Foundations for Sexual Minority Health

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Learning Objectives

- Describe the estimated number and distribution of sexual minorities in the United States, how these estimates are derived, and how to critically assess their utility.
- Identify the most significant health concerns and barriers to healthcare access of LGBT persons, within the context of health disparities.
- Use a social ecology model to discuss social, institutional, and policy-related contexts influencing the quality of life that sexual minorities can expect to achieve.
- Describe the initiation and ongoing development of a public health response to the healthcare needs of lesbian, gay, bisexual, transgender (LGBT) and intersex persons.
- Identify opportunities and challenges in sexual minority public health.
• Population Characteristics
• Health Concerns and Disparities
• Social Ecological Model
• Public Health Response
• Opportunities and Challenges
Defining Sexual Orientation

- Definitional issues create significant problems for representative sampling.
- Sexual orientation first gained widespread research interest in the 1800s.
- Today, multiple dimensions are recognised.
- Researchers have growing interest to include sexual orientation as a demographic variable in studies.
- Operational definitions are critical.

Defining Sexual Orientation

- Conceptual definitions of sexual minority populations are rarely included in research reports.
- Operational measures in published studies do not always correspond with common conceptualizations of sexual orientation.
- Researchers must clarify what they are studying and recognize the effect of methods on findings.

Including Sexual Orientation Measures in Health Research

- In a review of English-language articles published 1980-1999, LGBT issues were addressed by 3777 articles, or 0.1% of all Medline articles; 61% of the articles were disease-specific, and 85% omitted reference to race/ethnicity.
- Research unrelated to STD addressed lesbians and gay men with similar frequency, bisexual persons were less frequently considered, and the least amount of research focused on transgender individuals.
- Findings supported that LGBT issues have been neglected by public health research and that research unrelated to sexually transmitted diseases is lacking.

What Is Not Captured Via the Census

No marriage like relationship

- Single adult
- Two Adults
- Three or more adults

Two related adults

Two unrelated adults

- Two men
- One man, one woman
- Women

Potential gay men and lesbians unobservable from the data

Potential same-sex relationships that are unobservable from the data
Census Data
Benefits and Limitations

**Benefits**
- Short form data readily available and can be used to look at geographic distributions
- Advanced query function

**Limitations**
- Inferring sexual orientation; miss uncoupled gay men and lesbians
- Controversy about recode procedures and comparability of households from ’90 to ’00
- PUMS are samples of samples; complex data set
Comparing RDD and APD sampling for sexual minority women’s surveys

Using best practices for data collection in both methods, very similar response rates were achieved. The percentages of lesbian and bisexual women were nearly identical and quite high (13%+), as were responses on health questions. Results showed that HH sampling can be successfully implemented with women of diverse sexual orientations in the Boston area, a politically and socially progressive urban area.
## Comparison 1

<table>
<thead>
<tr>
<th>Method</th>
<th>Our Total Cost</th>
<th>Our Cost Per CM</th>
<th>Burden on Researcher</th>
<th>Yield (N of lesbian HHs)</th>
<th>Utility</th>
</tr>
</thead>
<tbody>
<tr>
<td>HH survey</td>
<td>$51,163</td>
<td>$1,504.79</td>
<td>high</td>
<td>(gross yield): $34/767 = 4.6133%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(among enumerated HHs): $34/465 = 7.3118%</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(among HHs known to be eligible): $34/342 = 9.9415%</td>
<td></td>
</tr>
<tr>
<td>RDD survey</td>
<td>$25,571</td>
<td>$913.26</td>
<td>medium</td>
<td>(gross yield): lesbian only $17/1250 = 1.36% and $28/1250 = 2.24%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(among enumerated HHs): lesbian only $17/681 = 2.4963% and $28/681 = 4.1116%</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(among HHs known to be eligible): lesbian only $17/216 = 7.8704% and $28/216 = 12.963%</td>
<td></td>
</tr>
<tr>
<td>PUMS (with equip.)</td>
<td>$7,466</td>
<td>$2.47</td>
<td>low</td>
<td>(gross yield): $3,028/5,140,746 = 0.0589%</td>
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</tr>
<tr>
<td>PUMS (with equip.)</td>
<td>$11,548</td>
<td>$3.81</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
## Comparison 2

