The Graying Rainbow: A Culturally Competent Approach to the Care of the Older LGBTQ Population

PLENARY TALK

June 8, 2017

Inter-professional Team: Matthew Gayton
Noelle Marie Javier, Jim Palmer III, Jeffrey Weiss,
Evan Zazula

Mount Sinai

NO FINANCIAL DISCLOSURES

EDUCATIONAL OBJECTIVES

- To review and define basic terms, concepts, and constructs pertaining to the LGBTQ population
- To provide an overview of the historical perspective that has shaped this population
- To describe the epidemiology and disparities in healthcare
- To discuss key points in the multi-dimensional approach to LGBTQ health care
- To provide standard and effective culturally competent strategies in the care of the Older LGBTQ adult

TOPIC OUTLINE

- Introduction/Definition of terms
- Short Historical background
- Epidemiology
- Health disparities
- Medical Domain
- Key points in Transgender medicine
- Psychological Domain
- Social Domain
- Spiritual Domain
- Palliative Care/EOL care Considerations
- Laws & regulations

A ROSE BY ANY OTHER NAME……

…LGBTQI, gay, lesbian, bisexual, queer, dyke, MSM, WSW, same gender loving, transgender, trans* transsexual transman transwoman transvestite crossdresser genderqueer androgyne bigender pangender drag queen drag king femme queen ambigender non-gendered agender gender fluid intergender DQ T-girl TG FTM MTF Two-Spirit Mixu'ga Na'dleeh He'eman Agi/Axi Wi'kta/Wingkte' Lila Witkowin Kwido Ihamana Osha'pu Hoobuk Bote /Bade Biatti /Miati Hijira Fa'afafine Kathoey Mahu…

BASIC TERMINOLOGY

Gender Identity	Refers to a person's basic internal sense of being a man/boy, woman/girl, or another gender (transgender, bigender, gender-queer, intersex, gender-non-binary)
Gender expression or Gender presentation	Denotes the manifestation of characteristics in one's personality, appearance, and behavior (PAB) that are culturally & socially defined as masculine or feminine
Gender role conformity	Refers to the extent a person's gender expression adheres to the socio-cultural norms
Gender dysphoria	Refers to a persistent discomfort with one's sex assigned at birth (natal sex)

BASIC TERMINOLOGY

Homosexual	Orientation toward someone of the same gender in affection, attraction, sexual behavior, and/or self-identity (AABI)
Lesbian (L)	Homosexual women
Gay (G)	Homosexual men or women, more commonly men
Bisexual (B)	Orientation toward both males & females (AABI)
Transgender (T)	Broad category of people whose gender identity and expression do not match their biological sex, including transsexual, transvestite, and intersex individuals
Questioning or Queer (Q)	Uncertain about which group to fall under

SOGI

Sexual Orientation vs Gender Identity

Basic SOGI: Keeping it Simple

Gender Identity

Sense of oneself as male ,female, masculine, feminine, both, neither, leaning towards

It involves social and personal identity, behaviors and roles

Transgender: Describes a person whose gender identity or expression is different from the sex assigned to them at birth

Sexual Orientation

Romantic, sexual and affectional attraction to others

Includes straight or heterosexual, gay, lesbian, bisexual, asexual

LGBTQ= shorthand for lesbian, gay, bisexual, transgender, queer/questioning

ittle Cry the

Gay and Transgender Patients to Doctors: We'll Tell. Just Ask.

THE DOCTOR'S WORLD
The Earliest Signs of Brain Damage in Athletes? Listen for Them

PERSONAL HEALTH
A New Drug for A.L.S., but the Diagnosis Remains Dire
PAID POST: HENNESSY
Finding the Desert's Hidden Voice
Hennessy PARADIS IMPERIAL

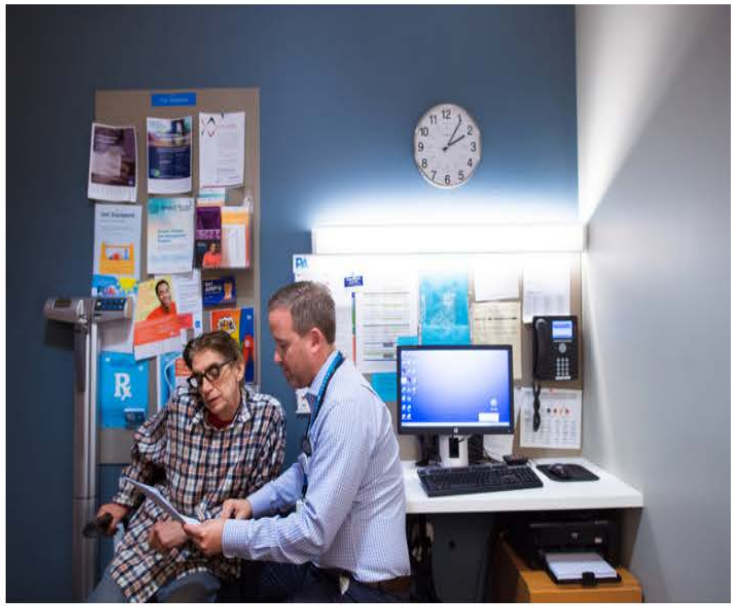
China's Ill, and Wealthy, Look Abroad for Medical Treatment

THE NEW HEALTH CARE
Science Needs a Solution for the Temptation of Positive Results

HEALTH

Gay and Transgender Patients to Doctors: We'll Tell. Just Ask.

By JAN HOFFMAN MAY 29, 2017



Dr. Alex Gonzalez, the Medical Director at Fenway Health in Boston, meeting with a patient earlier this month. Gretchen Ertl for The New York Times

The EQUALITY Study 2017

Emergency Department Query for Patient-Centered Approaches to Sexual Orientation and Gender Identity

- Design: exploratory, sequential, mixed-method design using qualitative interviews in Baltimore and D.C. followed by on-line surveys
- Sample: 53 patients, 26 health professionals for the interviews; 1516 pts and 429 ED providers for the on-line surveys
- Main outcomes: to obtain perspectives on the data collection for sexual orientation; quantitative survey to gauge patients' and providers' willingness to provide or obtain sexual orientation information

Haider A et al. JAMA Intern Med. 2017;177(6):819-28

The EQUALITY Study cont'd…

- Mean age patient: 49
- Mean age provider: 51
- Qualitative interviews: Patients are less likely to REFUSE to disclose SOGI
- 10% of patients reported refusal for SOGI information
- 77.8% of providers THOUGHT patient would refuse to provide SOGI information

Haider A et al. JAMA Intern Med. 2017;177(6):819-28

CLINICAL BOTTOM LINE

Implement a standardized patient-centered approach for routine collection of SOGI data

***Is It Okay To Ask*: Transgender Patient Perspectives on Sexual Orientation and Gender Identity in Healthcare**

- Methods: survey conducted from a nationally recruited sample of self-identified transgender patients on SOGI data collection
- Results: 54.5% (male gender), 58.4% (white), 33.7% (SO other than LGBS)
- 89% felt that SO was more important to disclose to primary care than GI
- 89% Females > 80% males to report medical relevance to chief complaint as a facilitator to GI disclosure

Maragh-Bass A et al. Acad Emerg Med. 2017; 24:1-13

Is It Okay To Ask cont'd…

- Many patients reported that medical relevance to chief complaint and an LGBT friendly environment would increase willingness to disclose SOGI.
- Patients also reported need for educating providers in LGBT health prior to implementing routine SOGI.

Maragh-Bass A et al. Acad Emerg Med. 2017; 24:1-13

CLINICAL BOTTOM LINE

Patients see the importance of providing GI more than SO to providers; nonetheless willing to disclose SOGI in general

HIGHLIGHTS in HISTORY

HISTORICAL AND COHORT EFFECTS

- Key concept in gerontology: Each age cohort has unique life experiences that influence attitudes, behaviors, cognitive functioning
- Each subgroup of older Americans has its own timeline of important events: African American, Hispanic Americans, Asian American, women, immigrants
- Engagement with older adults and subgroups of older adults is enhanced by knowledge of those collective and subgroup historical experiences

HISTORICAL TIMELINE

- 1950: U.S. Senate Report Issued: “Employment of Homosexuals and Other Sex Perverts in Government”
- 1952: American Psychiatric Assn. lists homosexuality as a “sociopathic personality disturbance”
- 1953: President Eisenhower bans homosexuals from working for the federal government
- 1956: Psychologist Evelyn Hooker concludes that hetero- and homosexual persons do not different significantly in adjustment
- 1967: *Look* magazine publishes the article: “The Sad Gay Life of the Homosexual”
- 1969: Stonewall Riots: Beginning of Gay rights movement

HISTORICAL TIMELINE

- 1973: American Psychiatric Assn. votes to remove homosexuality as a mental illness
- 1979: National March on Washington for Lesbian and Gay Rights
- 1981: New York Times reports on first cases of what will later be called AIDS
- 1986: Supreme Court upholds right of states to criminalize sex between consenting same sex adults
- 1987: National AIDS advocacy group, ACT-UP is founded.
- 1993: Military issues “Don’t Ask, Don’t Tell” directive
- 1996: President Clinton signs “Defense of Marriage Act” defining marriage as between one man and one woman

HISTORICAL TIMELINE

- 2003: Supreme courts rules that sodomy laws are unconstitutional
- 2004: Massachusetts legalizes gay marriage.
- 2011: Obama administration ends “Don’t Ask, Don’t Tell” in military
- 2013: Supreme Court strikes down “Defense of Marriage Act”
- 2015: Supreme Court legalizes same sex marriages through the country

EPIDEMIOLOGY

EPIDEMIOLOGY

- Gallup poll 2012 Williams Institute – 3.4% of American adults identify as LGBT (US population of 314.1 million)
- NHIS 2014 – 1.6% identify as LG, 0.7% as transgender (US population of 318.9 million)

EPIDEMIOLOGY

National survey 2014 by SAGE

- 43% of older and single LGBT & 60% of older LGBT in their 6th or 7th decade ~ sexual orientation not known to their providers
- 2/3 (65%) of transgender adults ~ felt limitation of healthcare as they grow older

Out and Visible: The Experiences and Attitudes of Lesbian, Gay, Bisexual, and Transgender Older Adults, Ages 45-75: A national survey by SAGE, 2014

NYC Numbers

1. **4.1% LGB in New York City or about**

   344,000 LGB residing in NYC and as many as 780,000 in New York State

   (NYC DOH CHS 2007, NYS ATS 2008**)**

2. **Transgender estimates range from 1 in 30,000 to 0.3 - 0.5 % (NYS =57,000, NYC = 24,000) but the number of transgender people seeking health services is growing**. (Gates,G. 2011. LGBT population in the United States, Williams Institute, UCLA)

3. 0.6% (1.4 million people) identify as transgender in the US; younger transgender adults > older transgender adults (2014 BRFSS study)

