At the End of the Rainbow: Sexual and Gender Minority Well-Being at the End of Life

Caroline Dorsen, PhD, FNP-BC, FAAN (she/her)

May 6, 2022
Caroline.dorsen@rutgers.edu
You have worked so hard to make your practice inclusive!
<table>
<thead>
<tr>
<th>Preferred Pronoun:</th>
<th>□ He</th>
<th>□ She</th>
<th>□ They</th>
<th>□ Ze</th>
<th>□ A pronoun not listed</th>
<th>□ No pronoun preference</th>
</tr>
</thead>
</table>

We require the following information for the purposes of helping our staff use the most respectful language when addressing you, understanding our population better, and fulfilling our grant reporting requirements. The options for some of these questions were provided by our funders. Please help us serve you better by selecting the best answers to these questions. Thank You.

<table>
<thead>
<tr>
<th>Preferred Spoken/Written Language:</th>
<th>English</th>
<th>Spanish</th>
<th>American Sign Language</th>
<th>Other: [ ]________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language interpretation services needed?</td>
<td>□ No</td>
<td>Yes, language: [ ]________</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sexual Orientation:</th>
<th>Lesbian</th>
<th>Gay</th>
<th>Straight</th>
<th>Bisexual</th>
<th>Something Else</th>
<th>Queer</th>
<th>Decline to Answer</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Gender Identity:</th>
<th>Male/Man</th>
<th>Female/Woman</th>
<th>TransMale/TransMan</th>
<th>TransFemale/TransWoman</th>
<th>Genderqueer/Gender nonconforming</th>
<th>Something Else</th>
<th>Decline to Answer</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Race: <em>Select all that apply</em></th>
<th>American Indian/Alaska Native</th>
<th>Black and/or African American</th>
<th>White/Caucasian</th>
</tr>
</thead>
<tbody>
<tr>
<td>Native Hawaiian/Pacific Islander:</td>
<td>[ ] Native Hawaiian</td>
<td>Guamanian or Chamorro</td>
<td>Samoan</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity:</th>
<th>Non-Hispanic/Latino</th>
<th>Dominican</th>
<th>Cuban</th>
<th>Mexican, Chicano/a</th>
<th>Puerto Rican</th>
<th>Other Hispanic/Latino</th>
<th>Decline to Answer</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Veteran?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Migrant Worker?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>How did you first learn of Callen-Lorde?</th>
<th>Friend/Patient</th>
<th>Referral</th>
<th>Health Fair/Presentation</th>
<th>Callen-Lorde Website/Internet</th>
<th>Callen-Lorde Brochure/Ad</th>
<th>Facebook/Social Media</th>
<th>TV/Radio/Print Media</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Housing Status:</th>
<th>Stable Housing</th>
<th>Homeless</th>
<th>Decline to answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>If homeless, select which best applies:</td>
<td>Street</td>
<td>Homeless Shelter</td>
<td>Transitional</td>
</tr>
<tr>
<td>------------------</td>
<td>----------------</td>
<td>----------</td>
<td>-------------------</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex Assigned at Birth:</th>
<th>Male</th>
<th>Intersex</th>
<th>Female</th>
<th>Decline to Answer</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Do you have a non Callen-Lorde primary care provider that you want to continue to see?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>


Your new patient
Some questions…?

• What does your patient’s SOGI have to do with their health?
• How might their SOGI impact your relationship with them and their support persons?
• What are the “best practices” in caring for LGBTQ+ patients? Are there any best practices?
Agenda

• Introduce commonly used language and concepts re: SGM health
• Discuss health disparities and current issues in the health and care of SGM persons
• Apply content to the special issues for SGM persons and their loved ones at the end of life
• Concrete suggestions for creating an affirming and inclusive environment
• Have an open and honest dialogue
Happy, Healthy, Fulfilling Lives
What is the difference between sexual orientation (SO) and Gender Identity (GI)?
## LGBTQ+ health: defining terms

### LGBTQ+ vs. SGM

<table>
<thead>
<tr>
<th>Gender identity Terms</th>
<th>Sexual Orientation Terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Transgender</td>
<td>• Lesbian</td>
</tr>
<tr>
<td>• Cisgender</td>
<td>• Gay</td>
</tr>
<tr>
<td>• Genderqueer</td>
<td>• Bisexual</td>
</tr>
<tr>
<td>• Non-Binary</td>
<td>• Pansexual</td>
</tr>
<tr>
<td>• Gender-diverse</td>
<td>• Sapiosexual</td>
</tr>
<tr>
<td>• Gender non-conforming</td>
<td>• Asexual</td>
</tr>
<tr>
<td>• Two-spirit</td>
<td>• Queer</td>
</tr>
<tr>
<td>• Intersex</td>
<td>• Same loving</td>
</tr>
</tbody>
</table>
Identifying the population

The U.S. Census Bureau in July, 2021 began asking Americans about SOGI.

