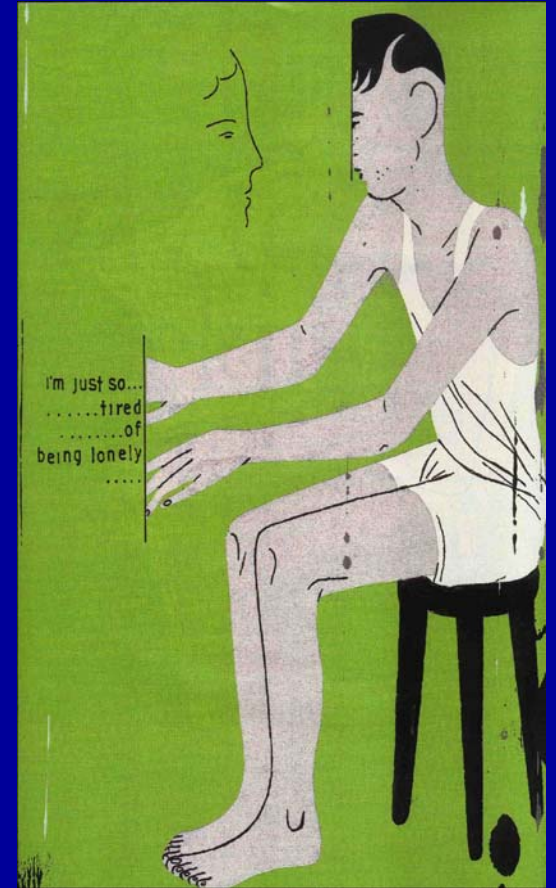
Methods



- **On-line survey and interviews**
- **How and why MSM use the Internet, including sexual purposes**
 - Likes and dislikes about the Internet
 - Internet's impact on gay community
 - Assess the relationship between sexual behavior on- and off-line
 - Willingness to participate in online HIV prevention programs
 - On-line norms (e.g, honesty, disclosure)
- **\$30 - \$50 electronic gift certificates as incentives**

Participants

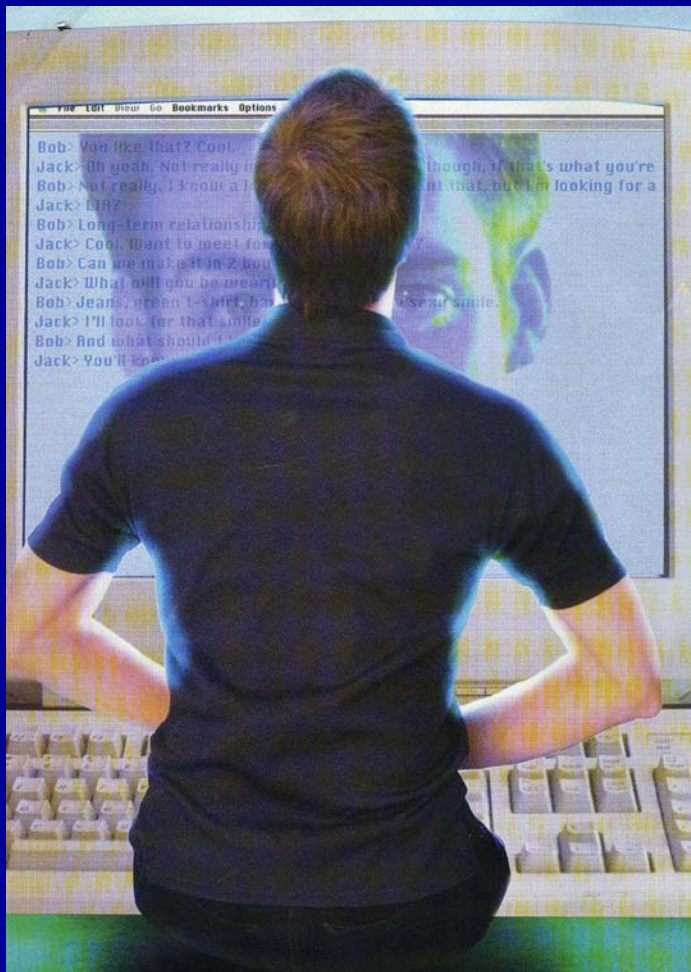
- **Research assistant recruits from M4M chat rooms (e.g., gay.com, AOL)**
 - Recruitment dates and times systematically chosen to maximize representation
 - Participants initiate most contacts
 - Polite invitations sent to some potential participants
 - No on-line advertising
- **Eligibility screening**
 - Sexually active MSM
 - on-line sexually-related behavior AND
 - in-person sexual activity in last 2 months
 - At least 18 years old