NUMBERS IN NEW JERSEY

Population of New Jersey 8.9 million x

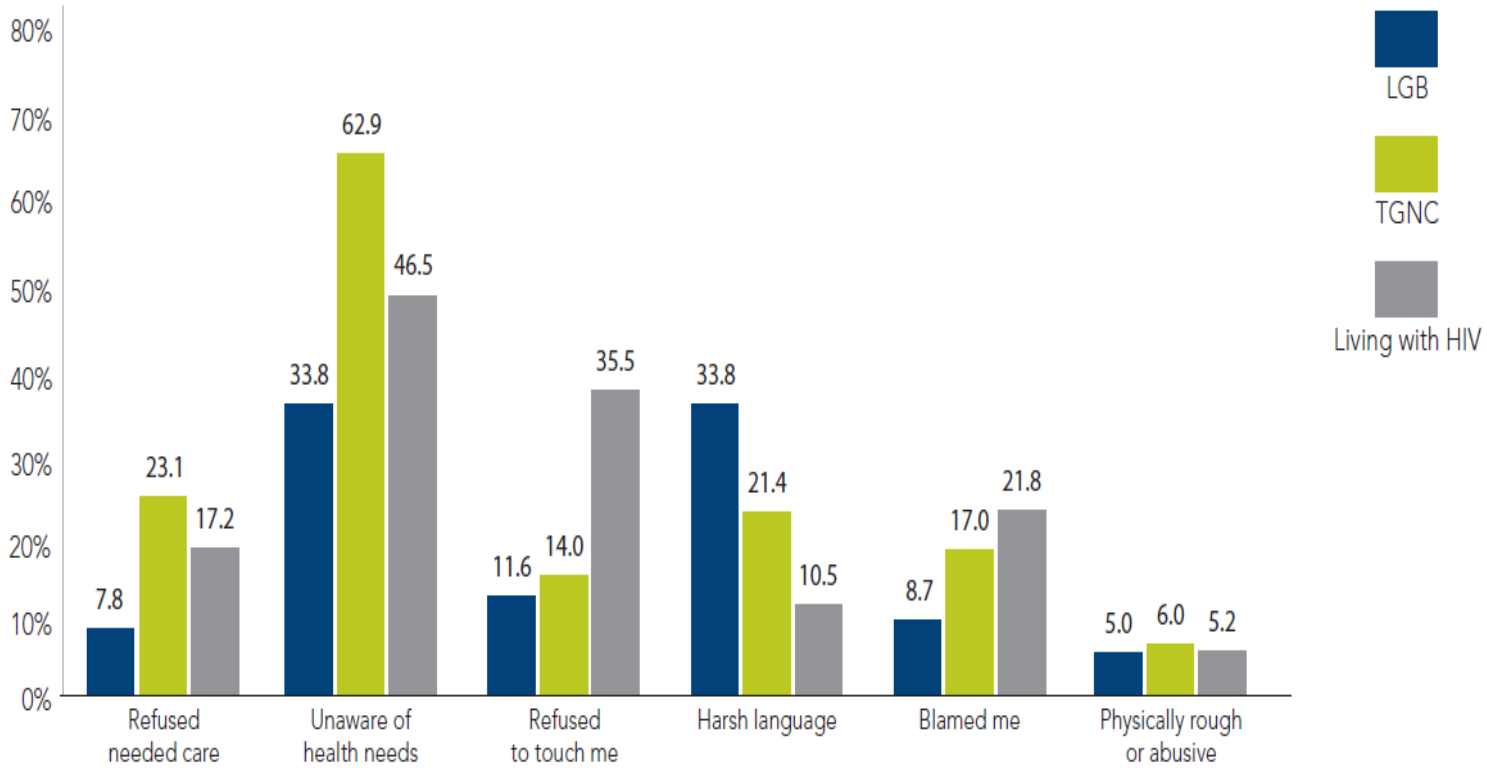
Survey	Ages	% Identify as LGBTQ	% Same Sex Partner	% Same Sex Desire	# LGBTQ in NJ
National Survey of Sexual Health and Behavior 2010	18+	11.3	n/a	n/a	**1 + million**
General Social Survey 2008	18-44	8.2	20	n/a	**712,000**
NSFG 2008	18-44	8.2	17.7	20.5	**712,000**
NHSLSS 1992	18-59	4.2	10.9	15.2	**373,8000**

http://worldpopulationreview.com/states/new-jersey-population/

LGBTQ Health Disparities = Intersection between social determinants of health, health risk behaviors, genetics, and immune functions related to minority stress

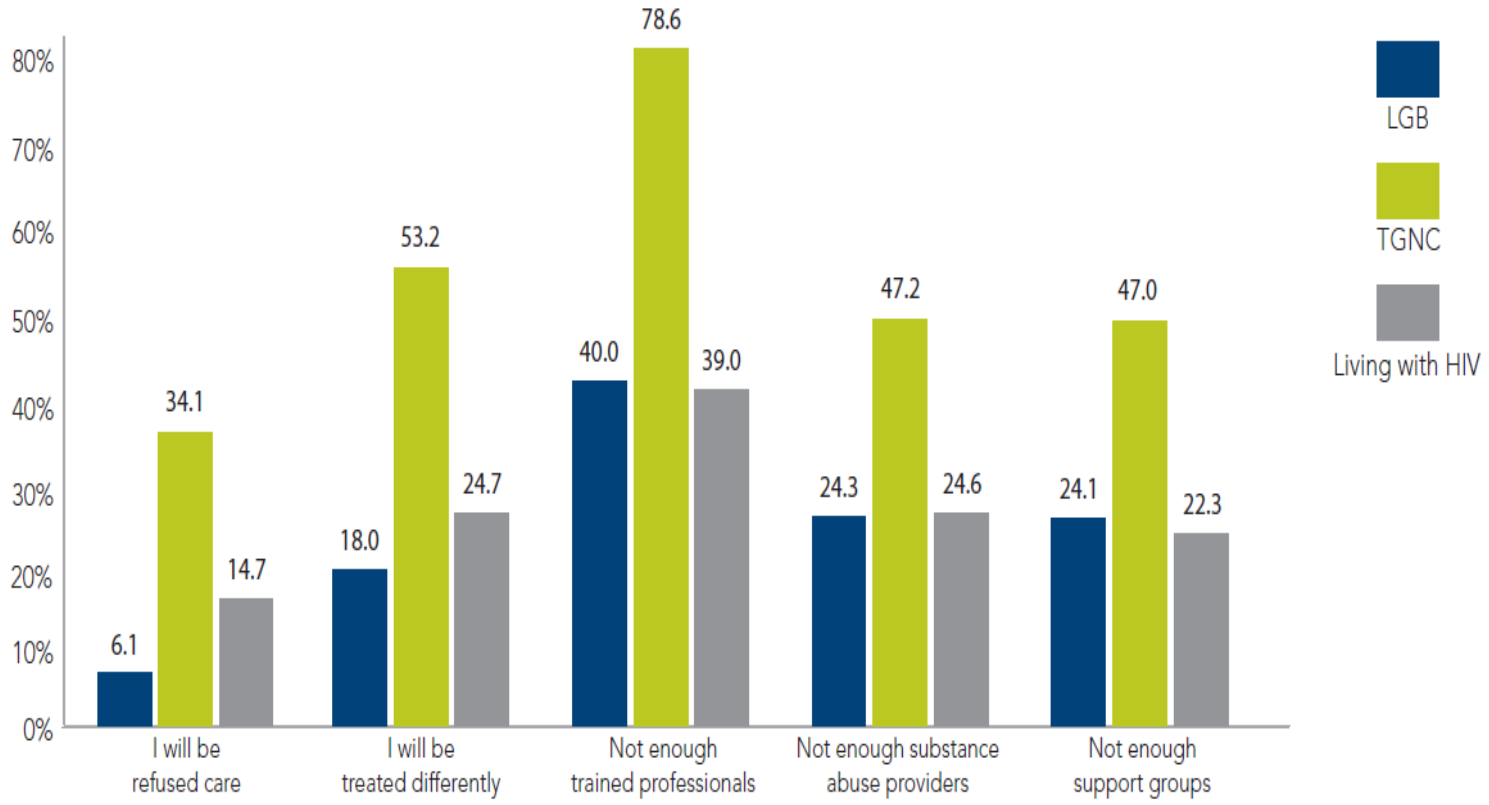
- Avoiding or delaying screening and care
- Minority stress: increased cortisol, inflammation, etc.
- Economic and/or geographic access to care
- Example : possibility that these conditions and interactions may account for elevated risk for breast and ovarian cancer and heart attacks in LB women.

Discrimination and Substandard Care: Older Adults and Adults Living with HIV



When Health Care Isn't Caring Lambda Legal's Survey on Discrimination Against LGBT People and People Living with HIV (New York: Lambda Legal, 2010.) Available at www.lambdalegal.org/health-care-report

Fears and Concerns about Accessing Healthcare: LGBT Older Adults and Older Adults Living with HIV



When Health Care Isn't Caring Lambda Legal's Survey on Discrimination Against LGBT People and People Living with HIV (New York: Lambda Legal, 2010.) Available at www.lambdalegal.org/health-care-report

National Health Interview Survey

- **Current smoker** Bi>LGB>Straight
- **Five or more alcohol drinks in past 3 days** Bi>LGB>Straight
- **Health status "excellent"** LG=Straight>Bi
- **Obesity** LG=Straight<Bi
- **Experience serious psychological stress in past 30 days** Bi>LG>Straight
- **Received Flu vaccine** LG>Straight>Bi
- **Have a usual place to go for medical care** Bi<LG<Straight
- **Failed to obtain medical care due to cost** Bi>LG>Straight

CDC/NCHS National Health Interview Survey, 2013

Compared to Heterosexuals…LGB individuals have…

- Higher prevalence & early onset of disabilities e.g. use of assistive walking device (Conron, Mimiaga, & Landers 2010)
- Higher rates of asthma (Landers, Mimiaga, & Conron 2011)
- Higher rates of allergies (Lock & Steiner 1999)
- Higher rates of osteoarthritis & chronic GI issues (Sandfort, Bakker et al 2006)
- Lesbians & bisexual women ~ higher risk for breast cancer and cardiovascular disease (Brown & Tracy 2008; Conron, Mimiaga, & Landers 2010)
- Gay & bisexual men ~ higher rates of cardiovascular disease; migraine headaches, and urinary incontinence. (Wang, Hausermann et al 2007; Sandfort, Bakker et al 2006)

Lesbian, Gay, Bisexual and Transgender Health Disparities in New York City

Somjen Frazer, Jonathan Rodkin and Casey Weston, Strength In Numbers Consulting Group, Inc.
for The Empire State Pride Agenda Foundation, 2014

Fig. 5: Prevalence of obesity among gay/lesbian, bisexual, and heterosexual adults, by race/ethnicity

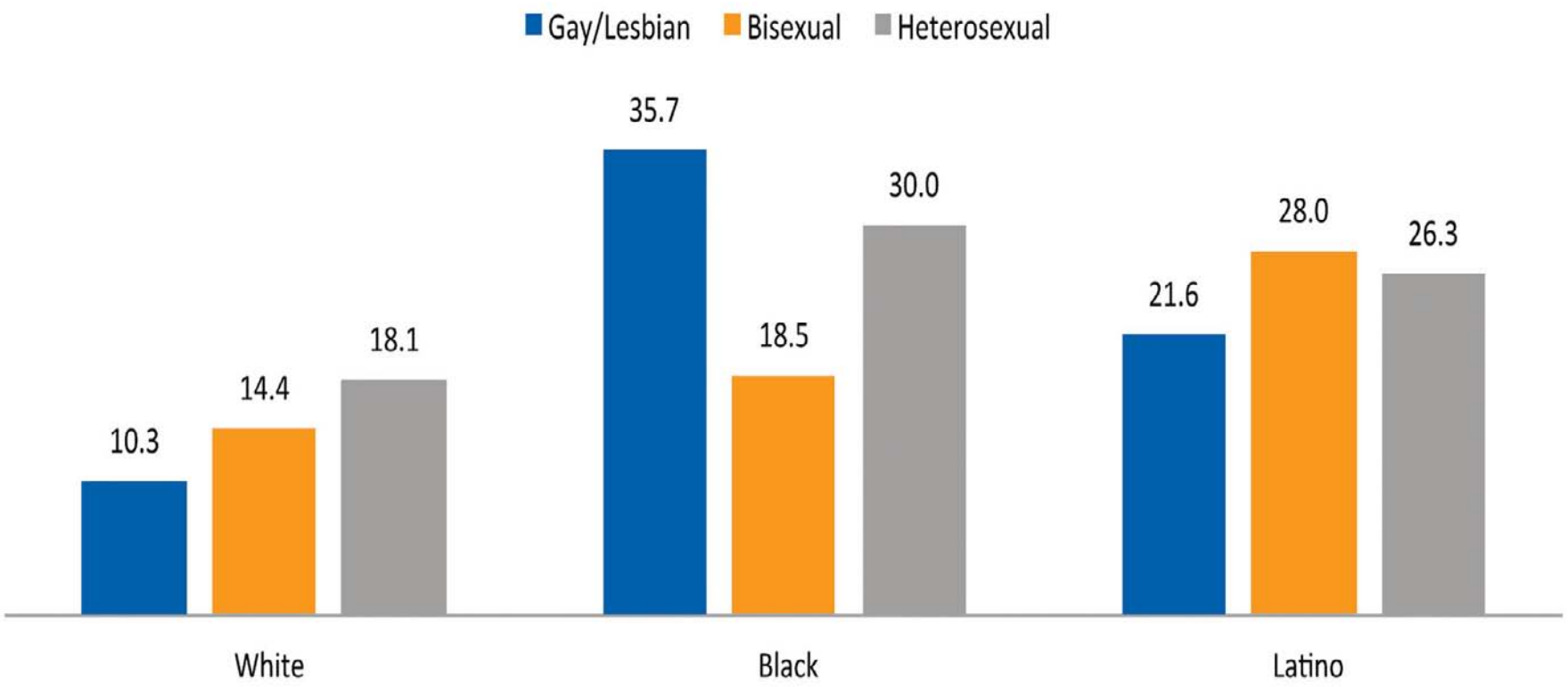


Fig. 10: Prevalence of depression diagnosis among gay/lesbian, bisexual, and heterosexual adults, by race/ethnicity

