Sex and secrecy: Disclosure to intimate partners among YPLWH

Linda-Gail Bekker
The Desmond Tutu HIV Centre
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Adolescents (10 – 19) Living with HIV

2.1 million [1.6 million – 2.6 million] of whom 60% are girls (2011)

Note: The map is stylized and not to scale. It does not reflect a position on the part of UNICEF on the legal status of any country or territory or the delimitation of any frontiers.

Source:
- Country data: UNAIDS 2009 estimates
Two populations-

**Perinatally infected youth, pHIVa**
- F=M
- Younger
- Developmental stunting
- >treatment experienced
- Unaware of status
- Transitioned ex Paediatric Care
- Transition into Adult Care

**Sexual and IDU Transmission, bHIVa**
- F > M in Africa
- M>F elsewhere
- Older
- Treatment naïve
- Aware of status
- Transition into adult care
New HIV Infections in Adolescents in 20 Countries with Highest Number of New HIV Infections, 2012

Source: UNAIDS 2012 HIV and AIDS estimates
36% are slow-progressors with median survival = 16.0 years.

Adolescents (10-19yo) living with HIV: South Africa.

Leigh Johnson 2013
Adolescents with chronic disease...

- Developmental delays
  - Psychosocial, emotional, physical
- More social isolation, suicide and depression
- More likely to take risks that impact health
- Poor adherence to have greater impact
- Concerns about body image overshadowed/exaggerated
- Feelings of isolation when all adult focus on condition.

Additional issues with HIV infection.

- Cognitive, physical, emotional delays
- Parental loss, family sickness.
- Increased perceptions of stigma and discrimination
- Issues with disclosure to HCW, partners, others
- Issues with sexuality, fertility intent.
Positive youth

• Take treatment, be retained and virally suppressed- for the next 50 years.
• Sexually active?
• Safer Sex
  – Condoms all the time
  – No casual partners
  – Partner testing
  – Partner disclosure
  – Safer conception
Disclosures: a tough rap

WHO: 
Process As soon as able to grasp

Parents Other significant family

pHIV

bHIV

May often be linked to other concealments, Eg. MSM, IDU

??

Partners Others others

Partners
A NARRATIVE : Thanda (16yo)

• Thanda met her boyfriend at church, exchanged some messages over social media and have been dating for 2 months.
• She considered it too early in the relationship to disclose her status.
• In addition, since they were both from a “moral community” where premarital sex is frowned upon, Thanda feared being exposed and stigmatised.
• Whilst pre-marital sex was one thing, Thanda considered her HIV status a marker of deeper immorality.
• Since she was using the injectable contraceptive and felt she wasn’t at risk of pregnancy, she concealed her HIV status, prioritising the pleasure of sexual and romantic intimacy and avoiding rejection, exposure and ostracism she feared HIV disclosure could bring.

(16yo F; Eastern Cape)
Disclosure

Is a critical aspect of the experience of people who live with concealable, stigmatised identities.

Self-disclosure is the sharing of personal information by verbal communication.

Chaudoir S, Fischer J: Psychol Bull 2010 136(2);236-256
Benefits of disclosure


• Better relationships
  » Rochat T, et al 2013

• More likely to get ART and join support group
  » Mitbe T et al 2012

• May improve adherence to ART, retention, survival
  » Blasini 2004; Arive 2012; Ferris 2007

• May boost self esteem and cope better with stigma
  » AAP1999; Mditibi 2012

• May increase feeling of cohesion and support
  » Hosek, et al 2000

• May improve coping abilities and autonomy
  » Mburu 2013

• May adopt safer sex practices
  » Fair 2012; Marques 2006.
Laws and mandatory disclosure

• 2011, a total of 67 laws that focus on PLWH had been enacted in 33 states.
• In 24 states, laws require persons who are aware that they have HIV to disclose their status to sexual partners.
• 25 states criminalize one or more behaviors that pose a low or negligible risk for HIV transmission.
None of them has been accused of transmitting HIV.

IOWA - Nick Rhoades used a condom, had an undetectable viral load and was sentenced to 25 years for non-disclosure. The judge reconsidered the sentence and released him after a year, but he must register as a sex offender for the rest of his life.