Characteristics

- 13 HIV+ gay men were interviewed online
- Age (mean=38, range 23 to 51)
- 100% gay identified
- **Race/ethnicity**
 - 8 White
 - 1 API
 - 3 Latino/Hispanic
 - 1 Black/African American
 - 0 Native American
 - 0 Other/missing
- **Geography**
 - 4 Pacific
 - 6 North East
 - 2 Mountain States/Southwest
 - 1 Midwest

 - 9 Urban
 - 3 Suburban
 - 1 Small town



Likes: Convenience of hooking up

- “I’ve met good people through it...”
- “For a lot of men I think it’s easier to ‘hook up,’ you don’t have to leave the house, you can chat or find personals without ever leaving the house”
- “The anonymous edge can be very exciting if there’s a strong connection once you finally meet. The whole “hunting” aspect can be fun. It can also be very frustrating, and if the guys are flakes, or not serious, you can waste a lot of time and effort for nothing. I hate that. Guys that lie about themselves or their desires are a real drag. Almost makes me want to give it up sometimes ... but not yet!”



Likes: Accessing information

- “I’ve been able to find information in various personal interests in a quick and inexpensive way.”
- “ease of communication, ability to anonymous access g/l info (if one is questioning)”
- “easy to get information about health issues and gay news...”
- “i use it for research... hiv chat sports as in espn.com... aol radio... then let’s see...there is a lot of info on AIDS meds and talk on how the meds effect on the people using”