<table>
<thead>
<tr>
<th></th>
<th>Gross yield</th>
<th>Among enumerated HHs</th>
<th>Among known eligible HHs</th>
<th>N</th>
<th>Cost</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HH</strong></td>
<td>4.61</td>
<td>7.31</td>
<td>9.94</td>
<td>34 lesbians</td>
<td>$51,163</td>
<td>$1,504.79</td>
<td></td>
</tr>
<tr>
<td><strong>RDD</strong></td>
<td>1.36/2.24</td>
<td>2.49/4.11</td>
<td>7.87/12.96</td>
<td>17 lesbians; 28 by Laumann</td>
<td>$25,571</td>
<td>$913.26</td>
<td></td>
</tr>
<tr>
<td><strong>PUMS</strong>*</td>
<td>.0589</td>
<td></td>
<td></td>
<td>3,028 HHs 6,056 inds.</td>
<td>$11,548</td>
<td>$3.81</td>
<td></td>
</tr>
</tbody>
</table>

* includes equipment costs
Principal challenges for survey researchers I

• Usual issues:
  • sampling frame issues
  • geographic or other clustering
  • targeting strategies
  • representativeness
  • generalizability
Principal challenges for survey researchers 2

- Additional issues
  - risky disclosure
  - definitional issues
  - characteristic not necessarily overt or observable
  - relative lack of resources to do research
  - lack of criterion data
Health Concerns and Disparities
Purpose of the White Paper

Provide a comprehensive review of:

1) methodologically sound GLBT health studies
2) methods to better study the health of GLBT people

Why? To inform policy: for example, the Healthy People 2010 process
White Paper Contents

- Public Health Infrastructure
- Access to Quality Health Services
- Health Education
- Educational and Community-Based Programs
- Cancer
- Family Planning
- HIV/AIDS
- Immunization and Infectious Diseases
- Mental Health and Mental Disorders
- Sexually Transmitted Diseases
- Tobacco Use
- Violence and Sexual Assault
- Methodological Challenges to Research

www.glma.org
Priority Health Concerns

- Mental Health
- AIDS, HIV
- STDs
- Cancer
- Tobacco
- Substance Abuse
- Provider lack of competence
- Non-responsive health systems
Behavioral/Mental Health

- Depression
- Child rearing decisions
- Nutrition, exercise
- Unique features of counseling
Substance Abuse

- AOD
- Poppers
- Methamphetamine
- Tobacco
Social Ecological Model
Context for Poor Access and Health Disparities

• Stigma
• Homophobia
• Lack of family and community
• Social disconnection

Result: vulnerable populations, subject to all concerns that go with this.
Public Health Response
**HP2010: Subgroups of Concern for Eliminating Disparities**

- Racial and ethnic minorities
- Populations defined by income, age, and/or gender
- Populations with disabilities
- Populations defined by sexual orientation
- Populations defined by educational attainment
- Populations defined by geographic locale
10 Leading Health Indicators

= LGBT disparities

• Physical activity
• Overweight and obesity
• Tobacco use
• Substance abuse
• Responsible sexual behavior
• Mental health
• Injury and violence
• Environmental quality (social)
• Immunization
• Access to health care
Probable Impact of Expanded Focus on Sexual Orientation

• Opportunity for sexual minorities to receive increased access and more culturally competent care
• Improve likelihood that sexual minorities will experience increased quality and years of healthy life
• Facilitate the elimination of health disparities for LGBT communities
• Creation of new approaches and dedicated resources
• Potentially substantive changes within the public health infrastructure
Advocacy Meets the Scientific Method: National Coalition for LGBT Health

• Conceived in late April 2000.
• First organizing meeting at the Millennium March.
• Second organizing meeting in June 2000 at Fenway, to develop coordinated plan with GLMA and HRSA to write the companion document.
• Formation meeting in DC October 2000.
Formation in 2000

January: • HP2010 conference edition released
        • white paper released
March: • HP2010 keynote at Scientific Workshop
        • short paper released
April: • meeting with Dr. Lurie in DC*
        • discussion with Marty Rouse at Fenway
May: • urban public health officials met in Boston
        • group discussion at Millennium March
June: • Boston meeting to join HP2010 companion document and coalition development
October: • DC meeting to form the coalition
HP2010: The Companion Document

- National workgroups broadly representative of LGBT communities
- Focus on gender identity as well as sexual orientation
- Leadership through GLMA, with HRSA funding
- Presentation of draft document at November APHA
Initial Concerns

- HP2010 companion document
- Inclusion of sexual orientation measures in Federal surveys
- Expanding coalition membership and diversity
- Communication within LGBT communities and with government agencies
- Representation on federal committees and advisor groups
- Consensus-building for advocacy efforts
Critical steps in development of LGBT research (selected)

