HIV Epidemiology, LGBT Health Disparities: Implications for Clinical Practice

April 23, 2013

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Funding: The New England AIDS Education and Training Center (NEAETC), established in 1988, is one of eleven Regional AIDS Education and Training Centers (AETC), and five National Centers, funded by Health Resources Service Administration (HRSA) with Ryan White Part F dollars and sponsored regionally by Commonwealth Medicine at the University of Massachusetts Medical School through a grant from the Health Resources & Services Administration, Federal Grant No. H4AHA00050.
Continuing Medical Education Disclosure

Program Faculty: Harvey J Makadon, MD  
Current Position: Director, the National LGBT Health Education Center, Clinical Professor of Medicine, Harvard Medical School.  
Disclosure: No relevant financial relationships. Content of presentation contains no use of unlabeled and/or investigational uses of products.

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HIV/AIDS in the United States
HIV/AIDS in the United States

- Approximately 1.2 million people are living with HIV.

- Nearly 600,000 people have died of AIDS since the beginning of the epidemic.

- There are ~50,000 new cases of HIV diagnosed every year.

CDC, 2012
HIV Incidence and Prevalence in Comparison to the US Population, by Race/Ethnicity

* According to 2010 US Census and CDC Data
HIV Incidence by Race/Ethnicity, US, 2010

- White: 31%
- Black/African American: 44%
- Hispanic/Latino: 21%
- Native Hawaiian/Other Pacific Islander: <1%
- Multiple Races: 2%
- Asian: 2%
- American Indian/Alaskan Native: <1%
HIV Incidence by Transmission Category, United States, 2010

- Male-to-Male Sexual Contact (MSM): 63%
- Heterosexual Contact: 26%
- Injection Drug Use (IDU): 8%
- MSM/IDU: 3%
- Other: <1%

Overall, male-to-male sexual contact is the primary mode of HIV transmission, followed by heterosexual contact.
HIV Incidence in the United States, 2006-2010

- = Incidence among MSM and MSM/IDU
  ▲ = Incidence among Black MSM 13-24. (Increased 60% from 2006-2010)

Thousands of people

2006: 60%
2007: 61%
2008: 59%
2009: 64%
2010: 66%
Why is HIV incidence highest among black MSM?

- Sexual risk behaviors and substance use do not explain the differences in HIV infection between black and white MSM.
- The most likely causes of disproportionate HIV infection rates are:
  - Barriers to access health care
  - Low frequency of recent HIV testing
  - High HIV prevalence in black MSM networks
  - High prevalence of other STI’s which facilitate HIV transmission
# New England Data: Incidence by State

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<tr>
<th>State</th>
<th>Year/Range</th>
<th>MSM</th>
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**51.3%**

HIV epidemiology: Transgender Women

- Transgender women have HIV prevalence rates as high as or higher than other high-risk populations in the U.S.
  - Meta-analysis of 29 studies
  - >25% laboratory-confirmed HIV seropositive

- Racial/Ethnic disparities
  - Black/African American trans women
  - > 50% laboratory-confirmed HIV seroprevalence

- High rates of unrecognized HIV infection (>10%), with the largest percentage among young transgender women ages 29 and younger

Herbst et al., 2008; Schulden et al., 2008
Data Suggests Bringing an End to HIV/AIDS will Require new Focus on Gay and Bisexual Men, and Transgender Women
Why LGBT Health?

Bias in Health Care

Stigma and Discrimination

Social Determinants

Health Care Disparities
Health Disparities Exist Across the Life Cycle
LGBT Disparities: Healthy People 2020

- LGBT youth
  - 2 to 3 times more likely to attempt suicide.
  - More likely to be homeless (20-40% are LGBT)
- LGBT populations have the highest rates of tobacco, alcohol, and other drug use
- Gay men are at higher risk of HIV/STDs, especially among communities of color.
- Lesbians are less likely to get preventive services for cancer.
LGBT Disparities: Healthy People 2020

- Transgender individuals experience a high prevalence of HIV/STI’s, victimization, mental health issues, and suicide.

They are also less likely to have health insurance than heterosexual or LGB individuals.

- Elderly LGBT individuals face additional barriers to health because of isolation and fewer family supports, and a lack of social and support services.
LGBT Demographics, Concepts, and Terminology
L,G,B,T Demographics, Concepts, and Terminology
LGB Demographics in the U.S.

- Identify as lesbian, gay, or bisexual
  - 1.7 - 5.6% (average 3.5%)
  - Women were more likely than men to say they were bisexual

- Same-sex sexual contact ever
  - 8.2%

- Same-sex attraction (at least some)
  - 7.5 - 11%

(Laumann et al., 1994; Gates et al., 2011)
Same Sex Families/1000 Households by County: 2010 Census

The Williams Institute
Understanding Sexual Orientation

Orientation

- Identity
- Attraction
- Behavior
Discordance between Sexual Behavior and Identity

- 2006 study of 4193 men in NYC (Pathela, 2006)
- 9.4% of men who identified as “straight” had sex with a man in the prior year
  - These men were more likely to:
    - belong to minority racial and ethnic groups,
    - be of lower socio-economic status,
    - be foreign born
    - Not use a condom