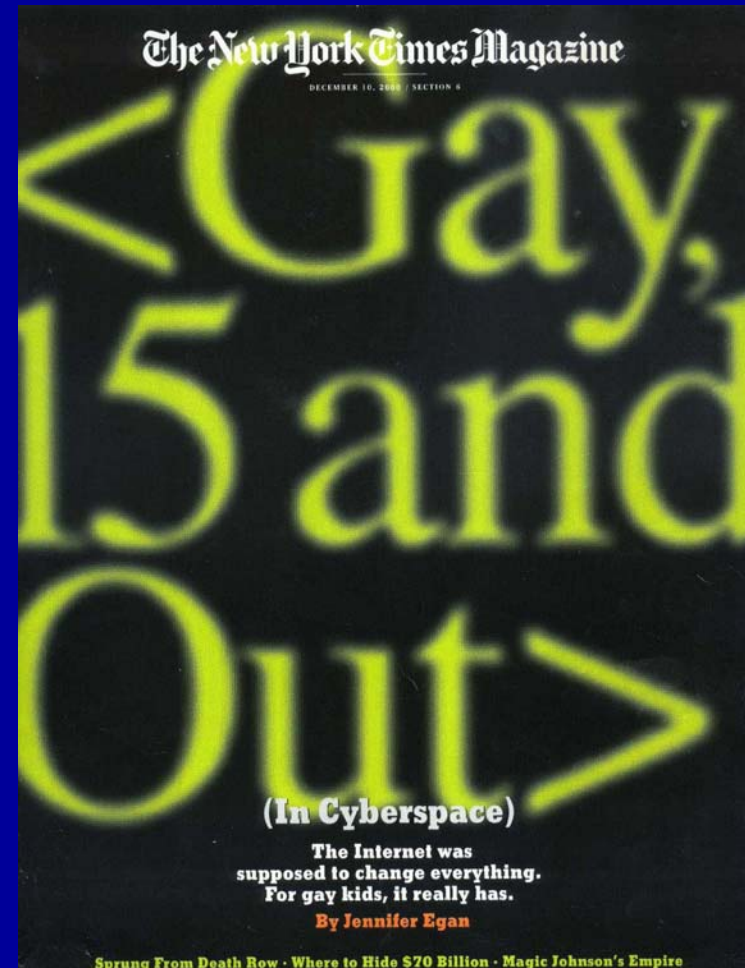
Likes: No fear of rejection

- “no real fear of rejection online if is not meant to be it is not meant to be”



Likes: Provide social support

- “I meet men who have recently seroconverted and need some advice and support. I am an activist and HIV+ since 1984 so that’s an area of concern to me. Also, I meet men who I see as trapped in their geographic circumstances and I tend to reach out to them...”

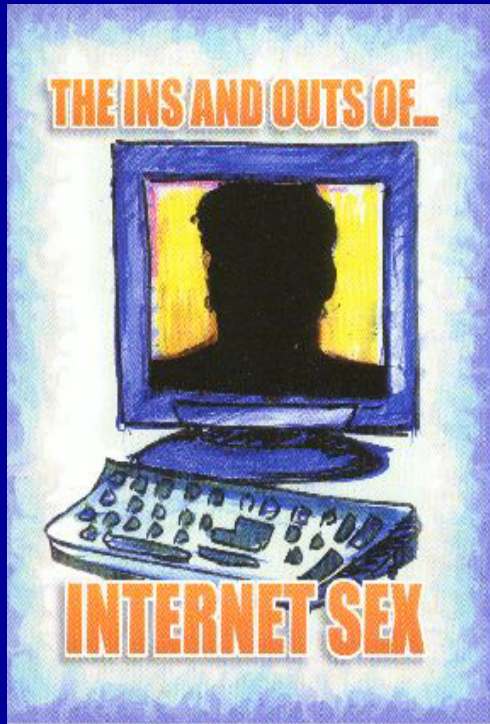


Dislikes: “Depersonalization” and isolation

- **“it keeps you from making face-to-face connections”**
- **“I think that also is [one] of the most negative effects - some men don’t go out and socialize at all - the internet is their social life either for sex or just recreation”**
- **“It has helped me in job searches and to make new acquaintances, but it has also kept me at home (isolated) much more.”**

Arranging dates/encounters

- **Online discussion of personal/sexual likes/dislikes**
 - “negotiations happen online... all boundaries are set online before we meet in person so there are no surprises or false expectations about what is or is not going to happen”
- **Immediacy & Convenience**
 - “The last [hook-up] was very fast ... the guy had been stood up for a sex hook-up, so he went into a Kinko’s and signed on using a public computer. He found my profile and IMed me. We only chatted for a couple minutes because we were both randy and wanted the same things ... The Kinko’s was 2 blocks from my house and we liked the look of each other so he came over. We smoked a little pot and did some poppers when we had sex. We had great sex.”



Examples of recent encounters

- **Could you to tell me more about the most recent one of these hook-ups?**
 - “one came over this morning that I met online 4 months ago, we keep missing each other’s times that we can meet. we ... he emailed me and asked if this AM would work for a visit and he came over and we had sex and will again. we seem to like each other’s company”
- **Did you talk about your respective HIV status with each other?**
 - “we talked about it the first time we met online, and talked about it this AM... when he came over we only did oral, but we talked about me doing him next time, and a condom will probably not be used. I will be on top.”
- **Is there another hook-up that went somewhat differently and you’d like to describe?**
 - “I have a poz guy that comes over and we have sex and I top him without the condoms. I only top poz guys without. I use them with neg if they want to bottom.”
- **How do you negotiate what type of sex you’re going to have with someone you meet online?**
 - “I’m a top and I look for bottoms, but if a top wants just to do oral with me, me being a top, we just blow each other and most he time when we talk we say what we want from each other in the bed before he comes over. most profiles say top or bottom. I always look for the bottoms”
- **In what way does the topic of HIV and/or condom use come up when you are looking for sex partners online?**
 - “when I’m IMed for a possible meet, I tell them right off that I’m poz. I mainly look for the profiles with “poz” in their profiles”