• Institute of Medicine report on lesbian health and research priorities (1999)
• March 2000 Scientific Workshop on Lesbian Health
• Healthy People 2010
  • white paper
  • companion document
• National Coalition on LGBT Health
• Lesbian Health Conferences 2001-2004
• Annual LGBT Health Summits
State-Level Response: Virginia Transgender Health Initiative

- Collaboration of VA Dept. of Health, Division of HIV/STD, the Virginia HIV Community Planning Group, and the Survey and Evaluation Research Laboratory, HIV Working Group.
- Multi-phase study, qualitative and quantitative.
- Purpose: determine healthcare needs and barriers, to support program development and capacity building
- First phase – focus groups, now concluding
Opportunities and Challenges
The Fenway Institute  
Fenway Community Health

...an interdisciplinary center dedicated to excellence in gay, lesbian, bisexual and transgender (LGBT) health, through active programs in research and evaluation, training and education, and policy and advocacy. The Institute was created in June 2002 as an integral component of Fenway Community Health, grounded in the reality of patient needs and the practice of interdisciplinary, comprehensive health and mental health care.
“Quitting with Friends”
Exploring the Potential of Close Social Networks

- Fenway Community Health
- Howard Brown
- LA Gay and Lesbian Community Health Center

Funded by the American Legacy Foundation, Priority Populations Initiative
Why do so many of us smoke so much?

• We have a special kind of added stress from being LGBT.
• We’ve learned to smoke where we socialize – the cost of quitting is not simple.
• Maybe we are not as concerned for our own health and well-being as others are.
• We set priorities, and short-term gains can seem more important.
• Many of us, probably most of us, need help to break the habit. And we also need to have our lives as LGBT people!
What makes it harder for us to quit for good?

• There’s something about smoking… it makes certain things easier. So, we have to change, learn to manage without the help of tobacco, and this is hard to do.

• We have to believe that we can do it, that we have what it takes to quit and stay that way.

• We must find, accept, and keep the support and reinforcement that we need.
CSN – what’s different about it?

• Makes use of core curriculum that has been found effective with “mainstream” groups and tailored for LGBT groups – “Queer Tips” (UCSF).

• Adds the new component of doing cessation with friends, people who know each other and who decide as a “close social network” to engage in change together.

• In 3 ways, further tailors the curriculum to make explicit use of CSN group and interpersonal dynamics.
Friends…

- Care for you when you need it and even when you don’t
- Want the best for you
- Will help you if they can and if they know how
- Try to do what they’ve promised
- Know where you live
and your LGBT friends...

In addition to all of the above, also...

- Share your struggles to live in a homophobic and genderphobic world
- Have been there, too
- Know what makes you laugh, how to be there when you cry, and where you like to play
Intersex Health
Pilot Study Design

• Sponsored by the Intersex Society of North America (ISNA) in 2001
• Sample = 50 pediatric endocrinology fellowship programs in US and Canada
• Two phases: pilot study by email (16 returned); revised survey by email and mail to non-responders (24 returned).
• Response Rate = 29/50 (58%) – 90% from US; 10% from Canada. 5 pilot respondents included for core questions.
Limitations

• Not all institutions include the same syndromes in their definition of intersex conditions.
• 5 respondents to the pilot survey did not receive the full set of questions.
• Coding challenges for open-ended questions.
Patients Seen

- Responding programs saw a combined approx. total of 700 patients annually.
  - 190 (27%) were infants.
  - Age range of patients – birth to 50 years of age.
  - 1-30 infants seen annually (average = 7); 1-100 all intersex patients seen annually (average = 30).
  - Age range = birth – 50.
Psychological Support

- 69% of the responding programs offered mental health services to patients and families.
- 59% had certified mental health professionals on staff.
- Types of support:
  - child psychologists, psychiatrists, and social workers
  - web site resources, patient advocacy groups, and support groups
- 7% of practices refer their patients elsewhere.
Physicians’ Comments

• “Not an integral part of group or our institution.”
• “Several involved – no one with particular expertise.”
• “We work in a county hospital with limited resources. It’s a depressing, deplorable state of affairs.”
• “Response to “Does your group include one or more certified mental health specialists?” ‘I answer no with great regret.’
Psychological Support

- 69% of the responding programs offered psychological support.
  - 19% of their patients and/or families received support during diagnosis.
  - 15% received support after diagnosis.
- What accounts for such limited acceptance?
  - Perhaps trust is an issue; support is usually given by physicians on the treatment team, rather than by trained mental health staff.
Physicians’ Comments

