Aging in LGBT Communities: Improving Services and Eliminating Barriers to Care

Harvey J Makadon, MD
Director, National LGBT Health Education Center
The Fenway Institute, Fenway Health
Clinical Professor of Medicine
Harvard Medical School
Boston, MA

Sean Cahill, PhD
Director, Health Policy Research
The Fenway Institute, Fenway Health
Adjunct Assistant Professor of Public Administration
New York University’s Robert Wagner School of Public Service

Health Care and the Aging:
National Primary Care Conference on Aging
April 30, 2012
Learning Objectives

- Understand how LGBT health disparities affect elders.
- Identify ways to effectively manage the clinical and social needs of LGBT elders.
- Understand policy initiatives which will bring an end to disparities among LGBT elders.
Topics

- Why LGBT Health
- Health Disparities
- Overcoming Barriers to Care
  - Getting to Know Patients
  - Education
  - Environment
- Health Policy and LGBT Elders
- Conclusion
Why LGBT Health?

- Bias in Health Care
- Stigma and Discrimination
- Social Determinants

Health Care Disparities
A Long History of Bias in Healthcare

- 1999 CA survey, 18.7% of physicians sometimes or often uncomfortable providing care to gay patients (Smith and Mathews, 2007)
- 2007 survey: 30.4% of patients would change providers upon finding out their provider was gay/lesbian (Lee et al., 2008)
- 2005/6 surveys of medical students (AAMC reporter, 2007)
  - 15% reported mistreatment of LGBT students at schools
  - 17% of LGBT students reported hostile environments
- 2011 survey of transgender people (National Center for Transgender Equality 2011)
  - Refusal of care: 19% of sample reported being refused medical care due to their transgender or gender non-conforming status, with even higher numbers among people of color
  - Uninformed doctors: 50% of the sample reported having to teach their medical providers about transgender care
The Impact of Stigma and Discrimination
Social Determinants of Health

Disparities

- Behavioral
  - Suicidality
  - Anxiety
  - Depression

- Chronic Non-Communicable
  - Smoking
  - Alcohol and Drug Use
  - Eating Disorders

- Communicable Diseases
  - STI’s
  - HIV
What Do We Know About Experiences in Health Care: Later Adulthood

- LGBT elders experience stigma and discrimination across the life course and may experience violence at higher rates than heterosexual elders.

- LGBT elders are less likely to have family for care and support.

- Limited research suggests that transgender elders may experience negative health outcomes as a result of long-term hormone use.

- Although HIV infection rates among young men are higher, older adults do get infected with HIV/AIDS. There are few, if any, HIV prevention programs that target older adults.
LGBT Demographics, Concepts, and Terminology
L,G,B,T Demographics, Concepts, and Terminology
There is diversity of expression in our own communities and globally.
Understanding Sexual 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)
Intersection of LGBT and Communities of Color

Hispanic Same-Sex Couples

Black Same-Sex Couples


Transgender: Understanding The T in LGBT

- Gender nonconformity refers to the extent to which a person’s gender identity differs from cultural norms for people of a particular sex.
- Terminology is culturally and time dependent and is rapidly evolving.
- Transgender people persistently identify and/or express their gender as the opposite of their biologic birth sex and often have hormonal and surgical treatment (sometimes called transsexualism).
- People who define themselves as a gender outside the either/or construct of male/female – e.g., having no gender, being androgynous, or having elements of multiple genders (some use the term bi gender or genderqueer).
- People who enjoy the outward manifestations of various gender roles and cross dress to varying extents (cross dressing).
Understanding Desire: Support for “Coming Out”

- Can happen at any age regarding sexual orientation or gender identity
- Ask patients who are coming out if they have family and community supports
Overcoming Barriers to Change
LGBT Invisibility in Healthcare

- Has your primary care clinician ever taken your sexual history?
- Has a clinician ever asked you about your sexual orientation?
- Has a clinician ever asked about your gender identity?
- Do you do any training at your health center about issues related to sexual orientation and gender identity?
How well do you know the people coming to your health center? How do you find out?

New Patients

New Lesbian/Gay Patients

How do people feel and what do they do when learning this?
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**

*The Fenway Institute*
Why gather data on sexual orientation and gender identity?

- Increases ability to screen, detect, and prevent conditions more common in LGBT
- Helps develop a better understanding of patients’ lives
- Allows comparison of patient outcomes with national survey samples of LGBT people
Healthy People 2020

- Health care providers should “appropriately inquire about and be...supportive of a patient’s sexual orientation to enhance the patient-provider interaction and regular use of care.”
LGBT data can be gathered at patient contact points during the process of care, and integrated into the EHR.
Enter the Electronic Health Record (EHR)
Institute of Medicine, 2011