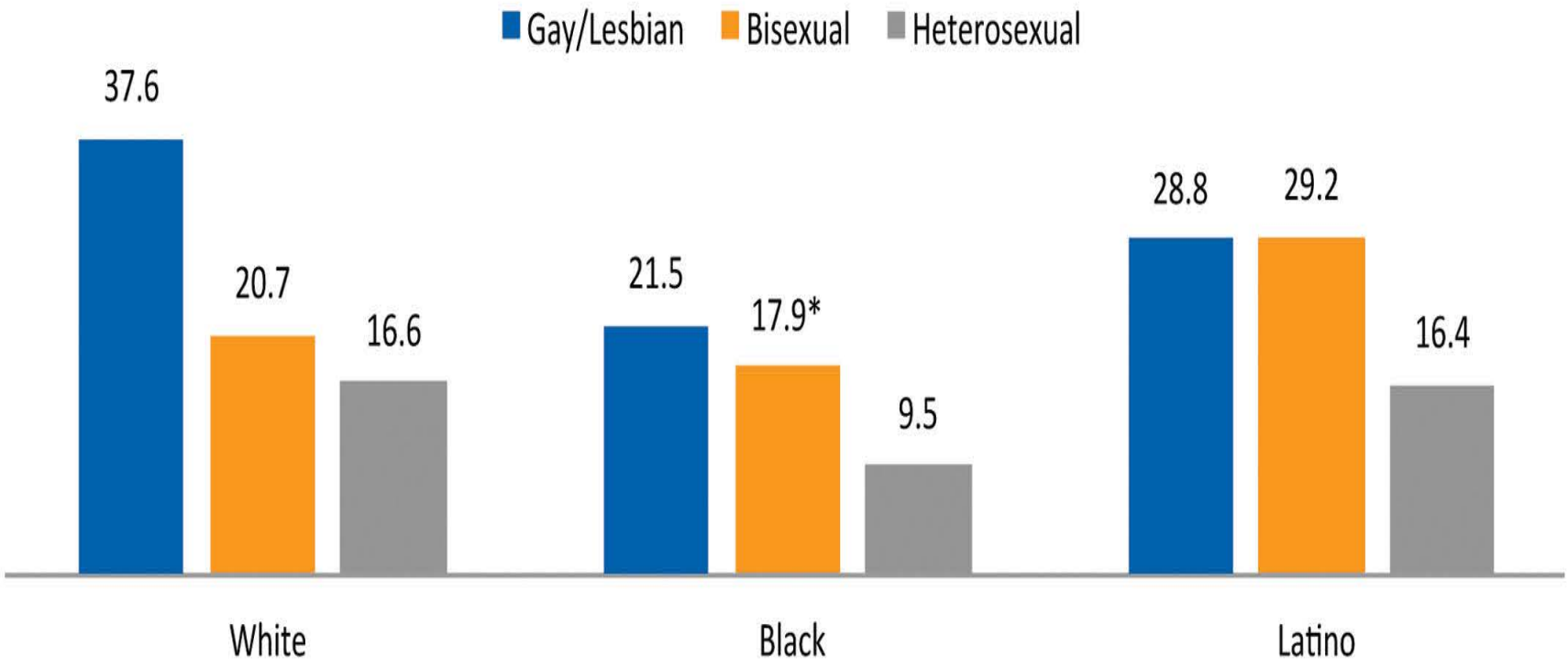
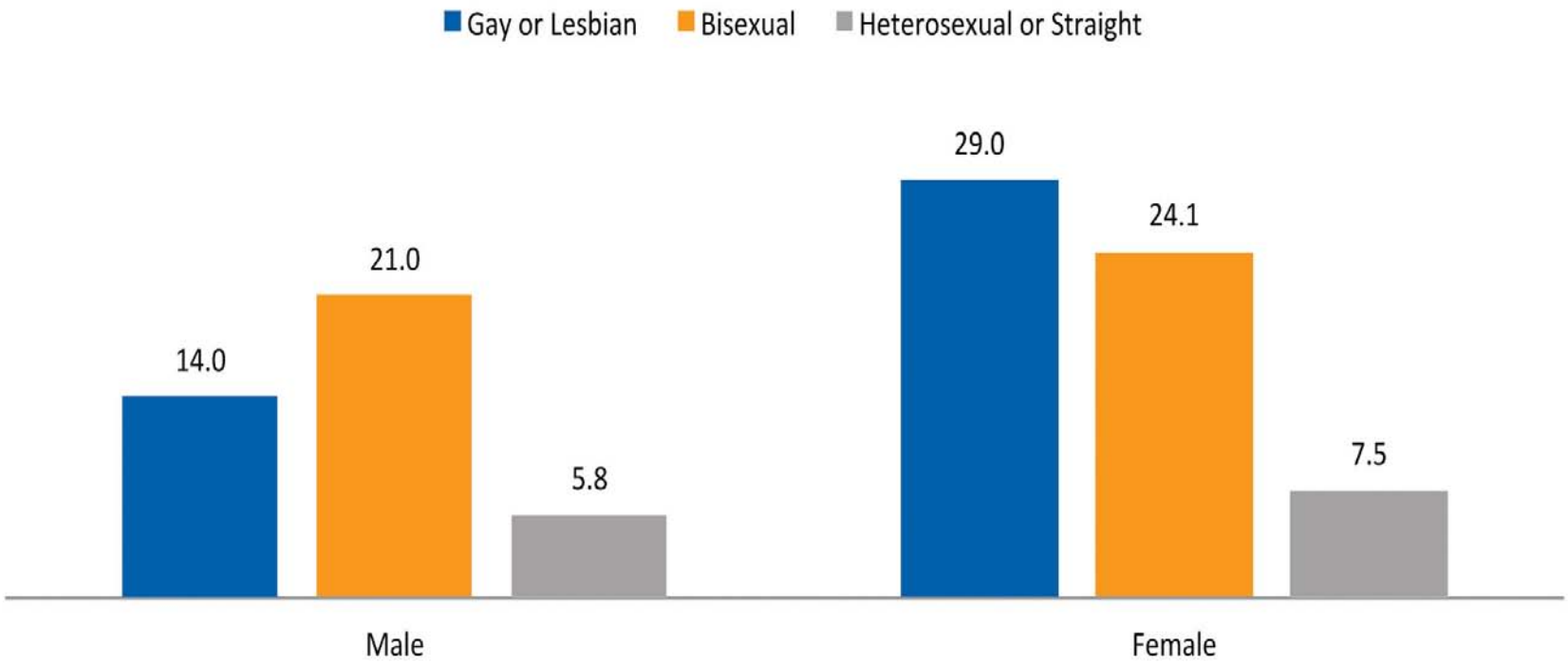


Fig. 8: Prevalence of suicide attempt among gay/lesbian, bisexual, and heterosexual high school students, by gender (12 months)



REFERENCES

- CDC/NCHS National Health Interview Survey, 2013
- GLMA, 2013. Compendium of Health Profession Association LGBT Policy & Position Statements. Retrieved from: http://www.glma.org/_data/n_0001/resources/live/GLMA%20Compendium%20of%20Health%20Profession%20Association%20LGBT%20Policy%20and%20Position%20Statements.pdf
- Equaldex, (2017). LGBT rights in New Jersey. http://www.equaldex.com/region/united-states/new-jersey
- Grant, J.M., Mottet, L.A., Tanis, J., Harrison, J., Herman, J.L., and Keisling, M. (2011). Injustice at Every Turn: A Report of the National Transgender Discrimination Survey, Executive Summary. National Gay and Lesbian Task Force. www.taskforce.org
- Human rights campaign, 2017. Score card on the issues. http://www.hrc.org/local-issues/new-jersey
- Human rights campaign. (2017). Healthcare equality index scoring criteria. http://www.hrc.org/hei/hei-scoring-criteria
- Health Care Isn't Caring Lambda Legal's Survey on Discrimination Against LGBT People and People Living with HIV (New York: Lambda Legal, 2010.) Available at www.lambdalegal.org/health-care-report
- Juster, R.P., Smith, N.G., Ouellet, É., Sindi, S., Lupien, S.J. (2013) Sexual orientation and disclosure in relation to psychiatric symptoms, diurnal cortisol, and allostatic load. Feb; 75(2): 103-16. Psychosom Med.
- UCLA Center for Health Policy. 2016. California Health Interview Survey. http://healthpolicy.ucla.edu/Pages/home.aspx
- Vespa-Papaleo, FJ. (2007). Recent Legislative Amendments to the LAD & FLA. Division on Civil Rights Director's Report. The State of New Jersey Department of Law & Public Safety. http://www.nj.gov/oag/dcr/report.html
- http://worldpopulationreview.com/states/new-jersey-population

Bias: Conscious vs. Unconscious

Research shows that our brains jump to assumptions and conclusions without us even knowing it.

This is the science of **“unconscious bias”.** Unconscious bias applies to how we perceive other people. We are all biased and becoming aware of our biases will help us mitigate them in the workplace and socially . Interestingly, the research shows that both men and women share and apply the same assumptions about gender.

EXAMPLES of GENDER RELATED BIAS

Societal

Assuming the husband's job caused the family to relocate.

And "Does your wife work?" vs. "What does your wife do?"

Work

If a woman in leadership is introduced as "This is one of our senior/executive *women* in leadership..."

vs.

"This is one of our senior leaders...". We never say "This is one of our senior men in leadership."

Examples for Sexual Orientation and Gender Identity

When asking a man who says he is married, "What does your wife do "

Or to a woman "What does your husband do"

Asking a man if he has a girlfriend or asking a woman if she has a boyfriend

A receptionist at a pediatrician's office asking a lesbian couple which of the pair is their child's "real" parent

Asking an openly identified transgender person when they changed their sex, or they have had "the" surgery - questions that within most social conventions are deemed too personal to ask when first meeting people perceived as non-transgender.

