Today’s Goals
In today’s workshop, we will
• Understand the reasons why disclosure can bring both good and bad consequences.
• Get a sense of the ways that other PLWH have made their decisions of whom to disclose to, how, and when.
• For your part, please write down: who would you like to disclose to, or help a friend or client disclose to?
• Keep this person in mind as we examine disclosure options and outcomes today.

What is Disclosure?
• “Disclosure” is the act of revealing one’s HIV status to another person.
• Disclosure may take place as an “acute” event (i.e. announced openly).
• More commonly, disclosure is incremental (hinting that there is something to discuss, “testing the waters” conversations, setting stage for passive disclosure, confirming.)

Isolating the Influences
• Think of times you’ve been hesitant about telling someone about something other than your HIV status.
• What made it difficult?
• Which of these influences seems to apply to you as you consider disclosing your HIV status?
• Which do you have control over?
Why Disclose?

- Some disclose for
  - expected support,
  - to protect loved ones from HIV risk or unexpected losses,
  - to clarify individualized needs, and
  - to decrease the burden of secrecy.

Disclosure to PLWH

- Children perinatally infected had 8-13 year survival by mid 1990s. Now longer.
- American Academy of Pediatrics recognized children’s right to know.
- Encourage disclosure, taking into consideration, age, psychosocial maturity, complexity of family dynamics, and clinical issues.
- For younger children, simple explanations about illness and what to do to stay healthy. Adolescents should be fully informed so that they can assist in their care and reduce the risk of HIV transmission through unprotected sex.


Non-disclosure + u/p Sex

- 1,828 HIV+ MSM, 46% disclose to all.
- If w/ casual, 42% always, 22% never.
- Disclosure related to: partner's perceived serostatus, relationship type, sex behaviors.
  - 37% reported u/p anal sex w/ HIV-/UNK partner.
  - 80% w/ casual partners had >1 u/p, w/o disclosing for 58%.
  - Non-disclose & casual u/p sex > likely if: identify as gay not bisexual, aware of status < 5 years, and have more partners.
  - Being on HAART, # of symptoms and VL not associated.


Giving PLWH a Bad Name

- Ronald Gene Hill, former San Fran health commissioner.
  - Insisted on anal sex in relationship. Partner refused until both tested. Hill apparently faked result. Began u/p sex. Infected his partner, who later found Hill had been on antiretrovirals for years.
  - Partner filed suit. Story in headlines brought forward another man who asserted Hill told him he was HIV-, insisted on u/p anal sex, and infected him, too. Others too?

Legal Lunacy Won’t Solve This

- Under Florida Statute 384.24, a diagnosed HIV positive person is guilty of a felony if he or she ever has sex with another person without having first disclosing HIV status … even if using protection.
- The standard for criminal behavior under California Health and Safety Code 120291 requires that the HIV positive defendant must have acted with the specific intent of infecting the other person.
- FL law seems overly punitive, CA law enabling.

Costs and Benefits of Telling

- Make a list of all the possible good outcomes of disclosing: for yourself, for the person, for your relationship.
- Now make a list of all the possible bad outcomes of disclosing.
- Key to remember: you cannot “unring” a bell. Better to wait until you are sure.
- One exception: if non disclosure is putting someone at risk. Then humanity should override.

Responsibility and Risk Behavior

- “How responsible did you feel for protecting him from your strain of HIV and other STDs?” compared to person with ‘high’ responsibility, odds of u/p anal sex with an at-risk partner are
  - ~ 8 times greater for ‘medium’ responsibility person
  - ~ 59 times greater for ‘low’ responsibility person.

Parallels Other Disclosures

- Similar to “coming out” process for LGBT.
- Similar to “coming clean” experience for substance users.
- Not as simple as “doing the right thing.” Must assess anticipated response, and prepare for unanticipated.
Don’t make me turn my back on safer sex!

"You’ve painted out guys that you know are HIV+. And you’ve told me that you could never date a positive guy.
"I’m part of your community, and I’m HIV+. I want to protect you. If I respect safer sex tonight, will you be talking about me next week?"

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Disclosure Can Have Costs
• 18% of surveyed HIV+ women reported experiencing disclosure related violence, whether verbal abuse or physical assault.
  Physical or verbal abuse was more common if the PLWH:
  ✓ had a prior history of abuse,
  ✓ or of drug use,
  ✓ was of lower socioeconomic status,
  ✓ or of younger age,
  ✓ shorter length of time since diagnosis,
  ✓ or had a partner who was not known to also be LWH.

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Why Is It Easier to Tell Some?
• Studies find rates of disclosure depend at least in part on who the “target person” is to the PLWH.
• Thinking in terms of “costs” and “benefits”, what differs for:
  ✓ Main partners?
  ✓ Casual sex partners?
  ✓ Close friends?
  ✓ Mothers?
  ✓ Fathers?
  ✓ Co-workers?