- As part of meaningful use, recommends collecting data on sexual orientation and gender identity in electronic health records.
- Also, recommends structured data elements to allow for the comparison and pooling of data to analyze the unique needs of LGBT people.
- HHS currently gathering public comment on adding this to demographics required to meet meaningful use criteria.
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.) Employment Status</td>
<td>Employed full time, Employed part time, Student full time, Student part time, Retired, Other ___________________</td>
</tr>
<tr>
<td>3.) Racial Group(s)</td>
<td>African American/Black, Asian, Caucasian, Multi racial, Native American / Alaskan Native / Inuit, Pacific Islander, Other ___________________</td>
</tr>
<tr>
<td>4.) Ethnicity</td>
<td>Hispanic/Latino/Latina, Not Hispanic/Latino/Latina</td>
</tr>
<tr>
<td>5.) Country of Birth</td>
<td>USA, Other ___________________</td>
</tr>
<tr>
<td>7.) Do you think of yourself as:</td>
<td>Lesbian, gay, or homosexual, Straight or heterosexual, Bisexual, Something else, Don’t know</td>
</tr>
<tr>
<td>8.) Marital Status</td>
<td>Married, Partnered, Single, Divorced, Other ___________________</td>
</tr>
<tr>
<td>9.) Veteran Status</td>
<td>Veteran, Not a Veteran</td>
</tr>
<tr>
<td>10.) Referral Source</td>
<td>Self, Friend or Family Member, Health Provider, Emergency Room, Ad/Internet/Media Outreach WorkerSchool, Other ___________________</td>
</tr>
</tbody>
</table>
Collecting Demographic Data on Gender Identity (Example)

1. What sex were you assigned at birth? (Check one)
   - Male
   - Female
   - Decline to answer

2. What is your current gender identity? (Check and/or circle ALL that apply)
   - Male
   - Female
   - Transgender Male/Transman/FTM
   - Transgender Female/Transwoman/MTF
   - Genderqueer
   - Additional category (please specify): ________________________________
   - Decline to answer

3. What pronouns do you prefer?_______________________

Adapted from: Primary Care Protocol for Transgender Patient Care, April 2011. Center of Excellence for Transgender Health. University of California, San Francisco, Department of Family and Community Medicine
Getting to Know Patients in Clinical Settings
Proportion of Physicians Discussing Topics with HIV-Positive Patients

4 US Cities (n=317)

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

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
The Core of the Cross-cultural Interview

Respect

Curiosity

Empathy

Adapted from Betancourt and Green
Taking a History

- The core comprehensive history for LGBT patients is the same as for all patients (keeping in mind unique health risks and issues of LGBT populations)
- Get to know your patient as a person (e.g., partners, children, jobs)
- For a new patient coming in for primary care, may talk about sexual orientation or gender identity by simply asking: “Tell me about yourself….”
- Avoid judgment or bias
- Assure confidentiality – and ask permission to include sexual orientation and gender identity in medical record
Taking a Sexual History

- Make it routine
- Place in the context of general history
- Be straightforward, but non-judgmental
- Use statement such as:
  - “I am going to ask you some questions about your sexual health that I ask all my patients. The answers to these questions are important for me to know to help keep you healthy. Everything is confidential.”
Taking a Sexual History

- Assess comfort with sexuality
  - Do you have any concerns or questions about your sexuality, sexual identity, or sexual desires?

- Ask about behavior and risk
  - Have you had sex with anyone in the last year?
  - Did you have sex with men, women, or both?
  - How many partners did you have?

- Ask about sexual health
  - Do you have any concerns about your sexual function?
  - How satisfied are you sexually?
  - Have you had any changes in sexual desire?
Discussing Gender Identity

- Can be complex due to fluidity of expression for some and rapidly changing terminology.
- Information on gender identity may be best obtained in advance of visit, self-report at home or at registration.
- In clinical settings, a provider can ask if patient has questions about gender identity.
- Follow up as appropriate.
Particularly for the Elderly

- Family and other supports
- Who will come in case of emergency
- Do you feel safe at home
Creating Change at Home: Better Environments for Caring, and Working
Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community

A Field Guide
Assessing the Current Environment

- Do you know if LGBT patients feel welcome and feel safe to disclose their sexual behavior and identity?
- Do you know if LGBT clinicians, staff, and students feel safe and accepted?
- Does everyone feel comfortable being themselves?
- Can everyone talk freely with colleagues?
- Are clinicians and staff being taught about LGBT health needs?
- Is the Board on board and clear on LGBT health issues?
- Is there a organizational structure to adjudicate concerns?
The Patient Environment

- Create intake forms that include the full range of sexual and gender identity and expression
- Ensure confidentiality on forms
- Train all staff to be respectful of LGBT clients, and to use clients’ preferred names and pronouns
- Post non-discrimination policy inclusive of sexual orientation and gender identity
- Display images that reflect LGBT lives (e.g., posters with same-sex couples, rainbow flags)
- Provide educational brochures on LGBT health topics
- Provide unisex bathrooms
Changes in Policy: Countering a History of Inequity for LGBT Elders
Who are LGBT Elders?