Disclosure of HIV status prior to sex

- **Passive Disclosure**

- “I’m honest if they ask me any specific questions. But I don’t volunteer information.”
- “In this case, it was understood from our profiles that we wouldn’t be using condoms because we were both poz”

- **Active Disclosure**

- “I always let the other person know my status before we even meet in person.”
- “Firstly, I mention clearly in my profiles that I am poz. If it seems that the other person is negative, then I will say to them (online), “Did you see that I’m poz?” I generally find that most negative guys are less passionate with a poz guy, so I wanna make sure that is very clear. Once that is clear, I will make sure that someone brings up online the use of condoms and we discuss how we feel about that.”
- “I am totally honest. It’s best that way. I think having HIV gives me a responsibility to be that way... I tell people before our first chat is over. Even my screen name indicates my status.”
- **Interviewer: Did you talk about your respective HIV status with each other?**
 - “yes we do... its not on our profiles... but we tell them as we are chatting on-line...”

Examples of non-disclosure

- **Safe Sex Without Disclosure**

- **how did you negotiate using or not using condoms? Did the negotiation happen online, offline, or was it mutually understood from a personal ad/user profile?**

- “no – safe sex only – no discussion of HIV status... no anal sex, just oral, no orgasms within orifices. Discussed in person, at time... HIV – rarely, I assume everyone is positive. Condom use almost always. I do not interact with people who are into or advertise they are into barebacking.”

- “didn’t come up... but did use a condom and water-based lube”

Reactions to disclosure

- **Easier when both are poz**
 - “before meeting YES we did discuss it [HIV status] ...well I mentioned very early on that I was POZ and he said he was too so that made things easier, I didn't have any reactions with this one but a LOT of men just stop chatting once they find out...we had both discussed on line that we liked bareback sex so condoms were not used or expected to be used”

Reactions to disclosure

- **Varied responses when other person is negative**
 - “most don’t care that we are poz... and ask us not to use rubbers... if we meet which tells me that they’re poz if say they don’t care if we are... 90% of our hook-ups are poz... if a guy IM’s us who’s profile says hiv- looking for same we tell them right off that we are poz and they stop talking to us... like i said most don’t care... guys who ask and we say yes we are... and they say that they’re neg... we ask if that’s a problem... if yes... most say thanks for being honest about and say have a good nite... it don’t bother me if a guy would hook-up with me cause of my HIV status... when guys tell me that they are to[o] i like that cause that mean that we will hook-up if there [sic] poz also”
 - “I’ve been doing it [disclosure] so long that it’s just what I do. Sometimes, I think people avoid me because of it and it hurts my feelings, but I have no control over someone else’s reaction”
 - “it felt strange...it’s hard to tell someone ur positive... u feel like an outcast if they are not”

Serosorting

- “I usually look for ads that specifically have either bareback or poz somewhere in the profile”
- **Did you talk about your respective HIV status with each other?**
 - “we met in the HIVm4m room and both had it in our profiles.”
- **Can you tell me more about the disclosure of your respective HIV status?**
 - “we were both HIV+ and said it in the profile it is a relief to have that up front and out of the way / most HIV+ men look for other HIV + men makes life very simple.”
- **If you had sex with him, how did you negotiate using or not using condoms?**
 - “we talked about it on line and both agreed no condoms would be used.”
- **In what way does the topic of HIV or condom use come up when you are looking for sex partners online?**
 - “Profiles will say HIV+ and BB bareback no condoms online you just confirm it... If Poz on Poz I prefer not to use and most poz are the same way... I basically will not date neg men”

