Addressing HIV and PrEP Stigmas Impacting LGBT Health

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Disclosures

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Learning Objectives

1. Explore the current landscape of HIV and PrEP stigmas in LGBT healthcare
2. Describe how HIV and PrEP stigmas can act as barriers to care
3. Identify culturally appropriate models and practices that address HIV and PrEP stigmas for integration in RWHAP settings
Obtaining CME/CE Credit

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State of LGBT Health
MSM and HIV

Gay, bisexual, and other Men who have Sex with Men (MSM)

• Approximately 2% of the US population
• Disproportionally affected by HIV
  • MSM represent 63% of all new HIV infections in 2010
• Racial and ethnic disparities
  • 1 in 2 Black MSM will be diagnosed with HIV in their lifetime if current trends persist
  • 1 in 4 Latino MSM will be diagnosed with HIV in their lifetime if current trends persist

Centers for Disease Control and Prevention; (2015); HIV Among Hispanics/Latinos. http://www.cdc.gov/hiv/group/racialethnic/hispaniclatinos/
MSM and Healthcare Engagement

- 29% of participants reported experiencing racial and sexual orientation stigma from healthcare providers
- 48% reported mistrust of medical institutions
- Black MSM living with HIV experienced stigma from health care providers, which was associated with longer gaps in time since last HIV care appointment
- Black MSM living with HIV and who reported greater levels of medical mistrust and stigma also were less likely to have high CD4 counts
- LGB people and people of color living with HIV were at least two times as likely to experience physically rough or abusive treatment by medical professionals compared to their white counterparts
- Less than half of Latinos living with HIV are receiving medicine to treat their infection


Transgender Individuals and HIV

- HIV infection rate among transgender individuals is four times the national average
- Estimated 28% of transgender women living with HIV
  - 56% of black transgender women live with HIV
- In NYC, 47% of transgender women reported delayed linkage to care after a HIV diagnosis
- Transgender women less likely to achieve viral suppression within 12 months of an HIV diagnosis compared to MSM

Transgender Community and Healthcare Engagement

- 70% of transgender and gender-nonconforming individuals experienced discrimination in healthcare
- 28% postponed or avoided medical treatment when sick
- 33% delayed or did not access preventative services
- Nearly 90% believe there are not enough properly trained medical personnel to care for them
- 50% report having to teach their providers about some aspect of their healthcare needs

PrEP and MSM

• PrEP is not being accessed by communities and individuals most impacted by HIV
  • Black MSM represent approximately 44% of new HIV cases annually in the US, but represent only 10% of PrEP consumers
  • Latino MSM make up 23% of new HIV cases annually, but represent only 12% of PrEP consumers

• Racial Biases affect providers’ willingness to prescribe PrEP
  • Some providers believe Black MSM more likely than white MSM to engage in increased unprotected sex if prescribed PrEP, leading to a reduced willingness to prescribe PrEP

• Concerns regarding increasing STI rates
  • PrEP only protects against HIV and does not protect against bacterial or viral STIs.


Defining Stigma
Stigma - Origins

Stigma is the result of existing stereotypes, prejudice, biases, and other forms of oppression in our society directed at individuals and/or groups.

Discrimination, prejudice and negative attitudes directed towards those in society with a stigmatizing health condition have been well documented throughout history.

Misunderstanding of the origin of mental health disorders, drug and alcohol abuse and leprosy are just a few examples.
Health Related Stigma Definition

- Health-related stigma is typically characterized by social disqualification of individuals & populations who are identified with particular health problems.

- Another aspect is characterized by social disqualification targeting other features of a person's identity—such as ethnicity, sexual preferences or socio-economic status—which through limited access to services and other social disadvantages result in adverse effects on health.
Health Related Stigma

• The concept of stigma, denoting relations of **shame**, has a long ancestry and has from the earliest times been associated with **deviations** from the ‘normal’, including, in various times and places, deviations from normative prescriptions of acceptable states of being for self and others (Leprosy)

• Stigma is a social opportunistic disease that attaches to many illnesses and increase morbidity and mortality rates (HUH Stigma Conference)
Group Discussion

• Identify common feelings associated with being stigmatized

• Identify the root causes and the factors that lead to HIV stigma
HIV Stigma
Defining HIV Stigma

In 1996, The National Institute of Mental Health brought together a panel of experts to discuss HIV related stigma, with the purpose of acknowledging the need to address stigma, and the negative impact it has fighting the HIV epidemic.