IDAHO - Kerry Thomas used a condom, had an undetectable viral load and is now serving a 30 year sentence for non-disclosure.

LOUISIANA - After a contentious breakup, Robert Suttle’s former partner accused him of not having initially disclosed. He served 6 months and must register as a sex offender for 15 years. He is Sero Project’s Assistant Director.

ARKANSAS - Mark Hunter used a condom, had an undetectable viral load and served two and a half years for non-disclosure.

SOUTH CAROLINA - Monique Moree had an undetectable viral load and told her partner to use a condom. She faced up to 10 years, but the U.S. Army ultimately dropped the charges.

TEXAS - A man (name withheld) is serving 35 years for spitting at a police officer.

NEW YORK - When a judge ruled that his saliva was ‘a dangerous instrument’, David Plunkett was sentenced to 10 years for assault and served 6 before being released after winning his appeal.

**Used condom, suppressed VL.** Sentenced to 25 yrs

**Used condom, suppressed VL.** Sentenced to 30 yrs

**Accused of non-disclosure after break up-6 mnths**

**Condom + Viral suppression: 2.5 years.**

**Suppressed VL, told partner to use a condom**
On the down side

- Associated with at least short term anxiety
- May result in MORE risky behaviours
- A bad experience may lead to greater fears and isolation
- Can lead to increased stigma and discrimination
- Disclosure to intimate partners- the most difficult

I have a boyfriend now but it isn't sexual. He doesn't know my status. I'm scared of telling him because he might leave. (Zambian 19 yo)

I only disclosed my status to one of my boyfriends. He understood me because we never had sex. When he started asking for sex we broke up. (Cape Town 18yo)

My (HIV) didn't affect anything in my health but in my relationship, it's not easy for me to tell someone I'm dating that I'm HIV. ... But if I'm dating that person I am using protection.. I'm scared like, of disclosing to my boyfriend about my status and then he runs away or makes fun about it (CT 19yo)
How are adults doing?

• Study of 630 adults in 5 ART clinics in Cape town (8% : 18-24 yrs)
• 1/5 had not disclosed status to intimate partner
• 1/2 didn’t know partner’s status
• 1/4 didn’t use a condom at last sex
  – Younger people less likely to disclose
  – Partner HIV status, stability of partnership, low perception of stigma: strongly associated with disclosure

Vu L, et al; AIDS Behav 2012; 16:132
Sex and Secrecy: How HIV status disclosure affects safe sex.

- 858 positive youth (10-19) from 41 ART clinics Eastern Cape (52% F; 68% pHIV)
- 68% knew their own status
- 15% had ever had sex (85% had current partner)
  - 41% knew partner status; 35% disclosed
- Knowing own status associated with safe sex
- Neither knowing partner’s status nor disclosure to partners were associated with safer sex.
  - Adolescents feared rejection, stigma and public exposure
  - HCW counseling focused on benefits of disclosure but didn’t address these fears nor impart any skills.
HCW attitudes

• She [counselor] doesn’t tell you about having goals, you can get married, you can be in love, you can have other children in future . . . she’s insisting that you’re HIV-infected and there are things that you cannot do, and if you want other things then you look like a stupid person. (YW, focus group)

• . . . there are [doctors] who put pressure on you [to disclose] You must not be forced . . . After you have disclosed you live a life of persecution . . . Everything that you do is being noted. (YM, focus group)
Lit review: Reproductive Health behaviours of young US women

Carter MW, et al AIDS Patient Care 2013

- 32 articles 2001-2012
- Substantial proportions of YW+ were sexually active
- Most sought sexual or romantic involvement
- Disclosure was difficult and most (50-80%) had not done so
  - "a major hurdle and a major concern" Leonard AD, 2010
- Most YW hoped to have children but many wanted to avoid pregnancy until later
- Condoms were a primary method of contraception
In 5 studies

• Disclosure to sex partners was positively associated with
  – The partner being main
  – The partner confirmed or believed to be positive
  – A greater number of sex acts
  – A longer time of known HIV diagnosis
  – Disclosure to family and/or friends