Serosorting

- **How worried are you about getting infected (or reinfected) or infecting your sex partners with HIV?**

–“I’m not worried about me getting [re]infected, I don’t get topped, and I am very careful with neg partners, I will not infect others even if they know I’m poz and they are neg and want it without condoms I do not do it”

- **How likely are you to bareback and/or under what circumstances would you do it?**

–“I BB when the bottom wants it that way and he must be poz and know I am. I am told that even though both are poz still shouldn’t do it and that crosses my mind I would rather use the condoms just for any possible risk but at times I don’t, but always if neg, but I hardly top neg men, it’s always the oral thing”

Condom use

- **Routine Condom Use**

- “when we were engaging in the act... it was automatic. I grabbed a condom and put it on. there was no discussion about it. It was automatic... I always use condoms regardless where I met the person”
- “IF sex occurred there was no negotiation. Condoms are a must wit me.... Condoms are a condition of sex...”.
- “mutually understood ...didn’t talk about it online or directly... just got naked put condom and started fucking... no oral just anal”

- **Internet May Facilitate Condom Use**

- “I think that online hookup relieve a lotta of the spontaneity thereby relieving those who are “caught up” in “the moment” of doing something they would otherwise regret. ya feel me?”
- **Are you more or less likely to use condoms with partners you find online as opposed to people you initially meet offline? If so, why?**
 - “More likely cuz with the net u really don’t get a feel on who they are and where they come...”

Barebacking

- **Poz-Poz barebacking was very common**
 - “I will sometimes bareback with another guy who is poz, if we are both into that.”
- **Preference for BB, but exceptions to the rule...**
 - **How likely are you to bareback and/or under what circumstances would you do it?**
 - “VERY likely the onle reason I wouldnt is if someone who I really really FOUND HOT required a condom then I would consider not barebacking”
 - “barebacking is the way we do it... on-line is agreed to us bareback... if the hook-up wants rubbers we say no that it won't happen... we have used rubber for guys mostly if they where very young like 18-21... then we always use rubbers on them.... i would only use rubbers if hook-up is 18-21... and i have had many who are that young and 90% want rubbers”

Drug use

- **Lack of condom use when partying**
 - “I don’t use condoms anyways so that never comes into conversation.... most guys who party and play don’t really care about HIV prevention b/c most are already positive... and the ones who are negative, I generally don’t interact with anyways so I can’t really tell you... I’m positive and the people I play with are positive also... I only bareback”
- **Partying interferes with sexual limit setting**
 - “I have met someone online, did party (a hit of very bad crack), did not discuss HIV statuses and did have unsafe sex, anal penetration not to orgasm without a condom, however did manage to stop the behavior and disengaged from the scene...”
 - “I think ... drugs remove inhibitions and ... can remove or diminish safeguards around safe sex. If it does that for me, I assume it does so for other guys. Maybe even more so for others cos I think about this issue considerably. However, if I were a speedfreak or other substance addict I would probably have no thought process around safe sex”
 - “If you’re high, it’s [barebacking’s] very easy, and desirable, to just want the guy to fuck you, or to fuck them ... right now ... no time for a condom ... no one wants a condom ..”