1. Acknowledgement by a federal agency that HIV related stigma has an impact on efforts directed at fighting the epidemic

2. Development of a definition of HIV stigma at the individual and cultural level

History of HIV Stigma: Origins

- First 100 cases and deaths were centered in cities where there were underground gay communities, people who inject drugs, and LGBT members being the vast majority of those becoming infected and dying.
- AIDS was at first called GRID (Gay-Related Immunodeficiency Disease) or gay syndrome.
- Members of conservative ideologies claimed the epidemic was God’s punishment for immoral acts.
- Reagan administration cut CDC budget by 25%, which halted HIV/AIDS research for years.

History of HIV Stigma Origins

- Assistant Secretary of HHS denied proof that HIV/AIDS was also transmitted heterosexually
- First antiretroviral developed was the most expensive prescription drug ever developed, out of reach for almost all clients
- Senator Jesse Helms famously struck down federal funding for safe sex education materials developed by an activist organization
  - Set the precedent that needle exchanges, safe homosexual sex education, and other prevention methods would not receive government funds
- San Francisco closed bath houses, claiming to stop transmission, but further stigmatizing the LGBT community
  - LGBT community had just earned civil rights to express themselves, were afraid these rights would be taken away

These are all examples of the way that stigma and prejudice shaped the epidemic at its inception and throughout history

HIV Stigma - Myths

Common questions:

- Is it safe to donate/receive blood?
- Could I contract it through mosquito bites?
- Can I use the same cup/plate used by an HIV patient?
- Can I hug/kiss on the cheek someone infected?
- How is the virus transmitted through sexual contact?
- Could I get it from sneezing, working alongside a person living with HIV?
HIV Targets of Stigma

Primary HIV Stigma is defined as the stigma directed at those individuals who are infected and/or those perceived as infected with the virus.

Secondary HIV Stigma is aimed at those individuals and/or groups associated with those infected, such as: partners, family members, friends, professionals, volunteers and agencies that have close proximity with those infected.
HIV Stigma

• In order to cope with primary stigma, individuals resort to the concealment of their seropositive status for fear of being shunned (stigmatized) by others
• Concealment of seropositive status often leads to social isolation and internalized feelings of self-loathing and cycle of hopeless
• Stigma can have an impact regardless of whether an individual is a person living with HIV or not
How is HIV Stigma Constructed?

HIV and Stigma:
A Conceptual Framework and research Agenda

Included in the final report from the research on HIV/AIDS and stigma, the panel reports that HIV/AIDS stigma occurs at two levels, (1) **the cultural** and (2) **individual** ends.

Stigma - Cultural Level

Cultural Level HIV Stigma

• Occurs at the society level and is evident in the manner in which HIV related stigma is manifested in society through the use of discriminating practices designed to castigate those infected

The most common are:

• Loss of employment based on HIV infection
• Loss of housing, and
• Denial of services
Stigma - Cultural Level

Factors that shape the cultural stigma are:

- Values toward sexuality, the disease, and gender
- Perception of drug abuse
- Perception towards persons who are members of racial/ethnic minorities
- Perception/action directed at those individuals/groups who are infected or are believed to be infected
Stigma - Individual Level

**Primary**: Directed at people living with HIV or those who are perceived to be at risk

**Secondary**: Aimed at persons and/or groups associated with people living with HIV

**Instrumental**: Defined as the fear of contagion due to the communicable nature of the disease

**Symbolic**: Associated with the meaning, and associations that have been attached to the disease with marginalized groups
HIV Stigma and Discrimination

There are four main causes of HIV stigma:

**Stereotypes**

*Sexuality*: sexual minorities = transmission of HIV
*Gender*: infected men = multiple sexual partners
*Race/Ethnicity*: infected minorities = immoral behavior
*Class*: HIV affects economically disadvantaged

These form the *vicious circle* of HIV stigma
HIV Stigma Scars
Heal the Pain. End the Shame.