This is the first time the federal government has tried to capture data on LGBTQ+ persons.
Record high of 7.1% of US population
Changing Demographics of SGM community

5.6 Percent of U.S. Adults Identify as LGBT

Share of American adults who identify as LGBT, by birth year

- Generation X (1965-1980)
- Baby Boomers (1946-1964)
- Traditionalists (before 1946)

Source: Gallup

LGBT share of U.S. population in 2020

- 2014: 3.8
- 2017: 9.1
- 2020: 15.9

5.6%

Statista
SGM disparities: Are they for real?
SGM Health Disparities

SGM persons have disparities in most of the leading US health indicators (*Healthy People 2030*):

- Access to and utilization of preventive and primary healthcare
- Chronic diseases including HTN, DM, some cancers
- Depression, anxiety and suicidality
- Reproductive and sexual health
- Substance use including tobacco, alcohol and illicit drugs
- Injury and violence
A few sobering statistics

• LGB youth 3-6x as likely to attempt suicide than heterosexual peers
  – Transgender youth 6x as likely

• 28% of transgender women are living with HIV
  – 56% of black transgender women are living with HIV

• 2-3x less likely to have health insurance

• Gay, bisexual, and MSM are about 20 times as likely as heterosexual men to develop anal cancer

• 20.5% of lesbian, gay, and bisexual adults smoke (as compared to 15.3% of heterosexual adults)
Intersectionality
HIV Disparities: The picture of intersectionality

New HIV Diagnoses in the US and Dependent Areas for the Most-Affected Subpopulations, 2019

Gay and bisexual men are the population most affected by HIV.
### Social Determinants of Health

#### Figure 1

**Social Determinants of Health**

<table>
<thead>
<tr>
<th>Economic Stability</th>
<th>Neighborhood and Physical Environment</th>
<th>Education</th>
<th>Food</th>
<th>Community and Social Context</th>
<th>Health Care System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td>Housing</td>
<td>Literacy</td>
<td>Hunger</td>
<td>Social integration</td>
<td>Health coverage</td>
</tr>
<tr>
<td>Income</td>
<td>Transportation</td>
<td>Language</td>
<td>Access to healthy options</td>
<td>Support systems</td>
<td></td>
</tr>
<tr>
<td>Expenses</td>
<td>Safety</td>
<td>Early childhood education</td>
<td>Social engagement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Debt</td>
<td>Parks</td>
<td>Vocational training</td>
<td>Discrimination</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical bills</td>
<td>Playgrounds</td>
<td>Higher education</td>
<td>Stress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td>Walkability</td>
<td></td>
<td>Quality of care</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Zip code / geography</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Health Outcomes**

Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations
Social Determinant Disparities

- Housing
- Education
- Employment
- Poverty (inclusive of access to food/food insecurity)
- Access to healthcare and health literacy
- Perception/Experience of stigma, discrimination and inequity
- Violence
Transgender Day of Remembrance

Saturday, November 20th 2021
5:30PM–6:30PM, Main Lawn

Join us to commemorate and honor the memory of the transgender people whose lives were lost in acts of anti-transgender violence.

Office of Diversity, Equity, & Inclusion
diversity@peace.edu
SGM social disparities during COVID

LGBTQ+ people often reported:
lost employment,
not have enough to eat,
be at elevated risk of eviction or foreclosure, and
face difficulty paying for basic household expenses

Census’ Household Pulse Survey
The Common Thread

STIGMA

Homophobia, transphobia, heterosexism and heteronormativity
Compounded by racism, sexism
Society at large, within healthcare, within communities & families
How does STIGMA impact health? Minority Stress Theory

![Diagram showing the impact of STIGMA on health through life stressors, psychosocial factors, behavioral factors, physiological factors, and cardiovascular risk factors.]

How does stigma impact access to care?

Delay care due to fear of real or perceived discrimination
Receive inappropriate or inadequate care
Be turned away from care
Less likely to have health insurance
Less likely to have enough healthcare providers, pharmacies
80% first year medical students expressed implicit bias towards LGBTQ persons, and 50% expressed explicit bias.

Nearly 56% of sexual minority and 70% of gender minority adults report having experienced some form of discrimination from clinicians (including the use of harsh/abusive language).

≈8% and 25% of sexual minority and transgender individuals, respectively, have been denied health care by clinicians.

LGBTQ+ People of color more than twice as likely to avoid seeing a provider than white counterparts.

