Study Background

• HIV Prevention with Positives (PwP) interventions in 15 clinical settings delivered by:
  - clinicians
  - support staff (health educators or social workers)
  - peers
  - combination of clinicians and support staff and/or peers

• 15 clinical sites and Evaluation Center at UCSF funded by the Health Resources and Services Administration (HRSA) Special Projects of National Significance (SPNS) HIV PwP in Clinical Settings Initiative
## PwP Intervention Types

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Disclosure and PwP

• Disclosure as a prevention and risk reduction strategy
• Responsibility to disclose to others
• Benefits of disclosure for social support
• Laws on HIV seropositive status disclosure
Presentation Objectives

• Review patients’ disclosure practices before PwP interventions
• Discuss impact of PwP interventions on patients’ intention to disclose and disclosure practices
Methods

• 60 qualitative interviews post-intervention with patients at 15 sites
• Audio-recorded interviews were transcribed and organized using Atlas ti©
• Data were coded and summarized and themes compared and contrasted
Patients’ Disclosure Patterns before The PwP Interventions

- Disclosure to everyone
- Only to family and friends
- Only to sexual partners (if sexually active)
- No disclosure
Influences on Patients’ Disclosure Patterns before the PwP Interventions

• Personal and sexual history
• Family situation
• Social context and geography
• Fear of rejection and stigma
Examples of Disclosure
Components of PwP
Interventions

• HIV Communication Module (ILI, Peer)
• Disclosure Skills Session (GLI, Support staff)
• Stages of change for HIV disclosure (computer-based assessment, Medical provider)
Disclosure Components of PwP Interventions

- Discussions on disclosure issues and practices
- Examining potential consequences of disclosing
- Exploring a sense of responsibility to disclose to sexual partners
- Identifying strategies on disclosure
  - Skills building
  - Decision-making
  - Assessment of when and how to disclose
Impact of the Interventions on Patients’ Disclosure

- Curriculum and explicit discussions about disclosure
- Context to talk about HIV prevention, risk behaviors and disclosure
- Opportunity to explore personal issues
  - Living with HIV/Sense of identity/Shared experience
  - Reflection and introspection
  - Self-esteem
  - Social isolation

Interventions influenced patients’ intention to disclose and/or disclosure practices

Interventions helped move patients through a continuum of disclosing HIV+ status whether to family, friends or sex partners.
Impact of the Interventions on Patients’ Disclosure

- Interventions influenced patients’ intention to disclose and/or disclosure practices.
- Interventions helped move patients through a continuum of disclosing HIV+ status whether to family, friends or sex partners.

Disclosure as a prevention strategy.
Shame and Fears

I: What were the most important issues that were addressed for you?
P: Discussing your status….with anyone, and discussing it with a potential partner that’s not positive, …just cutting down all the shame and the fears of having to disclose your status.”

- Latino gay male/Support staff, GLI
Confidence to Disclose

P: “I believe that secrets hold you hostage and you become enslaved to them. And so the more I'm honest and the more chances I'm given to be honest I take them. Just because I don't want to be prisoner to the secret. [Name of project] It definitely will make me think about disclosing prior to engaging in a sexual encounter and prior to dating someone…. Like I, in the past, I'm like ‘Whoa, you know I'll just make sure I'll do everything safe and they'll be no need for me to disclose.’ Since being in the project it's really taught me the importance of disclosure and how I can do it without panicking, pretty much.”

I: “Have you had the chance to practice that?”

P: “As soon as I started the project I started dating a guy. And it's the first guy that I've ever disclosed to...prior to engaging in any...like I knew we were getting to that point where we were going to be physical, and so I was able to say ‘Okay. There's something I need to tell you.’ And that was huge for me. And he dealt with it very well, so I was very fortunate that my first time, it didn't involve rejection directly. Later on there were some issues, but it gave me the courage to be able to do it a lot easier.”

- African American gay male/ILI Peer intervention
Disclosure to All Sexual Partners

I: “Let’s see, I know you talked a little bit about disclosure. Is that something that they have talked to you in the clinic about?”

P: Yes, very much so. And that’s why I said I thought that I had done something by being with someone that I didn’t disclose with….And like I said, when I mentioned it, and I got a spanking on the hands, and then they told me, ‘well, you know, it’s not fair to anyone else, or the other person if you do not disclose.’ Even though they might not be directly at risk, but you don’t know….So, that’s why it’s more important to be able to disclose than to keep the secret. And I feel that there are so many people that’s not able to disclose… Or they just don’t care about themselves and other people. So the study has been good for me to be able to disclose.”

- African American gay male/Medical provider intervention
Disclosure to Family

I: “What is the biggest stressor that you experience because of being HIV positive?”

P: “(clears throat) disclosure.”

P: “A lot of people in my family do not know that I’m HIV positive...

I: “Did you guys talk about disclosure?”

P: All the time. If it wasn’t for the group, I probably would never have told my ex-wife...

I: “But what about your family?”

P: “... I think it’s because I’m a little more embarrassed and, we did talk about it in our group.... ‘They’re not gonna love you any less’ and it’s true, they’re not....., what I really feel bad, is that I’ve hid it from them for so long. So, they’ll say..., why didn’t you tell us this all these years?”

I: “And why didn’t you?”

P: “At first it was the embarrassment, the guilt.... for years it’s had the stigma of being a homosexual disease,... they think oh, you’re a fag.... I mean, there are other ways of getting it - you could have been a drug user - which I was, but in my mind they’re gonna say I’m homosexual.”

P: “I guarantee ya, if you had a survey of straight men, straight women, gay women, gay men, .... and said, how many have a problem with disclosure, the highest percentage is gonna be the straight men.... Because you have this macho thing, a reputation to uphold..., peer pressure. But,... actually this trip.... I’m pretty sure I’m gonna sit my family down and tell them that I’m positive.... I need to get the weight off of me,... Cause I think about it all the time.”

- Latino heterosexual male/GLI Peer Intervention
HIV as a Secret

P: Everybody don't need to know your business, you know, that you're HIV positive.
I: So people don't know?
[Being HIV+] You're already a outcast. Because you sick. Well I just mind my business, take my medicine. I got friends, but we don't discuss this, you know. We discuss regular stuff like we used to discuss. We have a drink together. But never this. And I never will. It's my disease.
I: Well what do you think would happen if you told your friends?
P: I don't even think about it,... I'm telling you the truth. I ain't even going to think about it because I ain't going to do it.
- African American heterosexual female/ILI, Peer intervention
Disclosure and PwP

- Complexity of issues surrounding disclosure
- Disclosure as a process
- Tailoring of disclosure to patients’ situation
- Different strategies for disclosing
Conclusions/Demographics

• Ability to disclose may positively impact patients' well-being and self-esteem.
• Exploring disclosure issues, self-esteem, normalizing living with HIV, quality of life, responsibility to others and stigma may increase patients' self-efficacy to have protected sex and help avert new HIV infections.
• Disclosing may relate to an increased ability to negotiate protected sex and use condoms.
• The relationship between disclosure, personal and social responsibility, stigma and HIV infected patients' self-efficacy and risk of transmitting HIV to others needs to be further examined.
Acknowledgements

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