Learn how to stop HIV stigma at:
camba.org/antistigma
facebook.com/cambainc

CAMBA
where you can
Examples of Stigma in Healthcare

- Refusing to provide care and treatment to People Living with HIV (PLWH)
- Providing poor quality of care to PLWH
- Violating confidentiality
- Only providing care in settings that further stigmatize PLWH (clinics for HIV or sexually transmitted infections)
- Using infection-control procedures (e.g., gloves) only with PLWH, rather than with all patients
Examples of Stigma In the Work Place

- Requiring testing before employment
- Rejecting potential employees based on their HIV status
- Being dismissed because of HIV status
- Violating confidentiality
- Refusing to work with colleagues who are PLWH
Examples of Stigma, Family & Community

- Isolating people living with HIV (PLWH)
- Restricting participation of PLWH in local events
- Refusing to let children who are PLWH attend schools
- Ostracizing partners and children of PLWH
- Failing to support PLWH family members
Self-Stigmatization at Individual Level

What is it?
• Shame that PLWH experience when they internalize negative reactions of others

What impact does/can it have?
• Depression
• Withdrawal
• Feelings of worthlessness/hopelessness
• Isolation of the person
• Negatively impact ability to access services
• Substance use
• Not being adherent to treatment or medication
Stigma and Society

“My family and I held no hatred for those people because we realized they were victims of their own ignorance”

--Ryan White

“Stigmatization, at its essence, is a challenge to one’s humanity—for both the stigmatized and the stigmatizer.”

--The Social Psychology of Stigma
Barriers to Culturally Competent Care

- Lack of diversity in healthcare leadership and workforce
- Systems of care poorly designed for diverse patient populations
- Poor cross-cultural communication between providers and patients, lack of training
- Lack of provider training on engaging diverse communities in care
- Patient fears and distrust
- Cultural & individual stigma
Where do we go from here?

Why is cultural respect important?

• Cultural respect is critical to reducing health disparities and improving access to high-quality health care, health care that is respectful of and responsive to the needs of diverse patients.
PrEP Stigma
PrEP Stigma

• The term “Truvada whore,” coined in a popular opinion piece condemning PrEP as a gateway to unsafe behavior, captures the assumptions and negative sentiment associated with PrEP

Reaching MSM of Color
Recent Research

PrEP uptake among racially and ethnically diverse populations

- 50% of study participants aware of PrEP (mostly from social media)
- Participants knowledgeable on key PrEP facts such as its protectiveness and need for adherence
- Knowledge gaps in areas such as what PrEP is, how it works clinically, and potential side effects

Young Black Men who have Sex with Men (YBMSM)

- More likely to have supportive attitudes around PrEP uptake
- More likely to view PrEP as an added preventative benefit, specifically in relation to condom use

Barriers to Prescribing PrEP

Provider reluctance can stem from:

- Lack of comfort with, or knowledge of, a new procedure
- Desire not to over-medicate patients
- Belief that traditional prevention approaches, such as condoms or abstinence, are better
- Fear that PrEP could encourage riskier sexual practices and the disuse of condoms
- Discomfort or hesitance to positively recognize or discuss sexual behaviors
Barriers to Accessing PrEP

Cost
• Medication
• Ancillary services (HIV and STI testing, creatine clearance)

Adherence
• Medication
• Clinical visits

Behavior
• Increased risk-taking while on PrEP (self-reported)

Relationship status
• Participants in romantic relationships less likely to perceive PrEP need

PrEP – Best Practices

• Follow CDC PrEP guidelines
  • Assess risk – sexual health history
  • Provide essential PrEP information
  • Rule out chronic and acute HIV infection, measure renal function, and perform hepatitis serology
  • Support adherence
  • Provide simple explanations and education
  • Monitor adherence in nonjudgmental manner
  • Maintain trust and communication
  • Follow up visits every three months

• Improve cultural competency

Cultural Competency
Prominent Social and Cultural Drivers of Health Disparities for LGBT populations

**Socio-**
- Racism
- Sexism
- Heterosexism

**Cultural**
- Homophobia
- Implicit Bias
- Institutional & Structural Racism

**Inequity**
- Produces health disparities for LGBT individuals
Defining Cultural Competence

• Cultural competence is not an end goal, but a commitment to an ongoing engagement with welcoming and affirming behaviors, knowledge, attitudes and policies.