- 77-91% of lesbians had at least one prior sexual experience with men
  - 8% in the prior year (O’Hanlan, 1997)
Understanding the T in LGBT

- Significant disparities have been documented among transgender people
- The importance of understanding
  - gender identity
  - gender expression
  - birth sex
  - current anatomy
What does gender mean?  
Gender vs. sex

Traditional Construct
- Gender is binary (M/F)
- Synonymous with sex (chromosomes, genitalia)

Contemporary Construct
- Gender is a spectrum
- Defined by several criteria
- Separate from sex and sexual orientation
What does gender mean?
Components of Gender

- **Identity**: The psychological awareness or sense of where one fits in on the man-woman spectrum.
- **Role**: That part of behavior that is influenced by society’s expectation of what is gender-appropriate.
- **Expression**: The way in which one communicates his or her identity through appearance and behavior (mannerisms, dress, speech, etc.).
What does gender mean?

Gender in a Population
Transgender Terminology: Transition, Affirmation, Confirmation

- The process of changing from living and being perceived as the gender assigned at birth according to the anatomical sex (M or F), to living and being perceived as the individual sees and understands themselves

- Does not necessarily include surgery or hormones
Alternative Constructs of Gender Identity:

Medical Construct: Gender Reassignment Or Transitioning

Patient Centered Construct: Gender Affirmation
Transgender Terminology

- **Transgender, Transsexual**
  - Biological men and women whose gender identity most closely matches the gender opposite to that assigned at birth
  - The term transsexual is often used to specifically describe persons who have undergone hormonal therapy/genital surgery

- **Genderqueer**
  - Used to describe people whose gender identity does not fit neatly into either male or female categories

- **Crossdresser**
  - Individuals with a desire to wear the clothing of the other sex but not to change their gender; many are heterosexual men who crossdress for erotic arousal.

- **Transgender, Gender Variant, Gender Non-Conforming**,
  - Umbrella terms used to group the many gender different communities
  - People who transcend typical gender paradigms
  - Non-transgender people are sometimes called cisgender)
Sexual Orientation ≠ Gender Identity

- Sexual orientation not the same as gender identity
- Transgender people can be of any sexual orientation
  - Trans-women attracted to men and trans-men attracted to women may identify as heterosexual
  - Trans-women attracted to women may identify as lesbian
  - Trans-men attracted to men may identify as gay
  - Trans-people may also identify as straight, homosexual, bisexual, pansexual, omnisexual, asexual, queer, celibate, etc.

Source: Grant et al. (2011). Injustice at Every Turn: http://www.thetaskforce.org/downloads/reports/reports/ntds_full.pdf
Developing Clinically and Cost Effective Clinical Practices: HIV Prevention Programs
From Policy to Practice

- Ending LGBT Invisibility
- Optimizing the Test and Treat Cascade
- Creating a Welcoming Environment
Ending L,G,B,T Invisibility
Ending LGBT Invisibility in Health Care

- Has a clinician ever talked with you about your sexual history: behavior, health, and satisfaction?
- Has a clinician ever asked about your sexual orientation?
- Has a clinician ever asked about your gender identity?
How well do clinicians know those coming for care and their unique health needs?

New Patients

New Lesbian/Gay/Bisexual/Transgender Patients
IOM Recommendation: Data on Sexual Orientation and Gender Identity Should be Collected in Electronic Health Records

- Recognition of Challenges and Barriers
  - Confidentiality
  - Reluctance/Desire to Share
  - Need for Provider Education

- Direct benefit to individual patients, insuring quality, and evaluation of disparities at practice level to learn about educational needs for clinicians and staff.

- Critical to doing effective population health as part of patient centered medical homes or health homes.
Tools for Change!

Policy Focus:
**Why** Gather Data on Sexual Orientation and Gender Identity in Clinical Settings

Policy Focus:
**How to** Gather Data on Sexual Orientation and Gender Identity in Clinical Settings
Gathering LGBT Data During the Process of Care

DATA INPUT AT HOME

ARRIVAL

REGISTER ONSITE

SO/G DATA NOT REPORTED

PROVIDER VISIT INPUT FROM HISTORY

YES

INFORMATION ENTERED INTO EHR

NO

INFORMATION ENTERED INTO EHR

SELF REPORT OF INFORMATION ON SEXUAL ORIENTATION (SO) AND GENDER IDENTITY (GI)
# Collecting Demographic Data on Sexual Orientation

1. Which of the categories best describes your current annual income? Please check the correct category:
   - $<10,000
   - $10,000–14,999
   - $15,000–19,999
   - $20,000–29,999
   - $30,000–49,999
   - $50,000–79,999
   - Over $80,000

2. Employment Status:
   - Employed full time
   - Employed part time
   - Student full time
   - Student part time
   - Retired
   - Other ______________________

3. Racial Group(s):
   - African American/Black
   - Asian
   - Caucasian
   - Multi racial
   - Native American/Alaskan Native/Inuit
   - Pacific Islander
   - Other ______________________