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Finding the Power to Disclose
• Surveyed 155 HIV+ gay Latino males in NYC and DC: disclosure to main partners, closest friends, and mother/father.
• Target person’s awareness of PLWH’s sexual orientation: disclosure to all groups.
• Longer time of friendship: disclosure to close friend.
• Emotional closeness: disclosure to mother, acculturation: to father, and somewhat to mother.
• Disclosure does not happen across social networks, but is a case by case choice.

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How Will They React?

- Study 129 Latino HIV+ men: disclosure often reciprocal situations, but also more likely disclose than solicit partner’s status.
- Social isolation, or high expectation of negative responses → less disclosure.


Another study: 301 Latino HIV+ men using CASI.
- Proportions who had told closest friend (85%), male main partner (78%), mother (37%), and father (23%).
- More strongly related, though, to greater quality of social support, greater self-esteem, and lower levels of depression.


How to Tell

- “Floating balloons.”
- What is expected response?
- How does actual response impact further disclosure?
- How will you float balloons with someone you want to disclose to?

Can Meds Replace Disclosure?

- Reducing viral load does seem to lower—but not remove—chances of passing HIV.
- (Not based on Uganda study—untreated).
- Odds reduced +/- 53%, 60%, or 81%.

- Warnings: sometimes “viral disconnect.”
- Also, 9-in-10 have occasional viral spikes.

The Serostatus Solution?

- HIV+ guys now having fewer known HIV- partners.
- “Serosorting” esp popular on Internet.
- May help contain new HIV infections. But depends on knowing status and being honest when negotiating encounters.
- Also, not without health risks to PLWH.
Both HIV+ = No Big Deal?

- U of CA: 78 PLWH blood samples tested 2x, average 9.5 months apart.
- 3 same clade superinfections occurred (re: analysis of the pol gene from 15-20 clones).
- All got ↑ viral load (1.6 log) and ↓ CD4+ cell count (-13c !). Only 1 non resistant acquired 3TC-resistance.
- If representative, could impact 5% of PLWH each year!

No Secrets = Better Adherence

- Study of Canadian patients who started HIV treatment between 1996 and 1999.
- Checked adherence (pill counts and prescription refills); followed up in 2000.
- Patients who had taken ≥ 75% of their meds during their 1st year were 2.97x MORE likely to live at follow up.

Disclosure: Planning for Long Life

- Taking today’s HAART regimens slow progression to AIDS by 86%!
- Those who can manage their treatment without interruption can expect to stay on the same regimen for 20 years without viral rebound.

Mental Health Outcomes >

- Disclosure was associated with social support...
- The causal direction is not clear; it is possible that the relationship between social support and disclosure is bidirectional. Those who disclose may elicit more support, and those with more supportive networks may disclose more.**

<table>
<thead>
<tr>
<th>Table 1. Perceived General and Pratitudinal Consequences of Disclosure (N = 301)</th>
</tr>
</thead>
<tbody>
<tr>
<td>As a result of telling others that I am HIV-positive</td>
</tr>
<tr>
<td>I can openly do things to preserve my health</td>
</tr>
<tr>
<td>I feel free of a burden, more relieved, relieved</td>
</tr>
<tr>
<td>I became involved in HIV/AIDS-related activities</td>
</tr>
<tr>
<td>I feel less lonely then before</td>
</tr>
<tr>
<td>People now assume that I'm gay</td>
</tr>
<tr>
<td>I have been rejected by potential sex partners</td>
</tr>
<tr>
<td>Once they know I'm seropositive</td>
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<tr>
<td>Some people seem afraid of catching HIV from me</td>
</tr>
<tr>
<td>The possibility of staying in this country is not in danger</td>
</tr>
<tr>
<td>I have been insulted or threatened by others</td>
</tr>
</tbody>
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Coping Skills Add Years

- Disease is not just dis-ease. But peace of mind does help.
- 773 PLWH women, ages 16-55, semi-annual checks, 4 cities, 5 years.
- HIV progression (CD4 losses) and death lower if “psychological resources,” i.e.
  1. Positive affect
  2. Positive expectation of health
  3. Ability to find meaning in illness.
- Resources were better predictor than was viral load, symptoms, current treatment, age, race. Significant negative predictor was depression (p<.05), beneficial predictor was resources (p<.01).


Looking Within: Motives for Telling

- What would be a bad reason for disclosing?
  - Purging.
  - Blaming.
  - Handing off.
  - Trapping with guilt.

Looking Out: What Will They Feel?

- Does the person you want to tell have the resources to cope with the changes this means to both of you?
- Does s/he understand what HIV status means?
- Will s/he be in your life for the long term or just for awhile?
- Who can that person turn to when feeling overwhelmed?
Be Your Own Hero

- Living openly may bring new peace of mind.
- But random disclosure can backfire.
- Take the time to make the best choice for you.

- Disclosure does not have a deadline … unless you are putting yourself or another at risk.
- Then, if you can’t disclose just yet, take other steps to protect.
- Don’t go through this alone. Talk to others who have disclosed, and to professionals who can help you prepare and cope.

Thank You for Making a Difference!

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