



Experiences Seeking Health Care Among Transgender Adults and Youth

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**Issues in Medical Ethics
Mount Sinai Icahn School of Medicine
November 17, 2017**

Topics

- Health Disparities and Barriers to Healthcare Among Transgender People
- Facilitators and Barriers to Affirming Sexual Health Care for Transgender Youth
- Gender Affirming Training for Health Care Professionals

Health Disparities

Transgender people in US suffer from higher rates of:

- Depression, social anxiety and other affective disorders
- Substance abuse
- Poverty and homelessness leading to less access to care

Additional health disparities

- Exogenous hormones that increase risk of cardiovascular disease, but absence of research on these drug-drug interactions
- Transmasculine people should be screened for cervical cancer and possibly breast cancer—but many feel stigmatized in OBGYN office

Health Disparities Do Not Occur in Isolation

- Discrimination and Social Marginalization have a weathering effect on the health of transgender people



Public Accommodations Discrimination and Health

2013 survey transgender MA residents n=455 (S. Cahill, 2017)

- 65% report public accommodations discrimination past year
 - Transportation 36%, retail 28%, restaurants 26%, public gatherings 25%, healthcare 24%.
- Public accommodations discrimination associated with 2-fold increased risk of adverse physical and emotional symptoms in past 30 days.

Hate Violence and Health

Anti-transgender assaults are often the most violent anti-LGBT hate crimes

- Half of the 25 LGBT people killed in hate homicides in 2012 were transgender
- Transgender people 2.5x more likely than LGB to experience physical violence at hands of police
- **Only 15 states and District of Columbia include gender identity in state hate crime laws**

Source: National Coalition of Anti-Violence Programs 2012 report
(National Gay & Lesbian Task Force. Source: National Coalition of Anti-Violence Programs 2012 report)

Social Victimization and Mental Health

2015 Transgender Survey: www.ustranssurvey.org

- 46% reported verbal harassment in past year
- 9% reported being physically attacked past yr
- 39% reported serious psychological distress in past month (vs. 5% of US population)
- Nine times lifetime attempted suicide rate compared to general population (40% vs. 4.6%)

Barriers in Access to Care

2010 Lambda Legal report

70% of transgender patients nationwide reported discrimination in health care

- Ex: rough physical treatment, abusive language, refusal of services, etc.

Many did not subsequently seek routine & emergency care

Lack of Adequate Health Services

2015 US Transgender Survey

- 33% experienced mistreatment in health care past year
- 23% did not see a doctor in the past year due to fear of experiencing mistreatment
- 33% did not see a doctor because they could not afford it, did not have insurance
- *Half of transgender people said they had to teach their provider about transgender health care issues*

Best Practices for Transgender Affirming Care

National LGBT Health Education Center

- When addressing patients, avoid using gender terms like “sir” or “ma’am”
- Ask respectfully if name does not match health records e.g. “Could your chart be under a different name?”
- Politely ask if you are unsure about a patient’s pronoun or use gender neutral terms such as “they”
- Politely apologize if you feel you have used the wrong pronoun
- Only ask information required

Sexual Health Care for Transgender Youth: Barriers & Facilitators

HIV TESTING DAY APRIL 18, 2016

A NATIONAL HIV/AIDS TESTING AND COMMUNITY MOBILIZATION INITIATIVE
ENGAGING THE TRANSGENDER COMMUNITY.

JOIN US FOR A DAY OF COMMUNITY BUILDING, ORGANIZING, AND EMPOWERMENT.
GET TESTED AND KNOW YOUR HIV STATUS.

PRESENTED BY



COMMUNITY PARTNERS

THE SF LGBT
CENTER

FRESH MEAT

EVENT DETAILS

MONDAY, APRIL 18, 2016

FREE & CONFIDENTIAL HIV TESTING

10:00AM- 5:30PM

Empower yourself to know your HIV Status.
You may qualify to receive a \$20 Visa Gift Card.
NO appointments needed. Drop-ins are welcome.

MISS TRANSFORMSF
EMPOWERMENT PAGEANT &

HIV Infection Among Transgender People

CDC: 2009- 2014

- HIV diagnosis of transgender people more than 3 times national average.
- 22% of transfeminine people in the US living with HIV.
- HIV prevalence rates of transgender adolescents and young adults range from 5% - 22%.
- STIs prevalence rates range 1.4% - 2.8%.
- Of the 2,351 HIV seropositive transgender people in CDC report:
 - 84% transgender women;
 - 15% transgender men.
- Transgender people report significantly lower rates of HIV testing relative to cisgender gay and bisexual men.

HIV Risk Factors

- Family rejection
- Dual SGM status related stigma
- Lack of sexual health knowledge relevant to their needs
- Insensitivity and gender bias in healthcare settings
- Injecting hormones with shared needles in absence of prescriptions
- Reject PrEP out of unsupported concerns regarding interaction of medication with PBT and GHT
- To date, little is known on whether transgender adolescents experience similar challenges.