ETHICS: AMA

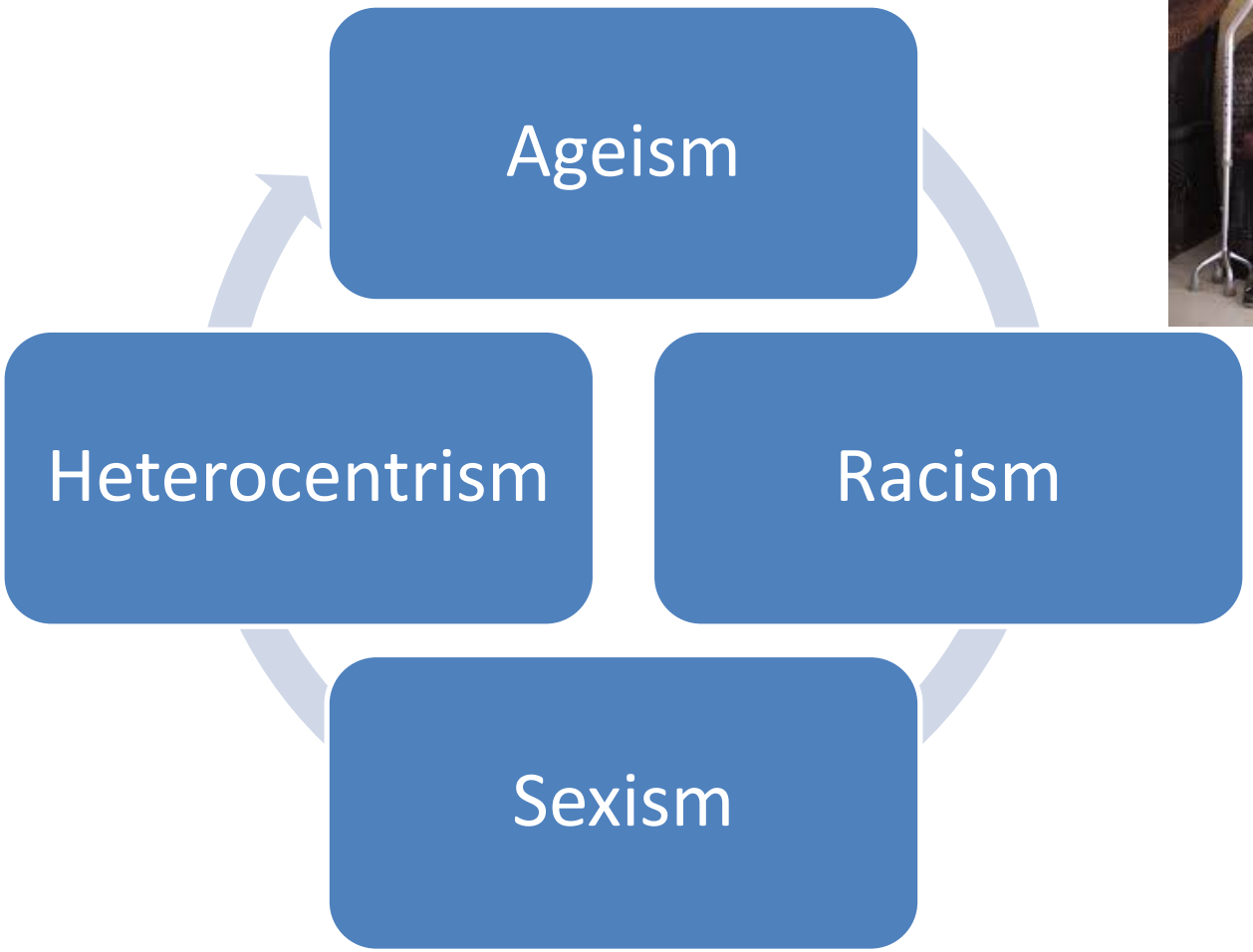
E-9.12 Patient-Physician Relationship: Respect for Law and Human Rights. …. However, physicians who offer their services to the public may not decline to accept patients because of race, color, religion, national origin, sexual orientation, gender identity, or any other basis that would constitute invidious discrimination....

HOLISTIC CULTURALLY COMPETENT & COMPASSIONATE CARE APPROACH

MULTIPLE DIMENSIONS OF CARE = HOLISTIC CARE

- Physical
- Mental
- Emotional or Psychologic
- Sexual
- Cultural
- Religious
- Financial
- Social

Be Mindful: Intersectionality



LGBTQ Aging

MEDICAL DIMENsion

Noelle Marie Javier, MD
Assistant Professor
Department of Geriatrics & Palliative Medicine

Mount Sinai

Overview of LGBTQ-specific Health Issues

Lesbian & Bisexual Women	Gay & Bisexual Men	Transgender Persons
Prevention/screening	HIV/AIDS	HIV/AIDS
STIs/sexual health	STIs/sexual health	STIs/sexual health
Breast cancer/gynecological care	Anal papilloma/anal cancer	Preventive care (screening for biological sex) & access to healthcare
Substance abuse	Substance abuse	Substance abuse
Cardiovascular disease	Prostate cancer	Hormone therapy
Mental health	Mental health	Mental health
Psychosocial issues	Psychosocial issues	Psychosocial issues

Discussion Points for MSM

- Safe or unsafe sex practices
- STIs, HIV screening
- History and risk for testicular, prostate, colon, anal cancer
- Immunization Hx eg hepatitis A/B
- ?anal pap smear
- Domestic violence
- Tobacco use and smoking cessation
- Substance use e.g. alcohol, recreational drug
- Nutrition concerns e.g. eating disorders
- Exercise or lack thereof
- Mood screening: depression, anxiety etc.

Discussion Points for LB Women

- History of and risk for CAD, HTN, DM, DL
- History of and risk for breast cancer
- Pelvic exam, screening for cervical cancer, endometrial cancer
- Mood screen for depression, anxiety
- Osteoporosis
- Exercise or lack thereof
- Tobacco use and smoking cessation
- Domestic violence
- Substance use e.g. alcohol, recreational drugs
- Nutrition issues: weight management, eating disorder

Discussion Points for Transgender Persons

- Access to appropriate healthcare
- Use of prescription and OTC medications
- History of injectable silicone use
- Risk for CAD
- Risk for hormone-related cancer; appropriate screening for biological sex
- Safe sex practices
- Screening for HIV, STIs
- Substance use: alcohol, recreational drugs
- Tobacco use and smoking cessation
- Mental health issues
- Nutrition: eating disorder
- Exercise or lack thereof
- Domestic violence

CASE

- 73 year old male comes to your office to establish primary care after his previous MD moves to another state
- Medical history is pertinent for hypertension and hyperlipidemia
- Upon asking his personal and social history, he informs you that he is single, no children but is accompanied by a male friend who happens to be a roommate for many years.
- He further points out that he is in the reception area waiting for him so he requests to hurry along and skip some parts of the exam.

QUESTIONS

- You are a thorough medical provider and interested in exploring more about his personal and psychosexual history.

- What appropriate line of questioning may be used to foster trust with this patient?

- How does one proceed with obtaining medical information in a non-judgmental way?

RELATIONSHIP(S)

- What is your relationship status?
- Who are the important people in your life?
- Do you have a significant other, partner?
- Do you live alone or with someone?
- Tell me more about yourself

SEXUALITY AND THE OLDER ADULT

- Older adults are sexually active
- 53% in the 65 year old to 74 year old age group
- 26% in the 75 year old to 85 year old age group
- 92% do NOT use condoms
- 48% do not use condoms regularly
- CDC 2013: older adults >50 years of age (regardless of sexual orientation or gender identity) represent 1 in 6 new HIV diagnoses
- Only 19% of adults >50 spoke to providers about HIV-AIDS

Lindau et al. NEJM 2007
CDC 2013 HIV Surveillance Report

Now, I have to ask some rather personal and sensitive information. Feel free to interrupt me if you have some discomfort with my questions. I ask all my patients these standard questions for a thorough assessment of sexual health.

- Are you in a relationship? If you are, do you have any sexual relations with this person? Have you got sexual relations with other person(s)? How many would you say? Are your sexual partners male, female, transgender, all of the above, or some combination?

SEXUALITY

- If not in a relationship, are you sexually active at the moment? Tell me more about it. May I ask if your partner or partners are male, female, transgender, all of the above, or some combination? How many partner(s)?

- Have you ever engaged in unprotected sex, multiple sexual partners, illicit drug use when having sex, alcohol, and sex?

- Do you currently have issues or concerns pertaining to sex?

SEXUALITY – Key Points

- Focus on the behavior and not necessarily the sexual orientation.
- Human sexuality includes orientation, behavior/practice, and attraction.
- Normalize the conversation. Applies to everyone regardless of sexuality.
- Allow the patient to take the lead in disclosure.

TRANSGENDER MEDICINE

Key Points

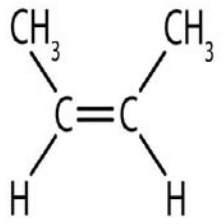
Table 1. Selected common terms used to describe transgender identities

Term	Definition
Transgender	An umbrella term used to describe individuals whose gender identity differs from the sex they were assigned at birth
Trans	Shorthand term for "transgender"
Transgender woman/Trans woman	Transgender person assigned male at birth, identifies as female
Transgender man/ Trans man	Transgender person assigned female at birth, identifies as male
Transvestite/ Cross-Dresser	A person who dresses in gendered clothing that differs from their own identity for entertainment or sexual purposes but does not necessarily identify as transgender
Genderqueer	Gender nonconforming person, a term increasingly used by youth
Transsexual	A term that is sometimes used to refer to transgender individuals who have undergone medical procedures to affirm their gender; currently a less favored term in trans-related literature

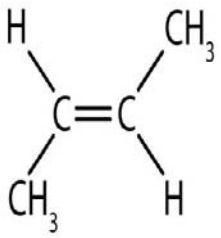
The opposite of transgender is:

CISGENDER

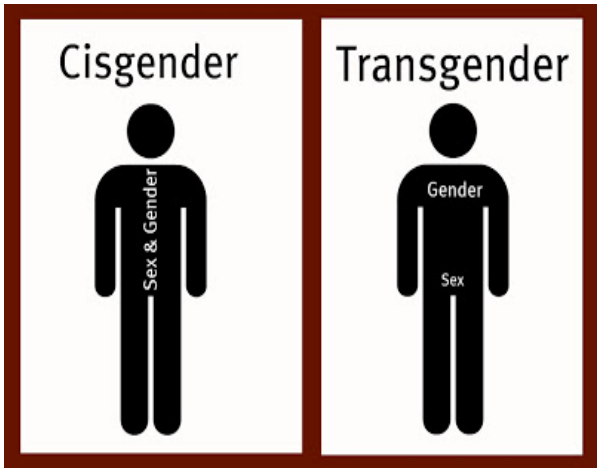
Birth sex matches gender identity



cis-2-butene



trans-2-butene



Why do we treat trans people?

- 42% suicide attempt rate compared to 8% in the general population (Williams Institute, 2014)

- Improvement in dysphoria and mental health outcomes (Murad, et al, 2009; Gomez-Gil, et al, 2011)
  - Not well understood in the literature and likely multifactorial
    - Increased validation in preferred gender
    - Decrease in dysphoria with body changes
    - Likely chemical component of having sex hormones that are congruent with identity/brain function/structure

- Changing appearance can also have many safety implications and affect how easily people move through the world

WHY ? Transgender Health Disparities Data

National Center for Transgender Equality, 2011

- **19% refused medical care** due to their transgender or gender non-conforming status
- **50% having to teach** their medical providers about transgender care
- **4 X national average of HIV infection,** with rates higher among transgender people of color (28% overall; 56% black/AA per CDC)
- **28% postponed medical care** due to discrimination

NYS LGBT Health and Human Services Network, 2009

- much more likely to be **homeless** (33% vs. 14%),
- more likely to have probable **depression** (31% vs. 16%)
- experience **loneliness** or have experienced **violence** (28%).
- **highest ratings of barriers to health care**

Trans shapes, Trans sizes

- There is no “typical” way for a transgender to present for care
  - People will be in different stages of transition
  - People may come in for transgender-sensitive care, but not want to undergo medical transition
  - People you may have been taking care of for many years may request transgender-related care without having discussed their gender identity with you earlier

Gender Affirming Approach to Physical Exam

- Let the patient take the lead.
- Use appropriate language e.g. proper pronouns, names of body parts etc.
- Avoid judgment.
- Be gentle and allow for refusal or postponement of the exam until a more trusting relationship is created.
- Recite and explain as you examine body parts.
- Examine only body parts pertinent to the visit.
- Preventative screening for existent body parts regardless of gender presentation or expression.

Gender Affirming Approach to Physical Exam

- Special consideration for neovaginal exam (transgender women): could use an anoscope for visual exam if indicated; respect towards use of garments to enhance presentation (tucking)
- Special consideration for pelvic exam for transgender men: pap smear for cervical cancer screening; support garment (binding)
- Offer a support person for the patient in the room.
- Offer a mirror for patients to appreciate the exam if they want to
- Priming techniques: vaginal estrogen, self-collection kits, benzo for severe anxiety etc.

