

Qualitative Comparison of Disclosure Between Perinatally and Behaviorally HIV-infected Adolescents

Idia B. Thurston, PhD;

Laura M. Bogart, PhD; Errol L. Fields, MD, PhD, MPH;

Caroline Hu, BA; Margie R. Skeer, ScD, MPH, MSW;

Elizabeth F. Closson, MSc; Steven A. Safren, PhD;

Matthew J. Mimiaga, ScD, MPH



Boston Children's Hospital



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

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Adherence & Disclosure

- Estimated adherence rate in HIV-infected youth: 28-69%
- Disclosure is related to adherence
 - Disclosure can be beneficial for HIV treatment adherence
 - Disclosure can also lead to negative consequences



Study Aims

- To conduct formative qualitative research to explore barriers to antiretroviral adherence in youth
- To examine disclosure patterns and adherence based on mode of infection
 - Perinatal vs. behavioral

Methods: Participants

- 30 adolescents and young adults
- Recruited from Aug 2010-Jun 2011 during outpatient clinic visits at a hospital and community health center in Boston
- Eligibility criteria:
 - HIV-positive
 - 13-24 years old
 - Prescribed/recommended ARVs in the past 6 months

Methods: Procedures

- Semi-structured interviews (45-90min) covering disclosure and adherence barriers
- Thematic analysis of transcripts
- Transcripts double-coded with excellent reliability
 - $Kappas >0.77$
- Compared disclosure codes by mode of infection



Results: Socio-demographics

- 30 HIV-infected youth
 - Mean Age = 20.2 years old (SD = 2.6, range 14-24)
 - Male (53%), Female (40%), Transgender (7%)
 - Straight (57%), Gay (23%), Bisexual (7%), Other (13%)
 - Black (50%), White (20%), Other (30%)
 - Latino (37%)
 - Perinatally-infected (60%)

Results: Disclosure Experience



Themes Consistent Among Perinatally and Behaviorally-Infected Youth

- At least one family member aware of diagnosis
 - Usually mothers; sometimes siblings, grandparents
- Concern about whom to disclose HIV status
 - Worries about who they could trust
- Expressed need for privacy
- Ambivalence about disclosure

Expressed Need for Privacy

It's not discussed really... It's not a shame factor, it's just its my business. Unless you need to know, you don't need to know.

24-year-old Female-to-Male
Transgender (behaviorally)

Ambivalence about Disclosure

I want to tell [my friends] but at the same time I don't want to tell them...I feel like people should know but then at the same time people get discouraged from it.
People don't like people that have it.

19-year-old Female
(perinatally)

Themes by Mode of Infection

Perinatally-Infected Youth

- Limited disclosers
- Indirect disclosure
- Early disclosure
- Silence due to parental HIV

Behaviorally-Infected Youth

- Both full & limited disclosers
- Disclosed to a variety of people
- Maintained contact after disclosure
- Desired sense of self separate from HIV

Silence due to Parental HIV

My father didn't want people knowing about my status, so it was better to just keep it hidden... we never really had any conversations about [HIV]...It was basically just take your medication and don't talk about it.

24-year-old Female
(perinatally)

Sense of Self Distinct from HIV

I just don't feel as though [my other friends] should know.
Like not that I don't trust them, I just...it's not me. It's
something I have but it doesn't make me, me.

24-year-old Male (behaviorally)

Results: Disclosure → Adherence



Fear of Discovery

There's always that paranoia...of you know, what if they stumble through my bag or what if they see me taking meds...even if I bring them with me to a place, I might not necessarily take them because there are too many people around.

20-year-old Female
(perinatally)

Disclosure Promoting Adherence

If I'm gonna take [my medications] consistently, if I'm gonna stay on track with it, it needs to be front and center. Not hidden away where people can't see

23-year-old Male-to-Female
transgender (behaviorally)

Disclosure Without Consent

One of my family members...ended up telling everybody that I know...about [my HIV]. It kind of made me feel like I didn't want to take [my medications] anymore.

17-year-old Male (perinatally)

Social Support

The first time I took [my meds] I didn't know what the actual side effects were. So I kinda got scared. One of my friends, thank God, her brother knows, well has HIV and knows what I'm going through. She helped me...She said, "...if you ever feel sad or scared"...to go talk to her.

20-year-old Male
(behaviorally)

Summary of Findings

- Perinatally and behaviorally-infected youth differ in disclosure experiences
 - Limited vs. mixed disclosers
 - Behavioral- want a sense of self separate from HIV
 - Perinatal- have little experience disclosing status
- Link between disclosure and adherence
 - Openness and social support promote adherence
 - Fear of discovery and disclosure without consent discourages adherence

Implications for Intervention

- Limited by small sample
- Ambivalence about disclosure may be addressed using Motivational Interviewing
- Given limited experience, perinatally-infected youth need to be taught how to disclose
- Address adolescent developmental needs for privacy, identity, and social support by teaching problem-solving

Acknowledgments

- **Sources of support:** Harvard Center for AIDS Research P30AI060354; Children's Hospital Boston Division of Adolescent/Young Adult Medicine & MCH/HRSA LEAH T71 MC00009; NIMH 3R34MH090790-02S1.
- **Research staff:** Jessica Ratner, BA and Madeline Wachman, BA
- **Community Partners:** Sidney Borum Health Center, Fenway Community Health Center, Boston HAPPENS and Children's Hospital AIDS Program



THANK YOU

QUESTIONS?

Idia B. Thurston, Ph.D.

Idia.thurston@childrens.harvard.edu

Demographics by Mode of Infection

	Perinatally Infected: 18 (60) N (%)	Behaviorally Infected: 12 (40) N (%)
Age	Range: 14-24 years Mean: 19 years (SD = 3)	Range: 17-24 years Mean: 23 years (SD = 2)
Gender	Male: 6 (33) Female: 12 (67) Transgender: 0 (0)	Male: 10 (83) Female: 0 (0) Transgender: 2 (17)
Race	Black: 10 (55) White: 1 (6) Other*: 7 (39)	Black: 3 (25) White: 5 (42) Other*: 4 (33)
Ethnicity	Latino: 2 (13)	Latino: 3 (25)
Sexual Identity	Gay, Bi, Other: 2 (11) Straight: 16 (89)	Gay, Bi, Other: 11 (92) Straight: 1 (8)
Education	Middle School: 1 (6) High School: 10 (55) College: 7 (39)	Middle School: 0 (0) High School: 5 (42) College: 7 (58)