• Cultural competence presentations and trainings are understood to be a beginning and an important step in learning to work more effectively with clients/patients, but they are not the only required step. Profound change also requires time, practice and self-reflection.
Cultural Competence Road to Success

Continuum of Cultural Competency

- Cultural Destructiveness
  - Forced assimilation, subjugation, rights and privileges for dominant groups only

- Cultural Incapacity
  - Racism, maintain stereotypes, unfair hiring practices

- Cultural Blindness
  - Differences ignored, “treat everyone the same”, only meet needs of dominant groups

- Cultural Pre-Competence
  - Explore cultural issues, are committed, assess needs of organization and individuals

- Cultural Competence
  - Recognize individual & cultural differences, seek advice from diverse groups, hire culturally unbiased staff

- Cultural Proficiency
  - Implement changes to improve services based upon cultural needs

SAMHSA
Cultural Destructiveness

- Individuals view cultural differences as a problem
- Individuals purposely attempt to destroy a culture
- Example: Treatment of Native Americans by immigrants from Europe since 1500
- Assumption that one race is superior and should eradicate “lesser” cultures
Cultural Incapacity

- Organizations lack capacity to help individuals from diverse cultures
- Do not intentionally seek to cause harm
- Believe in superiority of their own racial/ethnic group
  “Paternalistic Posture”
- Oppress by enforcing racist policies and stereotypes
- Employment practices are discriminatory
Cultural Blindness

- Belief that race makes no difference and that “all people are the same”
- People view themselves as unbiased
- Individuals cannot see, and cannot benefit from, the valuable differences among cultural groups
  - Unable or slow to accept that there are important differences between cultural groups
- Services and programs created by these organizations only meet the needs of dominant groups
- Lack of capacity to work with different levels or types of risk, need, services, etc.
Cultural Pre-Competence

- Recognition of weaknesses in their attempt to serve various cultures, lack of training and understanding
- Efforts to improve services to diverse populations, conduct resource and needs assessments
- Hire one staff member from different cultural/racial background to provide all services needed
- Belief that they have accomplished their goals and this fulfills their obligation to the diverse community
- Organization uses the “check the box” method of achieving cultural competence
  - i.e. hosting one listening session, one forum, or hiring one employee with culturally diverse background
Cultural Competence

- These organizations accept and respect differences
- Participate in self-assessment process regarding culture & community. They conduct constant “Resource and Needs Assessments”
- Continue to expand cultural knowledge, training and education campaigns for staff and community
- Adapt service models to better serve the needs of ALL the community
- Strive to hire unbiased employees and support staff
- Still occasionally “check the box” on cultural competence
Cultural Proficiency

- These organizations hold diversity of ALL cultures in high esteem
- Conduct research to increase knowledge of culturally competent practices
- They develop new educational and therapeutic approaches based on culture
- Their policies, procedures, hiring practices, service delivery, awareness, and education campaigns include principles of cultural competency
- **Note:** No one can learn all there is to know about a cultural group they are not a member of
- Therefore, all volunteers and staff members should adopt an attitude of **cultural humility**
Cultural Humility: No one can ever become an expert in the culture of another

- Cultural humility is the fruit of cultural competence
- **Cultural humility** is the disposition or attitude that each individual is the expert in their own experience and culture, and the provider is always secondary
- Cultural competence is characterized by training, gaining knowledge, changing language and practices, and adopting structural changes
- Cultural humility is a lifelong pursuit, always developing
What's the Difference between Cultural Competence, Awareness, & Sensitivity

• Cultural competence emphasizes the idea of **effectively operating** in different cultural contexts, and altering practices to reach different cultural groups.

• Cultural knowledge, sensitivity, and awareness do **not** include this concept.