Commonly Used Guidelines

- WPATH SOC 7 (2012)
- Callen-Lorde Revised Guidelines (2012)
- USCF Center for Excellence (2011)
- Endocrine Society of North America (2009)
- Fenway LGBT health guide (2007)
- Vancouver Coastal Health Service (2006)
- Tom Waddell Health Center (2006)

All based on expert opinion

Is Hormone Therapy Safe?

- There is a large body of evidence supporting the safety of hormone therapy
  - Gooren, et al 2007 showing no increased morbidity compared to general population with n=3112 following transgender patients on hormone therapy from 1975 to 2005

- Address modifiable cardiovascular risk factors in both transgender men and transgender women
  - Gooren, et al 2014 showing 7 VTE events among transgender women, all of whom were heavy smokers (n=236)

METHODOLOGY OF HORMONE CARE

- Informed consent involves educating patients on the risks and benefits of initiating hormone therapy
  - May or may not require a mental health professional to provide a gender dysphoria diagnosis according to prescriber preference
  - WPATH SOC 7 allows for health care providers to make the gender dysphoria diagnosis

- Requiring a real-life test is both antiquated and dangerous for transgender people, and is no longer required for obtaining hormone therapy or gender-related surgeries

MEDICAL MANAGEMENT

- Transgender women seeking medical care are often treated with one form of estrogen with or without a testosterone blocker
  - Suppressing testosterone will increase the pace of feminization as well as enhance subcutaneous fat redistribution
  - Progestogens may or may not help with breast development, but all oral testosterone blockers are some form of progestogen
- Transgender men are routinely treated with testosterone alone, and various forms of estrogen blockers are used to address some complications of therapy

What do hormones do?

TABLE 14. Feminizing effects in MTF transsexual persons

EFFECT	ONSET[a]	MAXIMUM[a]
Redistribution of body fat	3 – 6 months	2 – 3 years
Decrease in muscle mass and strength	3 – 6 months	1 – 2 years
Softening of skin/decreased oiliness	3 – 6 months	Unknown
Decreased libido	1 – 3 months	3 – 6 months
Decreased spontaneous erections	1 – 3 months	3 – 6 months
Male sexual dysfunction	Variable	Variable
Breast growth	3 – 6 months	2 – 3 years
Decreased testicular volume	3 – 6 months	2 – 3 years
Decreased sperm production	Unknown	> 3 years
Decreased terminal hair growth	6 – 12 months	> 3 years[b]
Scalp hair	No regrowth	c
Voice changes	None	d

a Estimates represent clinical observations. See Refs 81, 92, 93.
b Complete removal of male sexual hair requires electrolysis or laser treatment or both.
c Familial scalp hair loss may occur if estrogens are stopped.
d Treatment by speech pathologists for voice training is most effective.

Endocrine Society, 2009

What do hormones do?

TABLE 13. Masculinizing effects in FTM transsexual persons

EFFECT	ONSET[a] (months)	MAXIMUM[a] (years)
Skin oiliness/acne	1 – 6	1 – 2
Facial/body hair growth	6 – 12	4 – 5
Scalp hair loss	6 – 12	b
Increased muscle mass/strength	6 – 12	2 – 5
Fat redistribution	1 – 6	2 – 5
Cessation of menses	2 – 6	c
Clitoral enlargement	3 – 6	1 – 2
Vaginal atrophy	3 – 6	1 – 2
Deepening of voice	6 – 12	1 – 2

a Estimates represent clinical observations. See Refs 81, 92, 93.
b Prevention and treatment as recommended for biological men.
c Menorrhagia requires diagnosis and treatment by a gynecologist.

Endocrine Society, 2009

Cross-Sex Hormones: M to F

Table 1: "Feminizing" Regimens

MEDICATION & STRENGTH	INITIAL DOSE	MAXIMUM DOSE	INTENDED EFFECTS	POSSIBLE SIDE EFFECTS	LABS TO MONITOR
Estradiol Cypionate 5mg/ml (Depo-Estradiol)	2.5mg (0.5cc) Intramuscularly Every two weeks	5mg (1cc) Intramuscularly Every two weeks	Hypertrophy of breasts Impotence Redistribution of fat Testicular atrophy Reversal of androgenic hair loss Loss of body hair Softening of skin	Cerebrovascular Accident (Stroke) Deep Vein Thrombosis Pulmonary Embolism Depression Gallbladder disease Gastrointestinal upset Headache Hepatitis Hypercalcemia Hyperlipidemia Hypertension Impotence Loss of libido Mood changes Pituitary adenoma Sterilization	Lipids Liver enzymes Prolactin
Estradiol Valerate 20mg/ml or 40mg/ml (Delestrogen)	10-20mg Intramuscularly Every two weeks	20-40mg Intramuscularly Every two weeks			
Estradiol (Estrace)	1 mg Orally, twice daily	2 mg Orally, twice daily			
Estradiol transdermal Patch 0.1mg (Vivelle-Dot)	1 patch Topically, twice weekly	2 patches Topically, twice weekly			
Conjugated estrogens 1.25mg/2.5mg (Premarin)	1.25 mg Orally, twice daily	2.5mg Orally, twice daily			
Medroxyprogesterone acetate, e.g. Provera®	5mg orally, once daily	10mg orally once daily	Hypertrophy of breasts (disputed)	Weight gain, dyslipidemia, depression, dizziness In combination with estrogen: DVT: pulmonary embolism, stroke, myocardial infarction, Invasive breast cancer (in cisgender women)	Lipids, CBC, LFTs
Depo-medroxyprogesterone, e.g. DepoProvera®	150 mg Intramuscularly, every 3 months	150 mg Intramuscularly, every 3 months			
Micronized progesterone (Prometrium®)	100mg orally, Once daily	200 mg orally, Once daily			

Callen-Lorde Protocols for the Provision of Hormone Therapy (2012)

Cross-Sex Hormones: F to M

Table 3: "Masculinizing" Regimens

MEDICATION	INITIAL DOSE	MAXIMUM DOSE	INTENDED EFFECTS	POSSIBLE SIDE EFFECTS	LABS TO DRAW
Testosterone Cypionate 100mg/ml Or 200mg/ml	100 mg Intramuscularly, every two weeks --- Same dose for post-oophorectomy men	200 mg Intramuscularly, every two weeks --- 100 mg Intramuscularly, every two weeks for post-oophorectomy men	Clitoral hypertrophy Growth of facial and body hair Increase in muscle mass and definition Increase of androgenic alopecia Lowering of vocal pitch	Acne Amenorrhea Androgenic alopecia Depression Gastrointestinal upset Headache Hepatitis Hyperlipidemia Hypertension Mood Changes Polycythemia	Complete Blood Count Lipids Liver enzymes Prolactin
Testosterone Enanthate* 100mg/ml Or 200mg/ml	100 mg Intramuscularly, every two weeks --- Same dose for post-oophorectomy men	200 mg Intramuscularly, every two weeks --- 100 mg Intramuscularly, every two weeks for post-oophorectomy men			
Testosterone gel (Testim or Androgel) 1mg/g (1%)	2.5mg Topically daily	5-10 mg Topically daily			
Testosterone patch (Androderm) 2.5mg or 5mg	2.5mg Patch daily	5mg Patch daily		As above Local irritation	

* Testosterone Enanthate is supplied only in 5cc vials. Therefore, it is not listed as an option in the parts of the protocol that require prescribing less than 5cc. If a patient is hormone experienced and already taking Testosterone Enanthate, this can be substituted for Testosterone Cypionate.

Callen-Lorde Protocols for the Provision of Hormone Therapy (2012)

RISK LEVEL	FEMINIZING HORMONES	MASCULINIZING HORMONES
Likely increased risk	Venous thromboembolic disease (VTE) Gallstones Elevated liver enzymes Weight gain Hypertriglyceridemia	Polycythemia Weight gain Acne Androgenic alopecia Sleep apnea
Likely increased risk with presence of additional risk factors such as age	Cardiovascular disease	
Possible increased risk	Hypertension Hyperprolactinemia or prolactinoma	Elevated liver enzymes Hyperlipidemia
Possible increased risk with presence of additional risk factors	Type 2 Diabetes	Destabilization of certain psychiatric disorders Cardiovascular disease Hypertension Type 2 Diabetes
No increased risk or inconclusive	Breast cancer	Loss of bone density Breast cancer Cervical cancer Ovarian cancer Uterine cancer

Do Hormone Levels Matter?

- The goal of treatment is the reduction of gender dysphoria, which may or may not be related to circulating hormone blood levels
- There is no evidence for what hormone levels should be for someone who is transitioning
- Anecdotal evidence (n=˜600)
  - Transgender women report satisfaction at a wide range of levels
  - Transgender men report satisfaction when in the normal male range

Do Hormone Levels Matter?

- Suppress endogenous hormone production
  - Slowing of body hair growth and absence of spontaneous erections in transgender women
  - Cessation of menses in transgender men
- More important to monitor CBC for anemia/polycythemia
  - Use the normal range for H&H consistent with the dominant hormonal axis (female scale for transgender women, male scale for transgender men)
- Monitor liver and kidney function as well as potassium levels if spironolactone is used

Gender-Related Surgeries

- Role of hormone prescribers is often in writing letters supporting the need for surgery and coordinating care with surgeon

- Watch out for newer surgeons as new guidelines in NYS have led to less experienced surgeons offering gender-related surgeries

Primary Care Issues

- Access to care
  - Finding competent hormone care providers
  - Finding providers who are competent with trans* patients
- If you have it, screen it
  - Cervix, chest, prostate, rectum
- Silicone injection (mostly) in transgender women
- Fertility questions and the development of new knowledge and techniques
- Pelvic pain in transgender men with >5 years on testosterone

Mount Sinai Hospital

Gender Reassignment Surgery

We perform Male to Female and Female to Male surgeries

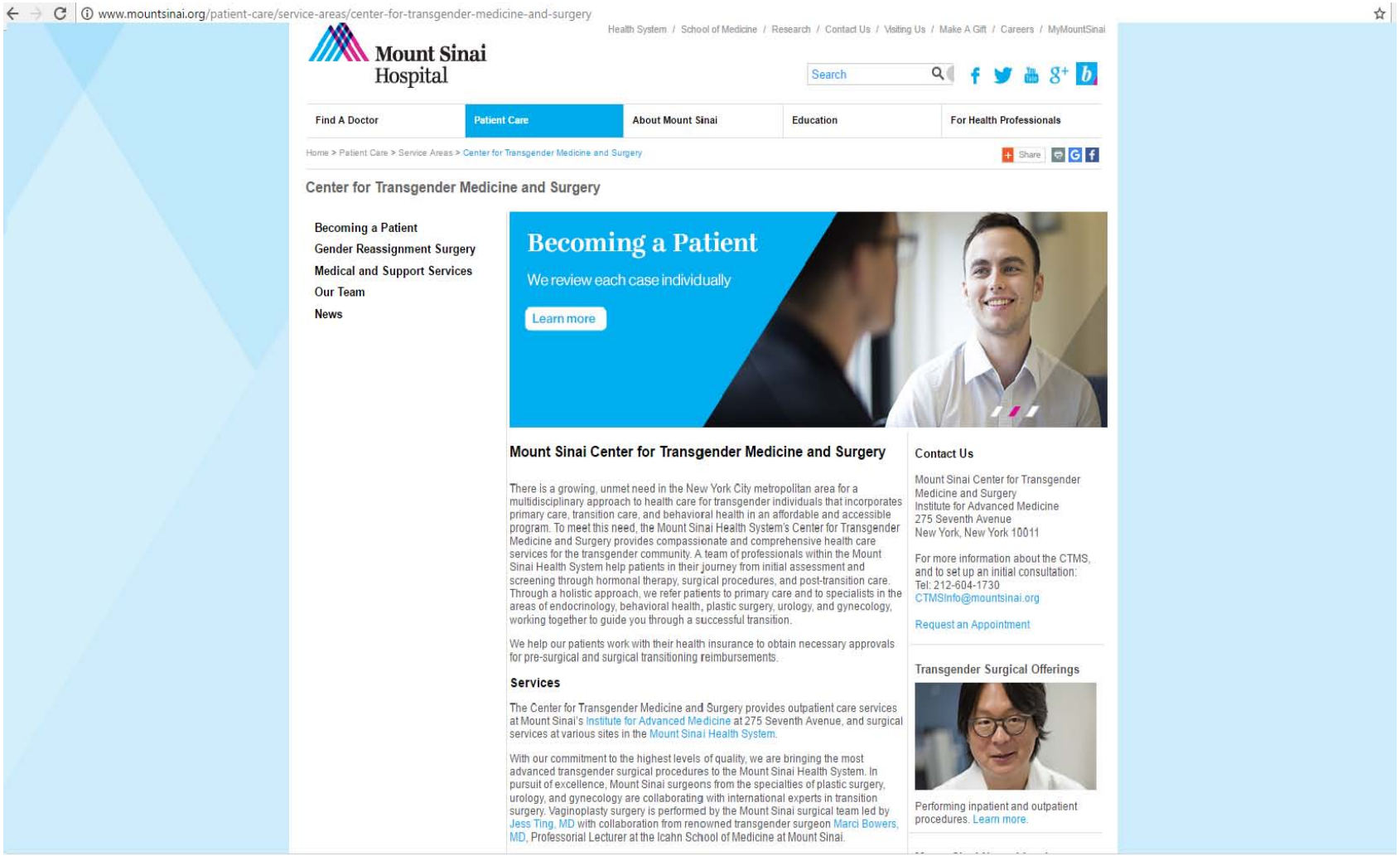
Learn more

Our Team

Meet our multidisciplinary health care team

Learn more

http://www.mountsinai.org/patient-care/service-areas/center-for-transgender-medicine-and-surgery