Drug Use

- **For some, partying does not affect sexual decision making**
 - “well, I can’t perform once I have taken the drug I party with, so the sex happens first with me, but he will start without me. the drug does not change my thoughts on whether or not I’m gonna use a condom or not; that is talked about first”

Partying and seroconversion

- “When I started exploring recreational drugs in 2001, I found it enabled me to try things that I never would have tried otherwise. Unfortunately, it also allowed me to be comfortable in lowering my guard with regard to unsafe sex, and I think it was integral to my seroconversion. I’m not saying it’s the drug’s fault ... I did it. But the drugs certainly made the behavior easier... Yes, I am poz. I wish I wasn’t, but there you go. I do think it was a direct connection to PnP-ing. After all, I have always had a lot of sex my whole life, but wasn’t unsafe until after I started PnP-ing. I’m glad that, if I have to be poz, I’m poz at a time when new treatments are available and it seems like there is more hope on the horizon. In some ways I feel like I have to “come out” all over again and that’s hard. But I’m dealing with it... I’m much more aware of HIV news now that I’m poz. Also, my partner is negative, so it’s important to me to be concerned for his safety.”

HIV+ experiences with PnP

- “in the past 8 years I have only partied a few times. It’s only been in the past year that I have partied more, meeting more people I guess. I did stop for a long time but I like to once in a while. I can’t all the time, my meds and health are at risk”

Attitudes about online prevention

- **Positive attitudes**

- “I think it’s very necessary. I find it useful and helpful. Specially for the many many young gay teenagers that have easy access to all this sexual environment... unfortunately our gay community only takes concern or interest once infected or ill. Awareness, or prevention programs are discarded. But I think chatrooms, perhaps websites could work. Or this type of programs, where you get to answer online survey one on one instead of clicking yes or no boring questionnaires are very helpful and useful because the participant gets to speak his mind rather than answer ‘I strongly agree’ or ‘I don’t know’”
- “they can talk to me, I’ll listen. It’s not like I’m a whore or a druggie and I do not infect neg people, they know I’m poz”
- “The message got lost some where along the way young gays don’t get it they think the drugs will get them thru and the poz on poz sub culture I know does not help. We do not think there is a need for “safe sex”. People are starting to die again don’t know the answer.”

Attitudes about online prevention

- **Recommendations**
 - “least effective... judgmental; effective tools or approach... probably from a harm-reduction aspect”
 - “well if they are trying to tell me how to have sex - that isnt going to work - if I choose to have bareback sex with a partner who knows my HIV status then thats our business, if the person doing HIV prevention work is going to get preachy about it or moralistic - I wont respond well”

Design Internet programs to fit the online environment

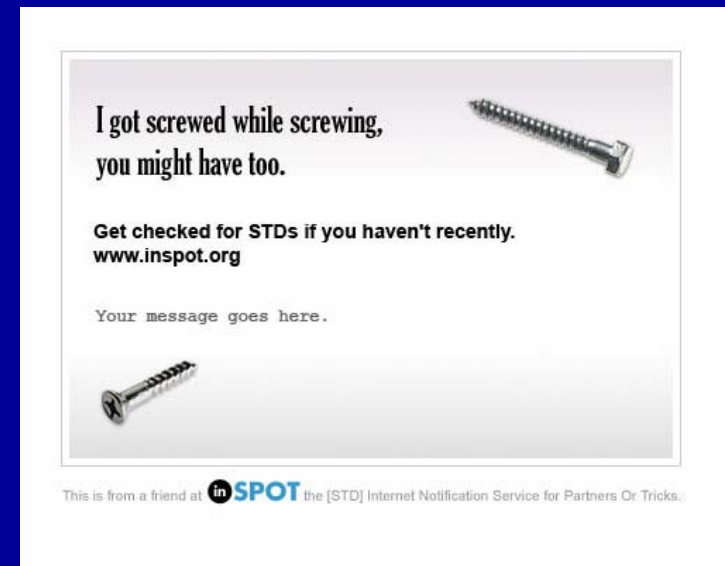
- “I think it needs to be done... but not the ideas u suggested only the one about a chatroom... but something quick and easy... no inconvenience to us when we are online... we just really want to hookup... no scenarios or questions that detour us from cruising, hooking up, and chatting... I would suggest lil blurbs every now and then... like ‘have u been tested?’ ‘do u know your status?’ and maybe offer incentives to get tested... something quick and easy...”