Under-Representation in HIV Prevention Research

- TF persons often grouped with and under-represented in studies of cisgender MSM
- TM persons excluded on erroneous assumption sexual relations are with cisgender females
- Adolescent recruitment challenges because of fear guardian permission requirements will out them to parents

Sexual Orientation

- Transgender adults and adolescents endorse multiple sexual orientation identities
- Youth may be reluctant to discuss sexual health needs because of concerns about both gender and sexual orientation anticipated stigma and healthcare discrimination.
- The intersection of sexual orientation and gender identity may challenge primary care providers in knowing what questions to ask to best inform HIV/STI prevention strategies

Parental Disclosure Barriers

- Majority of states permit HIV testing without guardian permission
- Although no states expressly prohibit HIV preventive care to minors -- state laws are inconsistent in expressly permitting youth independent access to HIV/STI prevention services and treatment.
- Even when such laws exist, youth, parents and providers may be unaware of or in disagreement about minors' right to confidential services.
- Or as in NYS it is up to provider discretion to decide if youth can independently provide consent

Importance of Patient-Provider Communication

- For many TGY, a family doctor may be the primary means of receiving informed HIV/STI preventive information and care.
- However, many pediatricians and general practitioners are not trained in discussing sexual health needs with TGY.
- Fear of outing gender identity, sexual orientation or sexual activity to parents is another concern, *especially in light of family health coverage and guardian access to health care records.*

Studying the Sexual Healthcare Experiences and Attitudes of Transgender Youth

- **Investigators:** Celia B. Fisher, Adam L. Fried, Margaret Desmond, Kathryn Macapagal, and Brian Mustanski
- **Funding:** NIMHD R01MD009561-01 PI's: Celia B. Fisher & Brian Mustanski



Study Questions

- Is TGY anticipation of sexual and gender discrimination a barrier to patient-provider communication?
- Is mistrust in confidentiality protections a barrier to patient-provider sexual health communications?
- What demographic and family variables are associated with receipt of affirming sexual health care?

Recruitment

- 14 – 21 year old transgender youth; attraction or sexual experience with cisgender males.
- Facebook posts specifically targeted to TGY
- **"Trans teens -- let your voice be heard! Earn \$20 in a study on trans health."**



Online Support for All Teens

- Youth not meeting criteria and all who completed the questionnaire were provided with links to support websites including RELAY Facebook page.



TGY Affirming Survey Language

- Focus groups and Interviews with TGY
- Expert panel
- Resources (Fenway Health, 2010)
- Began with “What is your preferred pronoun?”
- Inclusion of both open-ended and checklist items describing TG and SO identity
- TG respectful terms for sexual contact

Demographics

- First ID as transgender M = 13 (SD = 3.85)
- 30% TF and TM received GHT
- Mean # lifetime sex partners = 5
- Majority (77%) had disclosed gender and/or sexual orientation to parents
- But only 30% had parents who were accepting

Sexual Orientation

- Many youth endorsed non-traditional and multiple sexual orientations
- Few differences among TM, TF*, and GNB** youth

49 % Pansexual

39% Queer**

25% Bisexual

20% Gay

12% Heterosexual

10% Lesbian*

SGM Invisibility and Stigma

- **66%** of TGY indicated their primary provider was **unaware of their gender identity**
- **60%** reported their primary provider **believed they were heterosexual**
- **49%** *“I not discuss my transgender identity with my doctor because I worry or know my doctor will not be accepting of my gender identity.”*
- **42%** *“I not discuss my sexual orientation with my doctor because I worry or know my doctor will not be accepting of my sexual orientation.”*
- **Youth who had received GHT and were out to at least one parent about gender or sexual orientation were more likely to share such information with providers**

Parental Disclosure Concerns

- Over **25%** of youth did not ask their doctor for HIV/STI information because of fear the doctor will disclose:
 - Gender identity
 - Sexual Orientation
 - Sexual activity
 - STIs
- Younger youth and those who had not disclosed gender identity or sexual orientation to parents had significantly more confidentiality concerns.

Affirming Care

When I go for a medical checkup, my regular pediatrician or family doctor is helpful about sexual health issues specifically for...

22% Transgender People

21% LGB People

Youth who received GHT reported significantly higher levels of affirming care.

What Does this All Mean?

Majority of youth are not receiving HIV/STI prevention services relevant to their gender identity and sexual orientation.

Barriers to Patient-Provider Sexual Health Communications include:

- Anticipation that primary physician will have negative attitudes toward youth's transgender and sexual identities
- Distrust in the patient-physician confidentiality obligations
- Providers do not ask questions about gender identity or sexual orientation

To date, there are no evidence-based HIV prevention treatments for TGY...