A Surgeon's Perspective

- Age alone is not a barrier to surgery.
- Stable housing is an important factor to consider.
- Smoking, Diabetes, Vasculitis are considerations.
- Medicaid, private insurance would cover; Medicare not so clear; sliding scale offered
- Surgery itself (SRS, GRS, GCS) – 3 hours to 4 hours duration
- Post-op hospital stay for 3 days
- 200 surgeries done within the first year CTMS was launched in May 2016; oldest pt is 77 years old.

Mental Health (Psychological) Dimension

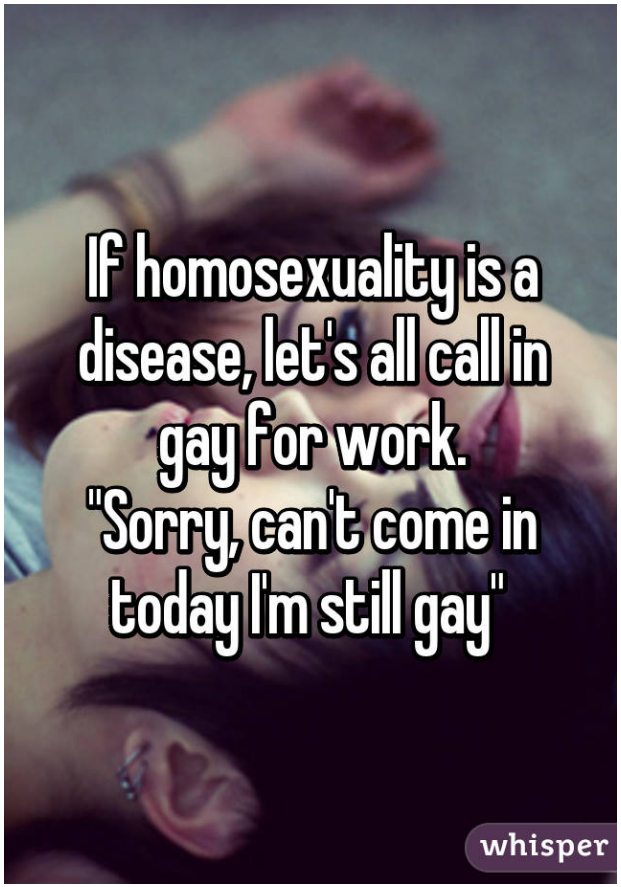
Jeff Weiss, PhD, MS

Associate Professor

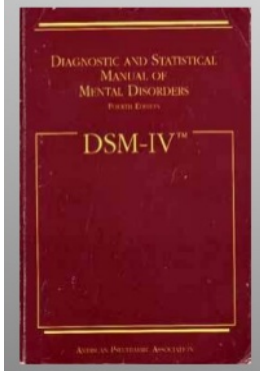
Division of General Internal Medicine

Mount Sinai

1973



DECLASSIFICATION AS A MENTAL DISORDER



The American Psychiatric Association (APA) removed homosexuality from its official Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1973.

"Homosexuality is not a mental disorder and thus there is no need for a *cure*."

–THE AMERICAN PSYCHOLOGICAL ASSOCIATION

Prevalence of Mental Disorders, Psychological Distress, and Mental Health Services Use Among Lesbian, Gay, and Bisexual Adults in the US

Cochran, Sullivan & Mays JCCP 2003

Nationally representative Sample of 2,917 midlife adults

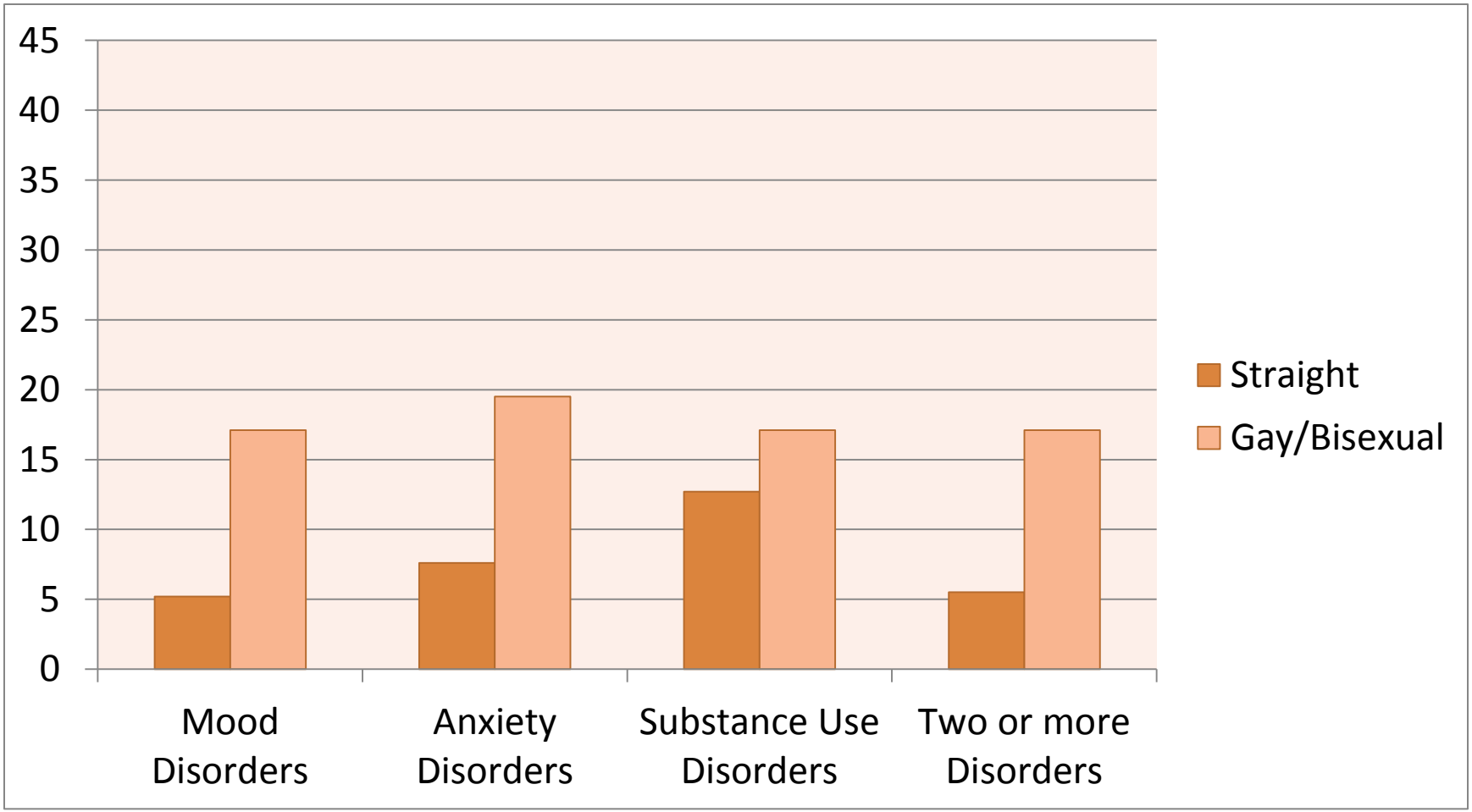
Prevalences of Mental Health Disorders in the National Survey of Midlife Development by Gender and Sexual Orientation: Twelve-Month Prevalences and Results of Multivariate Logistic Regression Analyses

	Men						Women					
	Heterosexual (n = 1,239)		Gay–bisexual (n= 37)				Heterosexual (n = 1,604)		Lesbian–bisexual (n= 37)			
Disorder	%	*SE*	%	*SE*	Adj OR	(95% CI)	%	*SE*	%	*SE*	Adj OR	(95% CI)
Major depression	10.2	0.9	31.0	8.0	3.57*	(1.71–7.43)	16.8	1.1	33.5	10.0	1.88	(0.71–4.98)
Generalized anxiety disorder	1.8	0.4	2.9	2.9	1.35	(0.19–9.34)	3.8	0.6	14.7	7.0	3.88*	(1.18–12.77)
Panic disorder	3.8	0.6	17.9	6.6	5.09*	(2.00–12.99)	8.6	0.8	17.1	7.1	2.05	(0.72–5.82)
Alcohol dependency	5.6	0.7	8.9	4.4	1.30	(0.40–4.23)	3.4	0.5	11.8	7.1	2.51	(0.60–10.48)
Drug dependency	2.7	0.4	9.2	5.4	2.46	(0.55–11.07)	1.5	0.4	6.5	6.2	3.45	(0.39–30.64)
Positive for at least 1 disorder	16.7	1.1	39.8	8.4	2.71*	(1.34–5.48)	24.6	1.3	43.7	10.3	1.86	(0.75–4.57)
Comorbid for 2 or more disorders	5.0	0.6	19.6	6.8	3.85*	(1.50–9.87)	7.7	0.8	23.5	9.0	2.88*	(1.02–8.15)

Note. Weighted percentages and standard errors are shown. Multivariate logistic regression analyses were conducted separately by gender. Odds ratios (OR) and their 95% confidence intervals (CI) were adjusted for age, level of education, relationship status (married/cohabiting vs. not), and race. Adj = adjusted.

*$p < .05$.

12-Month Prevalence in Men (NEMESIS 1 - 1996)



Sandfort, de Graaf, Bijl, & Schnabel, (2001). **Same-sex sexual behavior and psychiatric disorders: Findings from the Netherlands Mental Health Survey and Incidence Study (NEMESIS).** *Archives of General Psychiatry, 58*(1), 85-91.

What is *Minority Stress*?

describes chronically high levels of psychological and emotional stress faced by members of stigmatized minority groups. It may be caused by a number of factors, including poor social support and low socioeconomic status, but the most well understood causes of **minority stress** are interpersonal prejudice and discrimination.

DATA on LGBT Minority Stress

1. **Same-sex individuals 2X as likely as heterosexuals to have experienced discrimination in their lifetime;**

1. **5 X more likely to indicate that discrimination had interfered with having a full and productive life;**

2. **Perceived and actual discrimination correlated with mental disorders including substance use disorder**

Meyer, I. (2003) Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual Issues and Research Evidence. Psychol Bull. 2003 September; 129(5): 674–697.