Let’s think about this related to palliative care

- LGBTQ people may have:
  - Delayed primary and preventative care
  - Later diagnosis of chronic or serious illness
  - Increased risk factors for chronic disease and malignancy
  - Delayed referral to palliative care and/or hospice care
  - Inadequate pain control
  - Lower rates of completion of living wills and other advance care directives
  - Fewer available caretakers and support persons
  - Fewer choices for support services
Issues for the bereaved

- Disenfranchised grief (not being able to publicly grieve)
- Loss of health insurance, life insurance, housing
- Complicated grief, especially if not allowed to fully participate in care and decision-making of their loved one at the EOL
LGBTQ “boomers”: The Stonewall Generation
Younger generations

THE STATE OF

ANTI-LGBTQ+ BILLS

LGBTQ+ people are under a coordinated attack across the country. Over 330 anti-LGBTQ+ bills have been introduced this year and a record number may be signed into law.

LEARN MORE >
What about the US?
Wisconsin

Wisconsin's LGBTQ Policy Tally

Sexual Orientation Policy Tally: 12.75/20.5
MEDIUM

Gender Identity Policy Tally: 5.25/22
LOW

Overall Tally: 18/42.5
FAIR

See how Wisconsin compares to the rest of the country on the Snapshot page.

https://www.lgbtmap.org/equality MAPS/profile_state/WI
LGBTQ Global Health
What can you do? Attitudes and Knowledge

• Learn about the culture and healthcare needs of the LGBTQ+ community
  – History of LGBTQ civil rights struggles
  – Role of religion and spirituality in LGBTQ community
  – Mental and physical health disparities
  – Past experiences with healthcare providers and institutions, including any concerns about medical mistrust
  – Places of joy and resilience
• Know the legal landscape for your state and community
• Consider LGBTQ patients top concerns
  – Hormones
• Assess your IMPLICIT BIAS
Nurses’ Knowledge and Attitudes

A 2019 review of top 20 nursing journals found:
– 2009 and 2017 only 0.19% of the literature in the top 20 nursing journals focused on SGM health.

A 205 study on health care provider’s implicit and explicit attitudes towards lesbian women and gay men:
– Online survey 2338 MDs, 5379 nurses, 8531 mental health
– Heterosexual nurses held the strongest implicit preferences for heterosexual men and women

A 2013 survey of over 1,000 nursing faculty teaching in BSN programs indicates:
– The median time devoted to teaching LGBT health is 2 hours.
Hospice and Palliative Care Providers (2018)

N= 865 interprofessional hospice and palliative care providers
23.7% observed discriminatory care;
64.3% reported that transgender patients were more likely than cisgender patients to experience discrimination;
21.3% observed discrimination towards transgender patients;
15% observed the spouse/partner of LGBTQ+ patients having their treatment decisions disregarded or minimized;
14.3% observed spouses/partners or surrogates being treated disrespectfully

What can you do? Environment

Non discrimination statements
Intake forms and processes
Posters, pamphlets, PR and marketing

In New York City, it is illegal to discriminate on the basis of a person's sexual orientation, gender identity or gender expression in public accommodations, including in health care settings.

You have the right to:
1. Be treated with dignity, respect and professionalism in all health care settings by all providers and all staff.
2. Receive compassionate, judgment-free and comprehensive care that is mindful of your sexual orientation, gender identity and gender expression for all health services.
3. Respectful discussions with providers about your health and health care needs, including your sexual history and current sex life.
4. Have your gender identity and gender expression recognized, affirmed, documented and accommodated in all health care interactions.
5. Clear explanations of providers' requests for your health information.
6. Clear explanations of all medical procedures and risks, and the right to choose or refuse any treatment.
7. Access health insurance coverage and benefits without discrimination based on sexual orientation, gender identity and gender expression.
8. Choose who will make medical decisions for you if you are unable; and, if you are a minor, the right to have your voice and best interests included in these decisions.
9. Decide who may and may not visit you if you are admitted to a health care facility.
Creating an inclusive environment


**What does gender affirmation mean to you? An exploratory study**

Caroline G Dorsen, Noelle Leonard, Lloyd Goldsamt, Amy Warner, Kevin Gomez Moore, Nathan Levitt, Peri Rosenfeld

Affiliations + expand

PMID: 34535901  DOI: 10.1111/nuf.12648
Pronouns!
Basic inclusive and affirming history questions

- Ask of ALL patients. You do not know who will benefit from your inclusivity.
- LGBTQ+ Inclusive Palliative Care Interview Questions:
  - What name would you like me to call you?
  - What gender pronoun do you go by? (e.g., he/him, she/her, them/their, ze/zir, etc. [Ensure subsequent use of the patient’s preferred pronouns.]
  - Who do you consider to be your family?
  - Who is available to help you at home with your everyday needs when you are sick?
  - Chochinov’s dignity question:
    - What should I know about you to help me provide the best care for you?

What to do if you misgender someone?

- Brief apology
- Move on
- Try harder next time!
What can you do? Be an ally

The truth is, no one of us can be free until everybody is free.

— Maya Angelou —