- 1-2 million LGBT elders now; twice this # by 2030

- Among same-sex couples in Ohio, 20% were 55+, and 5.4% were 65+
  (Gates, Williams Institute, analysis of 2010 U.S. Census American Comm Survey)

- LGBT elders may be more likely to live alone: Mass. BRFSS 49% of gays, lesbians 50+ live alone vs. 33% of heterosexuals 50+
Polling Data Show Older Adults are More Homophobic

- Greater moral disapproval of homosexuality: 63% of Americans 70+ believe homosexuality “always wrong,” vs. 41% of 30- to 39-year-olds
- More likely to hold inaccurate, outdated views on casual transmission of HIV
- Given that half of older adults with HIV in US are gay/bisexual men, this is relevant, shapes attitudes toward gay people
Discrimination in Senior Services

- LGBT elders who have been “out” for decades don’t want to have to go back into the closet to receive senior services
- Many facilities have not welcomed same-sex couples
- Limited research shows that other clients, residents, staff at congregate living facilities, senior centers are sometimes homophobic and treat gay elders in discriminatory way
Concerns About Discrimination by Home Care Assistants, in LTC

- Significant concerns about vulnerability to home care assistants
- Instances of blackmail, neglect, abuse
- LGBT elders very concerned about potential neglect, abuse by personal home care aides, long-term care facility staff and residents (Gary Stein’s research)
- Need for competency training for staff caring for vulnerable elders
Federal Changes in Health Policy: Addressing Inequities

Executive Orders During Obama Administration:

- **Domestic partner health benefits** for civilian federal employees (2010)
- **Hospital visitation rights** for same-sex partners (2010)
- Clarified that same-sex partners/spouses have the same rights as others to name a **medical decision maker** (2011)
Federal Changes in Health Policy: Addressing Inequities

Executive Orders During Obama Administration:

- CMS Guidance to ensure same-sex partners may be afforded **treatment comparable to other spouses** when receiving long-term care, such as care in a nursing home under Medicaid (2011).

- “Spend down”: CMS clarified that states may protect assets of same-sex couples when one must spend savings for medical care (2011). Only enacted in MA, VT.
New HUD Nondiscrimination Guidelines Regarding Sexual Orient. & Gender ID

- Housing: 3 million senior housing units
  - Fair Housing Act doesn’t cover SO/GI. However, it does cover sex discrimination, which HUD now interprets to cover transgender people.

- HUD guidelines (March 2011)
  - No discrimination against LGBT people in government-backed mortgages or public housing (1/3 of U.S. mortgages).
  - 4.4 million housing units—including much senior housing.
  - Defines family to include same-sex couples.
Inequities Persist!

- **Domestic partner health coverage** for same-sex partners taxed as income

- **Income support programs** (Social Security, retirement plans, worker’s comp) affect LGBT families’ financial security

- **Family recognition policies** prevent same-sex partners from care-giving protections others take for granted (ex: FMLA)
Family and Medical Leave Act

- Family members provided up to 12 weeks unpaid leave to care for a family member experiencing “serious health condition” or birth, adoption of child
- Definition of family doesn’t include same-sex partner or spouse
- FMLA Inclusion Act (Maloney, Durbin) would rectify this inequity
Older Americans Act

- Funds $2 billion/year in services for older Americans
- Up for reauthorization
- Should designate LGBT elders, HIV+ elders as populations with “greatest social need”
- Would allow Administration on Aging to dedicate resources to states for community planning, social services, research/needs assessments, personnel training to ensure culturally competent, nondiscriminatory care
Accountable Care Act: Innovation to Enhance Clinical and Cost Effectiveness

Health Center

Patient Centered Medical Home
PCMH 2011 Core Standards

- PCMH 1: Enhance Access and Continuity
- PCMH 2: Identify and Manage Patient Populations
- PCMH 3: Plan and Manage Care
- PCMH 4: Provide Self-Care and Community Support
- PCMH 5: Track and Coordinate Care
- PCMH 6: Measure and Improve Performance
Implementing Change

- Elements of Population Health
  - Define and Identify Populations
  - Understand Unique Health Issues
  - Develop Best Practices
    - Quality
    - Cost

- LGBT Health
  - Transgender Health Care
  - Behavioral Heath
  - HIV Prevention and Care
The Community Responds

Many LGBT youth can't picture what their lives might be like as openly gay adults. They can't imagine a future for themselves. So let's show them what our lives are like, let's show them what the future may hold in store for them.
Enhancing Human Rights    →    Enhancing Health Care
Our Roots
Fenway Health

- Independent 501(c)(3) FQHC
- Founded 1971

Mission: To enhance the wellbeing of the LGBT community as well as people in our neighborhoods and beyond through access to the highest quality health care, education, research and advocacy

- Integrated Primary Care Model, including HIV services

The Fenway Institute

- Research, Education, Policy
HRSA (BPHC) National Cooperative Agreement: awarded 2011
- Training and Technical Assistance on LGBT health
- Grand Rounds for Faculty, Staff, and Trainees
- Co-sponsored by the American Medical Association
- Consultation on Creating Strategic Change
- Resources and Publications
The National LGBT Health Education Center: How Can We Help You?

- Discuss what we can do for health centers in your area
- Sign up for our updates and newsletter
- Contact us to speak with a member of our team:

  Harvey Makadon, Hilary Goldhammer, Dirk Williams, Jeffrey Walter  
  T 617.927.6354

lgbthealtheducation@fenwayhealth.org  
www.lgbthealtheducation.org