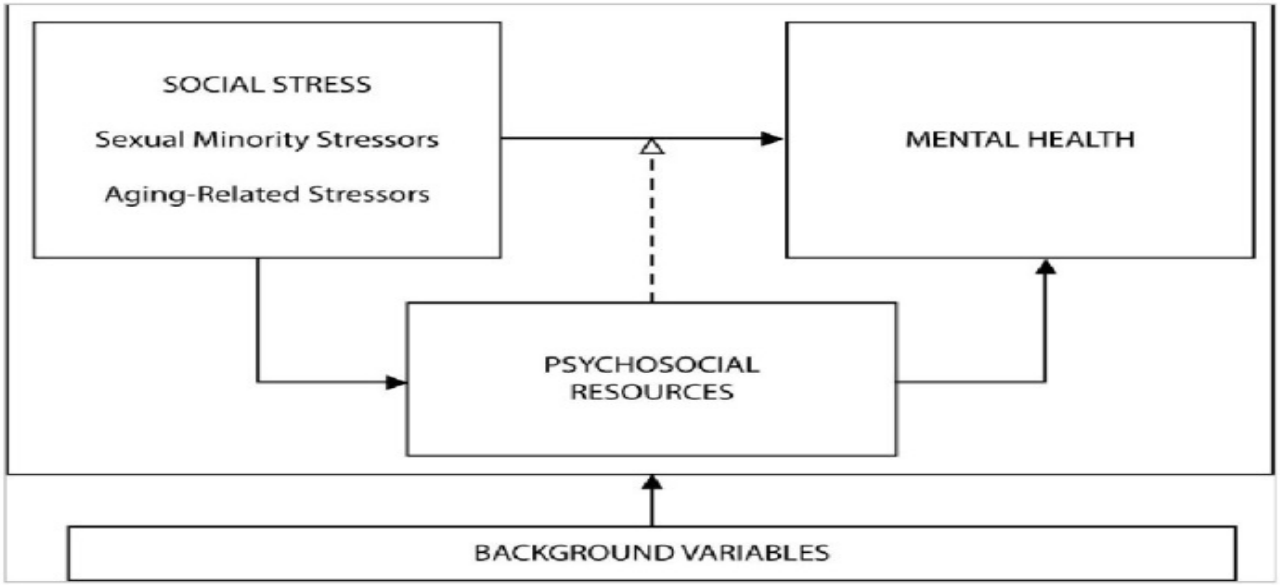
Wight RG, LeBlanc AJ, De Vries, B, Detels, R

Stress and Mental Health Among Midlife and Older Gay-Identified Men

PMC full text: Am J Public Health. 2012 March; 102(3): 503–510.
Published online 2012 March. doi: 10.2105/AJPH.2011.300384
Copyright/License ► Request permission to reuse

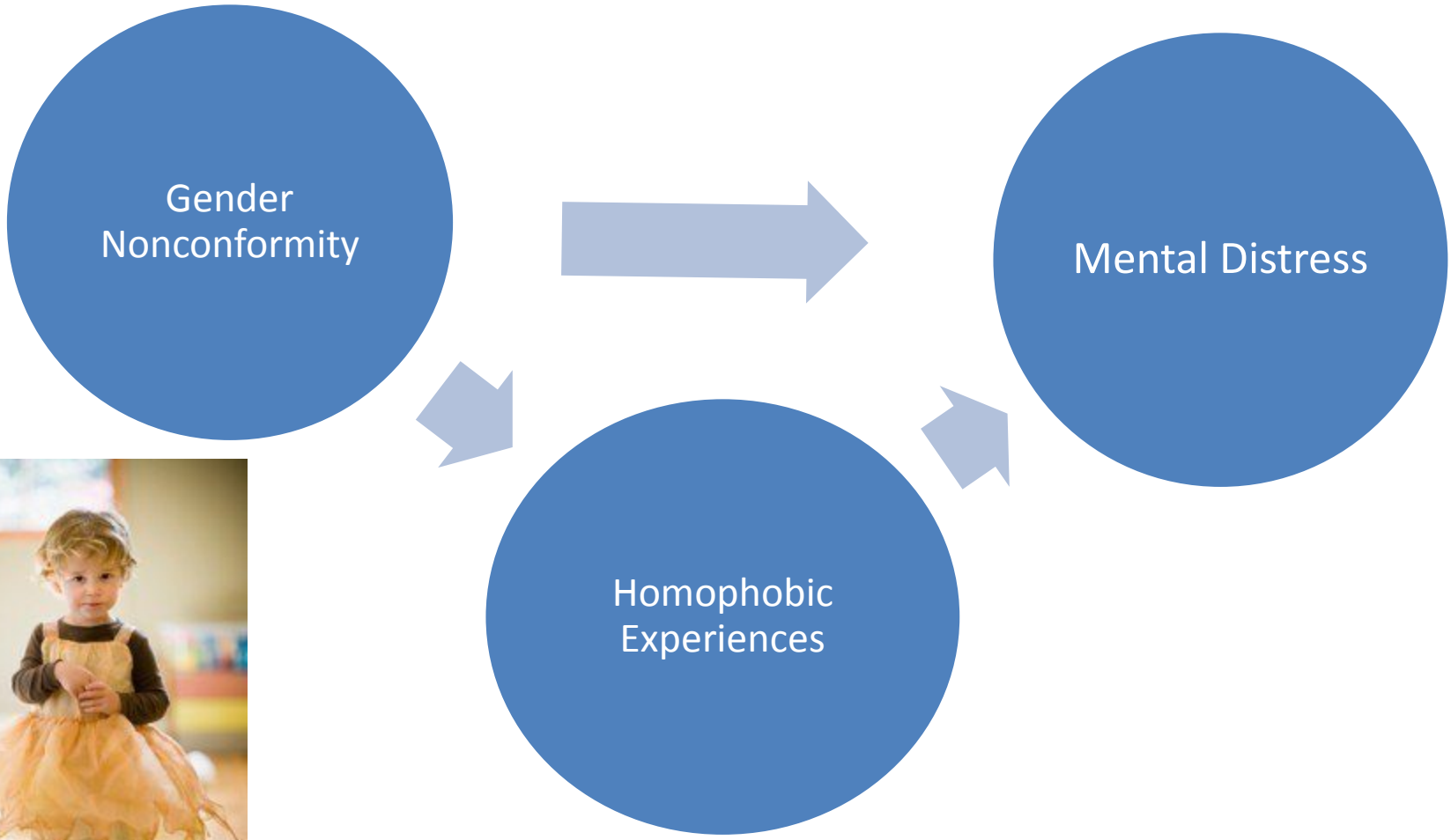
<< Prev FIGURE 1— Next >>

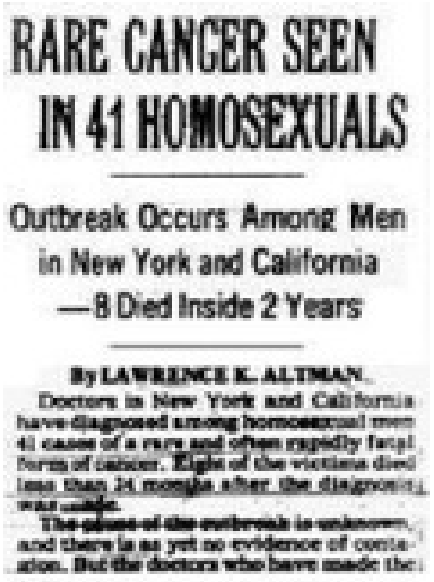
FIGURE 1—



Hypothesized associations between social stress and mental health among midlife and older gay-identified men.

Gender Non-conformity





RARE CANCER SEEN IN 41 HOMOSEXUALS

Outbreak Occurs Among Men in New York and California —8 Died Inside 2 Years

By LAWRENCE K. ALTMAN

Doctors in New York and California have diagnosed among homosexual men 41 cases of a rare and often rapidly fatal form of cancer. Eight of the victims died less than 24 months after the diagnosis was made.

The cause of the outbreak is unknown, and there is as yet no evidence of contagion. But the doctors who have made the

1981

GRID

AIDS

Internalized Gay Ageism, Mattering, Depression Among Midlife and Older Gay Identified Men

Social Science and Medicine 2015. 147; 200-208

- 312 gay identified men (mean age 60, range 48-78, 61% HIV negative) participating in the MACS study
- Method: social stress process framework

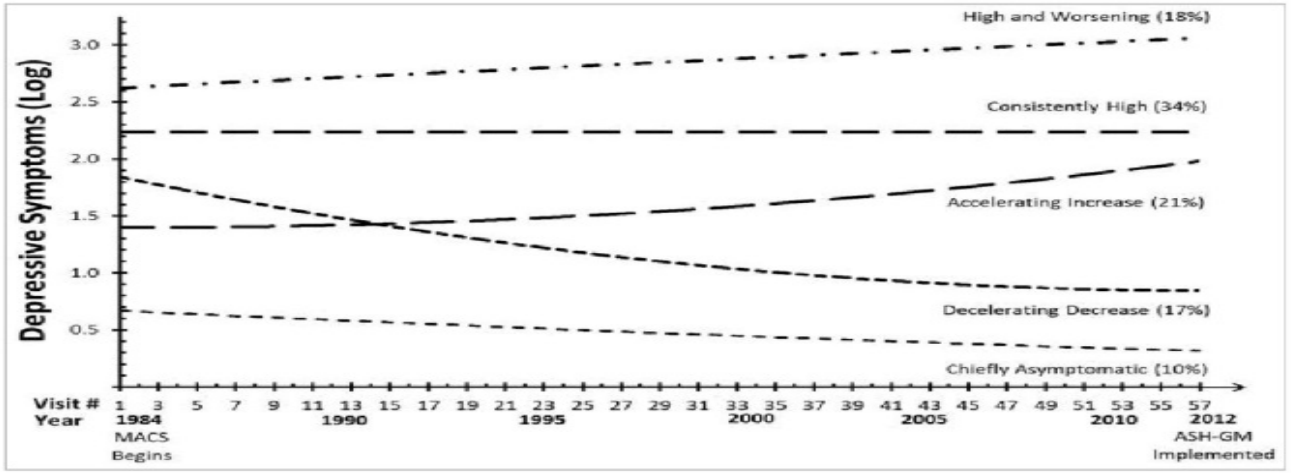
HIGHLIGHTS

- Midlife & older gay men are subject to feeling depreciated & socially invisible.
- Internalized gay ageism is the confluence between ageism and homophobia among gay men.
- Internalized gay ageism is positively associated with depression.
- Internalized gay ageism is a unique unexplored form of minority stress.
- One's sense of "mattering" offsets the health effect of internalized gay ageism.

PMC full text: Soc Sci Med. Author manuscript; available in PMC 2016 Dec 1.
Published in final edited form as:
Soc Sci Med. 2015 Dec; 147: 200–208.
Published online 2015 Oct 31. doi: 10.1016/j.socscimed.2015.10.066

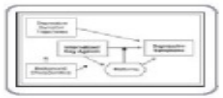
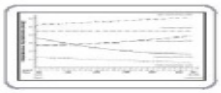
« Prev Figure 2 Next »

Figure 2



Three decade depressive symptom trajectories among gay men aged 48–78 years in 2012/13 (n = 312).

Images in this article

Click on the image to see a larger version.

2015

ADOLESCENT SUICIDE AND SAME SEX MARRIAGE

- Data from 47 states found that same-sex marriage policies were associated with a 7% reduction in the proportion of all high school students reporting a suicide attempt in the past year.
- The effect was concentrated among adolescents who were sexual minorities.