Current types of online programs

- **Internet-based program to improve information consumer skills for people living with HIV/AIDS**
 - Randomized control trial with 9 month follow-up (N=448)
 - Compared 8 sessions of Internet information consumer skills training to a time-matched support group
 - The Internet skills group used the Internet more for health information, coping, and social support than did the control group (Kalichman 2006)
- **Online tools for people to tell their sexual partners about an HIV/STD exposure**
- **Websites for information, community-building, peer networking**
 - Mostly not specifically tailored for HIV+
- **Online outreach programs**
 - For both HIV+, HIV-, HIV-unknown

inSPOT

- **Online tool for MSM to tell their sex partners about an STD exposure**
 - Began in 2004
 - >93,000 visitors in 2005
 - 40,000 people sent cards
 - 68,000 e-cards sent
 - Site contains STD information and referrals for testing and treatment
- **inSPOT added HIV-related e-cards in Dec. 2005**
 - >230 e-cards sent to an average of 2.3 recipients each (12/05 to 2/06)



CaliforniaMen.net

- New, interactive, community-oriented website for MSM in California
- Funded by UARP
- Developed through a formative research process
- Key components
 - Blogs
 - Hook-up site reviews
 - Little Black Book
 - Sexual health education
 - Links/Referrals
- Expected launch Fall/Winter 2006
- Will be marketed and evaluated



Online outreach efforts

- **We conducted interviews with 23 CBOs conducting active online programs**
- **Several of these programs had successfully reached HIV+ MSM**
 - “There are more people chatting online at any one time than you could find in all the gay bars in [our NE state] combined. I think it's almost 100% for sex, even though some men say it's for socializing. But I see very little of that myself. However, there is an exception, for HIV+ men, the Internet is the **ONLY** way they can connect with each other, the only way they can break through the isolation and rejection of the community.”
 - “Counseling happens [online] mostly with HIV+ individuals: once I disclose that I'm HIV-positive myself, then we often establish a certain level of counseling, but only as it relates to their HIV disease. It becomes a peer-to-peer counseling relationship, if you will.”

Observations of online ORWs

- **Some observe little online discussion of safer sex**
 - “Some assume that all the partners they meet online are positive as a risk-reduction strategy but when we asked if they discuss safer sex with their partners we found out that mostly they don't, they just limit themselves to discussing sexual likes and dislikes.”
- **Confirmation of popularity of HIV+ serosorting**
 - “I've noticed that [the Internet] it's also used a lot by HIV+ individuals who prefer to have sex with other HIV+ so they go online as they find it much easier to disclose online than in person.”
- **Concerns about serosorting**
 - **QUESTION:** Is the resurgence of barebacking taking place even among serodiscordant partners?
 - **ANSWER:** “Unfortunately, I think that it's often an issue of ‘no questions asked’ so it's hard to tell whether they're seroconcordant or not.”
- **Though, Carballo-Diequez (2006) found that HIV+ and HIV- MSM who used the Internet to seek sex were more likely to negotiate about sex and disclose than men who don't seek sex online.**

The Internet has lots of programmatic potential

- “I have developed a couple of ongoing phone relationships and a few online relationships. There's this one guy, for instance, who tested positive after I persuaded him to get tested and now he calls me regularly for support and trusts me in a way he doesn't feel comfortable doing with his primary care physician. It's the whole issue of disclosure and the sense of protection given by the relative anonymity of the medium.”
- “Reaching out to HIV-positive MSM in the state. Nobody else is doing that. And we're bringing them in to socialize with each other and break through their isolation. I've become friends with a lot of these poz guys. A small movement still, but it's a beginning.”
- “We recently had a guy who had never told anyone about his status. We were the first ones he revealed it to. And, as a result, he has started getting care and also getting into a dialogue with us and other positive men. I've really pushed the effort to do outreach to positives with the new funders, telling them we need more resources to reach out to them, so they can break through their isolation and eventually come together on their own and build their own support groups.”

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