HIV



The Ethical Challenge

- CDC recommends pre-exposure prophylaxis (PrEP) for high-risk populations to prevent HIV infection.
- YMSM, bisexual women and transgender youth 13 - 24 comprise majority of new HIV diagnoses.
- Despite funding, recruitment of TGY has been inadequate to generate sufficient sample sizes.

Guardian Permission as a Barrier to Research Participation

Perceived youth consent vulnerability



- Guardian permission



- Low recruitment



- Smaller unrepresentative samples skewing findings



- Lack of evidence-based HIV prevention programs for TGY

Justice: Fair Access

- **Without youth involvement in research, evidence-based, developmentally appropriate PrEP interventions will continue to be unavailable to TGY**

Interpretation of Mature Minor Laws

- Most state mature minor laws permit youth independent access to HIV testing and treatment (Culp & Cauci, 2013).
- Some, like NYS, permit youth independent access to PrEP if a physician determines their consent competence.
- Despite OHRP approval, some IRBs are reluctant to recognize youth “adult” status under federal regulations because the mature minor statutes do not specifically mention “research.”

Fisher, C. B. & Mustanski, B. (2014). Reducing health disparities and enhancing the responsible conduct of research involving LGBT youth. *Hastings Center Report*, 5, 28-31.

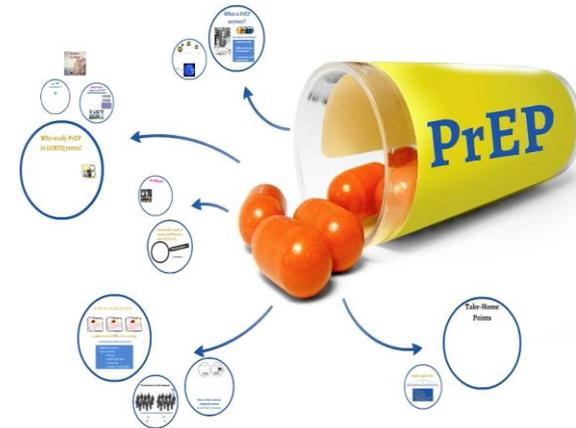
Failure to Identify Guardian Permission Risks

- “When guardian permission is not a reasonable requirement to protect the subjects (e.g. neglected or abused children)”
- For many SGMY, guardian permission may not be a reasonable requirement because it “outs” youth in ways that are harmful to their well-being.
- **For these youth, GP is not a “reasonable protection.”**

Guardian Waiver For PrEP Adherence Study

Participants: 68 sexually active 14 – 17 year old transgender males & females

Method: Provided descriptions of an HIV prevention study on adherence to PrEP daily pills and responded to web-based survey questions



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Fisher, C. B., Fried, A. L., Desmond, M., Macapagal, K., & Mustanski, B. (2017). Facilitators and Barriers to Participation in PrEP HIV Prevention Trials Involving Adolescent and Emerging Adult Transgender Men and Women. *AIDS Education and Prevention*, 29(3), 205-217.

Would you Participate in a PrEP Study if Guardian Permission is Required?

48% of transgender youth ages 14-17 would NOT participate in an HIV prevention study if guardian permission was required



- Simply being OUT to parents did not ease concerns.
- Only those whose parents were “accepting” of their transgender identity were more likely to feel positive about guardian permission.

Justice: Fair Access

- For many transgender youth guardian permission is not a protection against research risks *and* it is a significant barrier to participation in HIV prevention research.
- Adolescents have the ability to provide an informed choice *if informed consent is tailored to their abilities and support their needs.* (Fisher et al., 2016)
- As IRBs and providers seek to protect the rights and welfare of transgender youth – we need to re-conceptualize **independent access to HIV prevention trials and care as a critical health care right that requires protections against research exclusion.**

From Research To Practice

Tying it All Together

Rigid requirements for guardian permission



Absence of evidence –based, developmentally appropriate HIV/STI prevention strategies for TGY



Practitioner training will continue to lack the knowledge and skills to provide TGY with developmentally appropriate sexual health care.



Sustaining sexual health disparities among transgender youth

Training for Primary Care Providers of Transgender Adolescents & Young Adults: What we Know

- Avoid assuming patients are cisgender or heterosexual.
- Recognize and correct implicit or explicit personal and institutional biases.
- Recognize that traditional gender and sexual labels may not apply to TGY
- Develop TGY affirming skills in asking questions regarding gender identity, sexual behaviors and sexual partners relevant to HIV/STI risk.
- Become knowledgeable about and be able to deliver adequate services to increase safe sexual practices among TGY.
- Directly discuss with TGY their commitment to patient confidentiality rights

Acknowledgements

- NIMHD #RO1MD009561 (PI Fisher & Mustanski)
- Our colleagues Kathryn Macapagal, Adam Fried and Margaret Desmond
- Lienne Harrington and Leah Puri for assistance with formatting
- Our Scientific Expert Panel and Youth Advisory Board
- All the youth who generously responded to our surveys
- Pioneering investigators

Questions/Further Discussion

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