- “It’s offered to all but not generally chosen. Strange, isn’t it?”
- “I think our psychological evaluation and support here is not adequate for patient needs. Only most obvious problem ones seem to get support. Yet, probably the need is universal for all patients with this sort of condition.”
- “Very rarely given. We physicians try to provide as needed.”
Summary

• There appears to be:
  • a dearth of mental health practitioners with intersex experience
  • which may stem from a lack of intersex training programs for mental health professionals
• Available support is often not accepted by patients and families.
• It is unclear who determines the need for these services and on what basis.
• Patients who travel long distances for medical care may be unwilling and/or unable to also travel for support services, hoping to find them closer to home.
Needs

• Training on intersex conditions and family impact for medical and mental health providers, in community as well as institutional settings
• Increased multi-disciplinary provider teams
• Strategies for encouraging parents to accept help when offered
• Development of accessible, community-based services
• Additional research to explore reasons why parents do not accept needed help when offered
• Inclusion of effective mental health and social support components within comprehensive intersex management protocols.
Multicultural AIDS Coalition of Boston

- Forging collaboration between minority-based and research-based community HIV organizations
- Developing and evaluating culturally-based “Health System Navigation” for HIV testing and medical care engagement and retention
- African American Women, Faith Communities, MSM, IDUs
Lessons Learned

• Institutional cultures vary significantly between the agencies, which has a direct effect upon working styles.

• This gap need not become a barrier to partnership, especially when management of both agencies consider the longer-term benefit of partnership efforts and actively support its evolution.

• Substantial time must be invested at start-up to create an effective partnership and to build the infrastructure of agreements that can ensure its sustainability.
Sexual Minority Women of Color: A Summit for Building Community Research Partnerships

5th Annual Lesbian and Bisexual Women’s Health Research Forum
October 4, 2002
Beth Israel Deaconess Hospital
Boston, Massachusetts
Primary Objectives of the Forum

- Review previous and current research relevant to sexual minority women of color
- Identify research initiatives which will assist with the elimination of health disparities for lesbian and bisexual women of color
- Explore the benefits of research participation to community based organizations
- Identify and prioritize the health care needs of lesbian and bisexual women of color in Boston
- Identify the research interests of people who provide services to sexual minority women of color in Boston
- Identify barriers to conducting research that is sensitive to the concerns of sexual minority women of color and to the special outreach strategies necessary for study recruitment, and to
- Develop workable solutions towards overcoming these barriers
What are the barriers to doing community research with sexual minority women of color in Boston?

- Isolation
- Distrust
- Racism and Sexism
- Sexual Minority Identification
- Organizational Constraints
- Societal Constraints
Same-Sex Marriage: A Health Issue?
Research Findings

• A decade of research on marital interaction suggests that marital functioning is consequential for health, with gender-related differences.
• Marriage’s protective effects are stronger for men than for women.
• Marriage’s damaging effects are stronger for women than for men.
• Interventions with couples have proven efficacious, although not to the extent desired.
• Continued efforts to develop efficacious interventions have the potential for sizable yields in physical and mental health.

Same-Sex Marriage and the Federal Budget

- Congressional Budget Office report concludes that allowing same-sex marriages would improve the Federal budget’s bottomline by less than $1 billion in each of the next 10 years. (assumes that same-sex marriages are legalized in all 50 states and recognized by the Federal government.)
- Losses in some benefit areas would be offset by gains in others.
- Some same-sex couples would gain, others would lose.
Emerging Population

- The AIDS crisis opened a way to address broader challenges of LGBT health
- Community mobilization
- Integration of research, program development, and coalition building
- Increasing awareness of diversity among sexual minorities
- Continuously organizing for change
Desired Response from Federal Government

- Add sexual orientation measures to national data systems (ensuring parity with other populations noted for disparities)
- Develop funding opportunities to support researchers in addressing these issues
- Spell out detailed expectations for researchers.
- Complete the promise of HP2010.
From Academic Institutions

- Train and mentor the next generation of researchers.
- Develop studies to address the most critical questions.
- Do these things in partnership with LGBT community groups, health care providers, and sponsoring organizations.
Shared Responsibility

- Attain consensus on research priorities and pursue funding.
- Address methodological challenges with creative approaches.
- Use results to develop interventions for health promotion and quality of life.
- Disseminate results to LGBT communities, health care providers, and researchers studying sexual minority health.
National Leadership

- Gay and Lesbian Medical Association
- National Lesbian and Gay Task Force
- Human Rights Campaign
- Mautner Project for Lesbians with Cancer
- National Coalition for LGBT Health
- GLAD
- Gill Foundation