• Although they imply understanding of cultural similarities and differences, they do **not** include action or structural change.
Do not confuse Health Literacy with Health Education

• Health Education: Is a public health **activity** by which individuals & groups learn about health promotion, maintenance or restoration of health

• Health education programs should be designed with the Health Literacy **skills** of their target population in mind

• Health Literacy is a Cognitive & Social **skill** which determines the **motivation** & **ability** of individuals to gain access to, understand and use health related information
9 out of 10 adults have difficulty using everyday health information
Health Literacy Definition

Health Literacy is a Cognitive & Social **skill** which determines the **motivation & ability** of individuals to gain access to, understand and use health related information.
Health Literacy Screening Tools

- Rapid Estimate of Adult Literacy in Medicine (REALM)
- Rapid Estimate of Adult Literacy in Medicine - Revised (REALM-R)
- Test of Functional Health Literacy in Adults (TOFHLA)
- Short Test of Functional Health Literacy in Adults (S-TOFHLA)
- Newest Vital Sign (NVS)
- Brief Estimate of Health Knowledge and Action – HIV Version
- Single Item Literacy Screen
- How confident are you filling out medical forms by yourself?
- SOS Mnemonic
How Stigma Manifests in Healthcare Settings

- Location, proximity to other places
- Front Desk
- Volunteers, personnel
- Partner Networks
- Imagery and displays
- Online Resource Materials
- Provider/Patient Relationship
- Personal Beliefs of Providers in Healthcare Settings (based on race and/or sexuality)
Causes of HIV-Related Stigma in Health Facilities

• Lack of awareness among health care workers of what stigma looks like and why it is damaging
• Fear of casual contact stemming from incomplete knowledge about HIV transmission
• Association of HIV with improper or immoral behavior
• Assumptions about client based on their HIV status

Strategies to Become Culturally Competent

Cultural Awareness

- Self-examination of one’s biases
- Get to know YOU in an in-depth way!
- Learning about “ISMs” in healthcare delivery
Model for Cultural Awareness

Strategies to Become Culturally Competent

Cultural Knowledge

• Obtain a sound educational base about culturally diverse groups

• Integrating health-related beliefs and cultural values, disease incidence and prevalence, and treatment efficacy

• Begin sharing National CLAS Standards with your team
Strategies to Become Culturally Competent

Cultural Sensitivity

• Directly engage in face-to-face cultural interactions and other types of encounters
• Become proactive in addressing cultural competence in your department
• Continue Self Assessment to keep consistent in your behaviors, communication styles, and interactions with clients.
Strategies to Effectively Engage Those Who Seek Care

- Develop models to improve provider/patient relationship
- Provide continual professional development opportunities to explore the intersections of race, gender, and sexuality in provider health care delivery
- Engage community partners in the process of improving organizational responsiveness to clientele
Best Practices for HIV prevention among Transgender Individuals

- Ground work in the community
- One size does not fit all
- Use multidisciplinary approaches
- Get the facts
- Look in all the right places
- Increase access to healthcare
- Staff development

Provider Continuum of Action: Building Capacity & Creating Safer Spaces Through Cultural Competence

*Being An Ally – The Action Continuum*

Actively  Denying, Recognizing, Recognizing, Educating Educating  Supporting, Initiating, Participating  Ignoring  No Action  Action  Self  Others  Encouraging  Preventing

Supporting Oppression >>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>> Confronting Oppression

Conclusion

HIV Stigma impacts LGBT health
- MSM of Color and transgender individuals are populations at a high risk of HIV infection and face sexual orientation, gender identity, and HIV stigmas that negatively impact treatment and access to quality care
- Best practices and strategies to engage those who seek care

PrEP Stigma impacts LGBT health
- Reluctance to prescribe PrEP to high risk populations such as MSM of Color act as a barrier to HIV prevention services
- Best practices and clinical guidelines from CDC for PrEP
National Coalition for LGBT Health

• Join the Coalition at www.healthlgbt.org

• LGBT Health Training and Certificate Program
  • Building Trust with LGBT Clients
  • OUTcompetent
  • Healthcare Stigma Facing Transgender Individuals

• National LGBT Health Awareness Week
  • March 27 – 31, 2017

• State of LGBT Health survey
  • Providers and Consumers
Questions?
Contact Information

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