• Disclosure was negatively associated with
  – High number of partners
  – Partner being negative or of unknown status
  – Youth

Carter MW, et al AIDS Patient Care 2013
The Disclosure Processes Model

Chaudoir S, Fischer J: Psychol Bull 2010 136(2);236-256

Decision making process

Antecedant Goals

Approach Focused
- Pursue + outcomes
- Attend to + cues
- Approach coping

Avoidance Focused
- Pursue neg outcomes
- Attend to neg cues
- Negative affect

Outcome Process

Mediating Process
- Alleviation of inhibitors
- Social support
- Changes in social information

Disclosure event

Content

Reaction of Confidant

Long term outcomes

Individual

Dyadic

Social and external

Upward spiral toward visibility

Vs Downward spiral towards concealment
• Group Intervention to engage newly diagnosed youth
  • Conducted interviews & focus groups
  • Identified key messages/outcomes for new groups
  • Modified CBI tools to suit youth
  • Held practice sessions

General opinion of experts interviewed: “This is needed but it won’t work.”
Feasibility Pilot Study
[March to December 2010]

• Inclusion criteria: ages 16-24, HIV dx within year

• Three group sessions led by lay facilitators:
  1) Coping & Support: ‘5 Ws to TELLING’
  2) HIV Health (focus on CD4)
  3) Positive Prevention/Sexuality “SAFE SEX”

• Held in variety of venues: clinics, libraries, youth centres
Our 10 tips: Then practice!

1. Be selective.
2. Consider the five "W's" when thinking about disclosure: who, what, when, where and why.
3. Easy does it. In most situations, you can take your time to consider who to tell and how to tell them.
4. Consider whether there is a real purpose for you to tell this person.
5. Telling people indiscriminately may affect your life in ways you haven't considered.
6. Having feelings of uncertainty is a very common reaction.
7. Keep it simple.
8. Avoid isolating yourself.
9. Even if the response you receive in a specific situation, doesn't go the way you'd hoped, you're going to survive it and your life will go on.
10. Millions of others have dealt with this experience and have found their way through it. You will get through it too.
Hannan Crusaid,
Gugulethu
Hlanganani HCT model

Based on Hlanganani LTC Program.

- **10-12 years**
  - Disclosure
  - HIV information
  - Family support
  - Transportation

- **13-15 years**
  - Adherence to medication
  - Adherence to Program

- **16-18 years**
  - Sexual health
  - Preventive health
  - Positive prevention
  - Family planning

- **19-22 years**
  - Vocation/career
  - Independent living

**Paediatric Service**

**ADULT CLUBS**

**YOUTH ADHERENCE CLUBS**

- Theory: Safe Social spaces and social capital
- Monthly
- Group based
- Trained Lay Facilitator led
- Interactive

**ADDITIVE MODULES**
Direct referral to ART services

Referral to Hlanganani Plus Adherence clubs

Viral suppression, retention in care, contraception, condom use.

Ingrid Katz, Philip, Elzette
Some recommendations:

• EVERY YPLWH NEEDS TO KNOW THEIR OWN DIAGNOSIS
• Every YPLWH needs **appropriate safer sex** information
• Every YPLWH needs **access** to adolescent friendly (non prejudicial, confidential) SRHs including condoms, lube, contraception, safer conception, etc
• **Skills** on disclosure need to be learned and practiced through role play, etc. (practice content)
• Frank information (antecedant) on **pros** (approach) and **cons** (avoidance) of disclosure should be shared
• First disclosure should be “low hanging fruit” to ensure good outcome (ensure good confidant reaction)
  – Ensure positive feedback loop with resulting positive outcomes.
The Disclosure Processes Model

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**Antecedent Goals**
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  - Pursue neg outcomes
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  - Negative affect

**Disclosure event**
- **Content**
- **Reaction of Confidant**

**Mediating Process**
- Alleviation of inhibitors
- Social support
- Changes in social information

**Long term outcomes**
- Individual
- Dyadic
- Social and external

**Upward spiral toward visibility**
Hope for the future....

“These pills can help me. I will finish school.”
(14yo F).

“I will finish school and find work”
(11yo M).

“I want to marry and have children” (13yo F).

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