4. Ethnicity:
   - Hispanic/Latino/Latina
   - Not Hispanic/Latino/Latina

5. Country of Birth:
   - USA
   - Other ______________________

6. Language(s):
   - English
   - Español
   - Français
   - Português
   - Русский

7. Do you think of yourself as:
   - Lesbian, gay, or homosexual
   - Straight or heterosexual
   - Bisexual
   - Something Else
   - Don’t know

8. Marital Status:
   - Married
   - Partnered
   - Single
   - Divorced
   - Other ______________________

9. Veteran Status:
   - Veteran
   - Not a veteran

10. Referral Source:
    - Self
    - Friend or Family Member
    - Health Provider
    - Emergency Room
    - Ad/Internet/Media/Outreach Worker/School
    - Other ______________________

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**National LGBT Health Education Center**
A Program of the Fenway Institute
Collecting Demographic Data on Gender Identity

- What is your current gender identity? (check ALL that apply)
  - Male
  - Female
  - Transgender Male/Trans Man/FTM
  - Transgender Female/Trans Woman/MTF
  - Gender Queer
  - Additional Category (please specify)
    ___________

- What sex were you assigned at birth? (Check One)
  - Male
  - Female
  - Decline to Answer

- What pronouns do you prefer (e.g. he/him, she/her)?
  __________________

Center of Excellence for Transgender Health UCSF
Getting to Know Patients in Clinical Settings
Proportion of Physicians Discussing Topics with HIV-Positive Patients

- Adherence to ART  84%
- Condom use        16%
- HIV transmission and/or risk reduction  14%

4 US Cities (n=317)
Discomfort as a Barrier

“Ironically, it may require greater intimacy to discuss sex than to engage in it.”

*The Hidden Epidemic*
Institute of Medicine, 1997
Preparation for Collecting Data in Clinical Settings

- Clinicians: Need to learn about LGBT health and the range of expression related to identity, behavior, and desire. Staff needs to understand concepts.
- Patients: Need to learn about why it is important to communicate this information, and feel comfortable that it will be used appropriately.
- Data Collection: Critical, and has to be done sensitively without assumptions routinely on all, along with other demographic data.
Optimizing the Test and Treat Cascade

- HIV Infected: 1,148,200 (100%)
- Diagnosed: 941,524 (82%)
- Linked to HIV Care: 757,812 (66%)
- Retained in HIV Care: 424,834 (37%)
- On ART: 378,906 (33%)
- Suppressed Viral Load: 287,050 (25%)

Adapted from CDC, “HIV in the US-The Stages of Care” July 2012
Initial Approach to HIV/AIDS

Counseling and Testing  Care and Treatment
Changing Dynamics Press Toward Realignment in HIV Prevention, Care and Services

- **First National HIV/AIDS Strategy**
  - Reducing incidence of HIV
  - Access to care
  - Eliminating HIV Related Disparities

- **Affordable Care Act**
  - Implement synergies to bridge prevention, treatment, and care
Changing Dynamics Press Toward Realignment in HIV Prevention, Care and Services

- Scientific Evidence on Impact of Effective Use of ART
  - Improvement in Life of those Infected
  - Prevent 96% of Transmission to Uninfected

- Affordable Care Act Will Provide Greater Coverage including Coverage for Prevention
  - Significant limitations in states which do not expand Medicaid
Focus On Those Experiencing Disparities

- Insure that programs focus on the underserved
- Strengthen focus on gay and bisexual men and transgender women at high risk
  - Young gay men of all races are at highest risk for HIV, and only group for whom incidence is increasing.
  - Models of care for serving them are in short supply
  - Ryan White does not have a mechanism that directly focuses on this population
- New programs for high cost or vulnerable populations
Maximize Support at Each Stage of the Treatment Cascade

- Move to Population Focus
- Set Performance Goals for Each Step of the Cascade
- Provide Metrics to Guide Program Planning
  - More Consistent Use of Evidence Based Planning
  - Eliminate Barriers to Integrated Prevention and Care Planning
- IOM Recommendations on core indicators commissioned by ONAP
Remove Barriers to Continuous Care

- Data suggests Ryan White funds will be needed to continue to develop and support enabling services
- Prioritize use of funding to support help for transitions in care
The HIV Treatment Cascade

Adapted from CDC, “HIV in the US-The Stages of Care” July 2012
Segmented HIV Prevention and Care: A Patchwork

DPH

ASO’s

CHC’s
Creating Synergies for Continuity

ASO’s

DPH

CHC’s
Expanding the care continuum to optimize patient centered care in developing Patient Centered Medical Homes
Creating Change at Home: Affirmative, Inclusive Environments for Caring, Learning, and Working
Creating a caring and inclusive environment

- Are clinicians and staff taught about the health needs of LGBT people?
- Do LGBT employees feel respected and safe at work?
- Do forms reflect the full range of sexual and gender identity and expression?
- Is there a non-discrimination policy inclusive of sexual orientation and gender identity for patients and staff?
- Are there educational brochures on LGBT health topics?
- Are there unisex bathrooms?
Our Challenge: Quality Care for All, Including LGBT People
The National LGBT Health Education Center at The Fenway Institute:
We are here to help you!

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