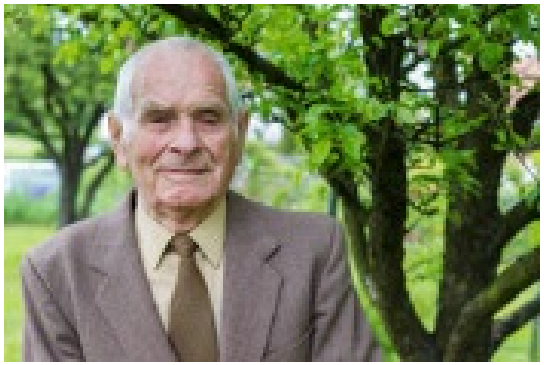
Injustice at Every Turn: National Transgender Discrimination Survey

Experiences of Discrimination and Violence in Public Accommodations

Location	Denied Equal Treatment	Harassed or Disrespected	Physically Assaulted
Retail Store	32%	37%	3%
Police Officer	20%	29%	6%
Doctor's Office or Hospital	24%	25%	2%
Hotel or Restaurant	19%	25%	2%
Government Agency/Official	22%	22%	1%
Bus, Train, or Taxi	9%	22%	4%
Emergency Room	13%	16%	1%
Airplane or Airport Staff/TSA	11%	17%	1%
Judge or Court Official	12%	12%	1%
Mental Health Clinic	11%	12%	1%
Legal Services Clinic	8%	6%	1%
Ambulance or EMT	5%	7%	1%
Domestic Violence Shelter/Program	6%	4%	1%
Rape Crisis Center	5%	4%	1%
Drug Treatment Program	3%	4%	1%

Grant, J.M., Mottet, L.A., Tanis, J., Harrison, J., Herman, J.L., and Keisling, M. (2011). Injustice at Every Turn: A Report of the National Transgender Discrimination Survey, Executive Summary. National Gay and Lesbian Task Force. www.taskforce.org

Event – 80 years old	Age at Time
Mental Illness	36
HIV	44
Gay Marriage	78



Event – 60 years old	Age at Time
Mental Illness	16
HIV	24
Gay Marriage	58

Event – 40 years old	Age at Time
Mental Illness	Prior to birth
HIV	4
Gay Marriage	38

"Coming Out" is Healthier

- Centre for Studies on Human Stress (CSHS) at the Louis H Lafontaine Hospital in Montreal
- Measures of psychiatric symptoms, cortisol levels throughout the day, and a battery of over twenty biological markers to assess allostatic load
- LGB People who were out to family and friends had lower levels of psychiatric symptoms anxiety, depression and burnout.
- Significantly lower morning cortisol levels than those who were still in the closet.

Juster, R.P., Smith, N.G., Ouellet, É., Sindi, S., Lupien, S.J. (2013) Sexual orientation and disclosure in relation to psychiatric symptoms, diurnal cortisol, and allostatic load. Feb; 75(2): 103-16. Psychosom Med.

LGBTQ AGING

Spiritual Dimension

Evan Zazula, MAPCC

Chaplain

Department of Geriatrics & Palliative Medicine

Mount Sinai

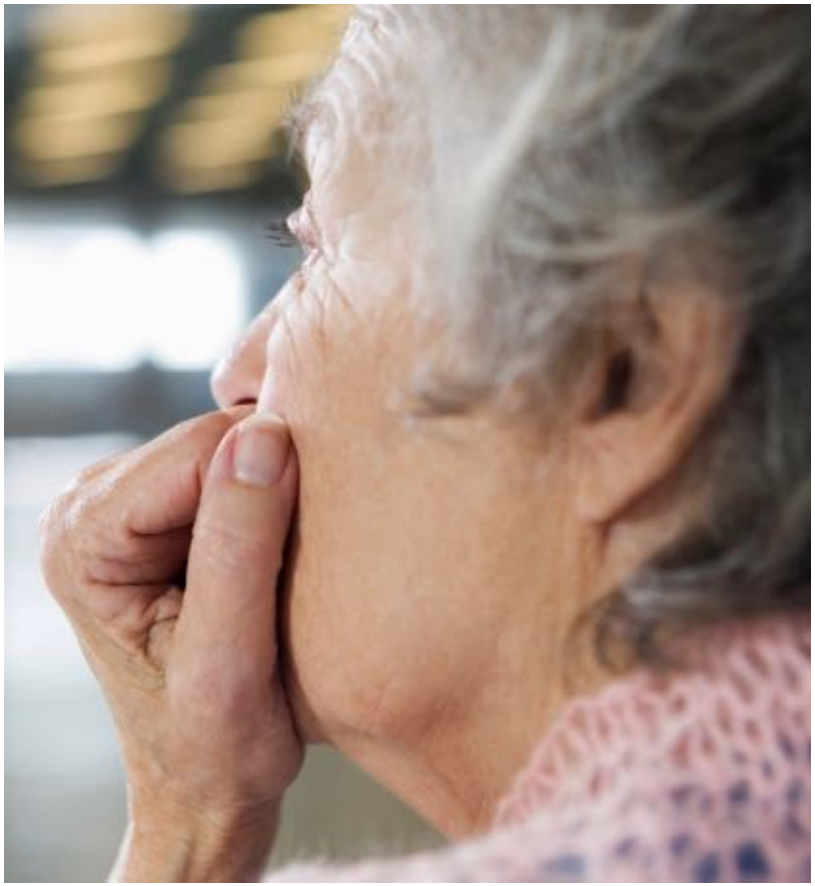
OVERVIEW

- LGBTQ Aging stressors and fears
- Definitions: religiosity and spirituality
- Religion's relationship with LGBTQ
- What do we know about LGBTQ Aging and their religious lives
- Spiritual coping and benefits
- How we can support our LGBTQ elders' spirituality

Love
and
Connection

STRESSORS THAT COMPROMISE SUCCESSFUL AGING

- Multi-morbidities
- Functional concerns
- Diminished social-supports
- Increased isolation/ loneliness
- Limited financial ability
- Age discrimination
- Racial discrimination
- Fear, anxiety of death



ABBREVIATED TIMELINE
LGBTQ AGING

- 1950 US Senate issues: “Employment of Homosexuals and Other Sex Perverts in Government”
- 1952 American Psychiatric Assn. lists homosexuality as a “sociopathic personality disturbance”
- 1953 Eisenhower bans homosexuals from working in the government
- 1967 Look article “The Sad Life of the Homosexual”
- 1969 Stonewall Riots
- 1973 APA votes to remove homosexuality as a mental illness
- 1981 NY Times reports on the first case of what will later be called AIDS
- 1986 Supreme Court upholds a state’s right to criminalize sex between consulting same-sex adults
- 1993 Military issues “Don’t Ask Don’t Tell”
- 1996 Clinton “Defense of Marriage Act” defines marriage as between one man and one woman
- 2003 Supreme Court rules sodomy laws unconstitutional
- 2004 Massachusetts legalizes gay marriage
- 2011 Obama Admin ends “Don’t Ask Don’t Tell”
- 2013 Supreme Court strikes down “Defense of Marriage Act”
- 2015 Supreme Court legalizes same-sex marriage throughout the US

LGBTQ AGING STRESSORS

- Homophobia
- Transphobia
- Lack of intimate relationships
- Compounded personal and community grief
- Abandonment: family, friends, faith
- Religious abuse (church hurt, church betrayal)

STEPPING OUT OF THE SHADOWS

"With the advent of the gay rights movement in 1969, lesbian, gay men, bisexual, and transgender people become the first generations to live openly and publicly."

Documentary:
A Wider Path, Elizabeth Tiger Rose, 2012

Stressors can be a source of feeling:

- Unloved
- Disconnected
- Unsafe
- Frightened
- Emotionally wounded
- Distrusting
- Unresolved trauma
- Disenfranchised
- Toxic shame
- Depressed
- Lonely
- Self-hating
- Low self-worth

FEARS RELATED TO HOSPITALS AND LTC FACILITIES

- **Hetero-normative assumptions**
- **Fears related to "de-transitioning" and/or going back into the closet**
- **Implicit bias: refers to the attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner**
  - These biases are activated involuntarily and without an individual's awareness or intentional control.
  - Residing deep in the subconscious, these biases are different from known biases that individuals may choose to conceal for the purposes of social and/or political correctness.
    - Implicit Association Test from Harvard University can be used to examine your implicit bias

Arthur (2015). Social Work Practice with LGBT Elders at End of Life: Developing Practice Evaluation and Clinical Skills Through a Cultural Perspective. Journal of Social Work in End-of-Life and Palliative Care,11:178-201.

Witten (2014). It's Not All Darkness: Robustness, Resilience, and Successful Transgender Aging. LGBT Health. 1(1) 24-33.

Kirwan Institute, "Understanding Implicit Bias," Kirwan Institute for the Study of Race and Ethnicity, 2015, http://kirwaninstitute.osu.edu

DEFINITIONS: RELIGIOSITY AND SPIRITUALITY

- Religiosity
  - Beliefs and practices connected to religious traditions with their own places of worship, rituals, liturgies, cycle of holy days, and structures of authority

- Spirituality
  - Connectedness to something beyond ourselves that gives us a feeling of transcendence; this can include religious traditions and practices, family, ancestors, nature, art, creativity, etc.

LGBTQ EQUALITY BY RELIGION

Judaism	
Orthodox	
Inclusion Prohibits same sex relationships. Gender roles based on birth biology. Sex between men a violation of biblical weight.	**Marriage Equality** Responding to Supreme Court's ruling: "Forbids homosexual relationships and condemns the institutionalization of such relationships as marriages."
Conservatism	
Inclusion Some are welcoming and affirming, ordaining LGBTQ rabbis and celebrating same-sex marriages. Others are not. As a denomination, however, Conservative Judaism has taken a firm and public stance for inclusion.	**Marriage Equality** Following the 2013 Supreme Court's ruling, the Rabbinical Assembly stated, "Our Movement recognizes and celebrates marriages, whether between partners of the same sex or the opposite sex."
Reconstructionist	
Inclusion The most welcoming and affirming. Allows LGBTQ ordination. Welcomes transgender individuals, students; ordains transgender rabbis.	**Marriage Equality** It recognizes and celebrates same-sex marriage.
Reform	
Inclusion In 1977 passed resolution "which decriminalizes homosexual acts between consenting adults, and prohibits discrimination against them as persons… including employment and housing."	**Marriage Equality** In 2000, the Central Conference of American Rabbis gave its full support to Reform rabbis who choose to officiate same-sex marriages.

LGBTQ EQUALITY BY RELIGION

Islam	
Inclusion LGBTQ Muslims rarely feel fully welcome. Transgender people recognized/accepted in many Islamic cultures. Idea of transgender is more likely to be accepted than homosexuality.	**Marriage Equality** Islam's sacred texts oppress LGBTQ people for centuries. Traditional Qur'an reading can lead to the condemnation of homosexual acts and same-sex marriage.
Pentecostal	
Inclusion Historically condemned homosexuality, and most denominations have doctrinal statements condemning homosexuality.	**Marriage Equality** "… maintained a strong position against premarital, extramarital, and deviant sex, including homosexual and lesbian relationships."
Roman Catholic	
Inclusion Names homosexual acts as "intrinsically immoral and contrary to the natural law." Doesn't consider "homo-sexual orientation" sinful per se, but has negative attitude.	**Marriage Equality** Does not celebrate or recognize same-sex marriages, yet the Catholic laity have been increasingly vocal in their support.
Seventh-day Adventist	
Inclusion God's Word that transcends time and culture does not permit a "homosexual lifestyle."	**Marriage Equality** The celebration of same-sex marriages is forbidden by the church.

LGBTQ EQUALITY BY RELIGION

Presbyterian	
Inclusion Many congregations are entirely welcoming and inclusive, but experiences may differ across communities. The church has adopted policies that allow for the ordination of LGBTQ ministers and for same-sex marriages.	**Marriage Equality** 2014 Assembly: "to use their own discernment to conduct same-sex marriage ceremonies where allowed by law." In June 2015, updates *marriage* as "a unique commitment between two people, traditionally a man and a woman."
Christian (Disciples of Christ)	
Inclusion While it affirms and welcomes LGBTQ people in all aspects of church life, including leadership, it does not dictate policy for individual congregations.	**Marriage Equality** Individual congregations would maintain their autonomy but added that "ministers whose consciences call for them to conduct weddings for couples regardless of sexual orientation and gender identity may now do so."
Baptist (American Baptist Church)	
Inclusion "The practice of homosexuality is incompatible with Biblical teaching," yet local churches can vary. Association of Welcoming and Affirming Baptist movement to further LGBT inclusion.	**Marriage Equality** "Submit to the teaching of Scripture that God's design for sexual intimacy places it within the context of marriage between one man and one woman..."

LGBTQ EQUALITY BY RELIGION

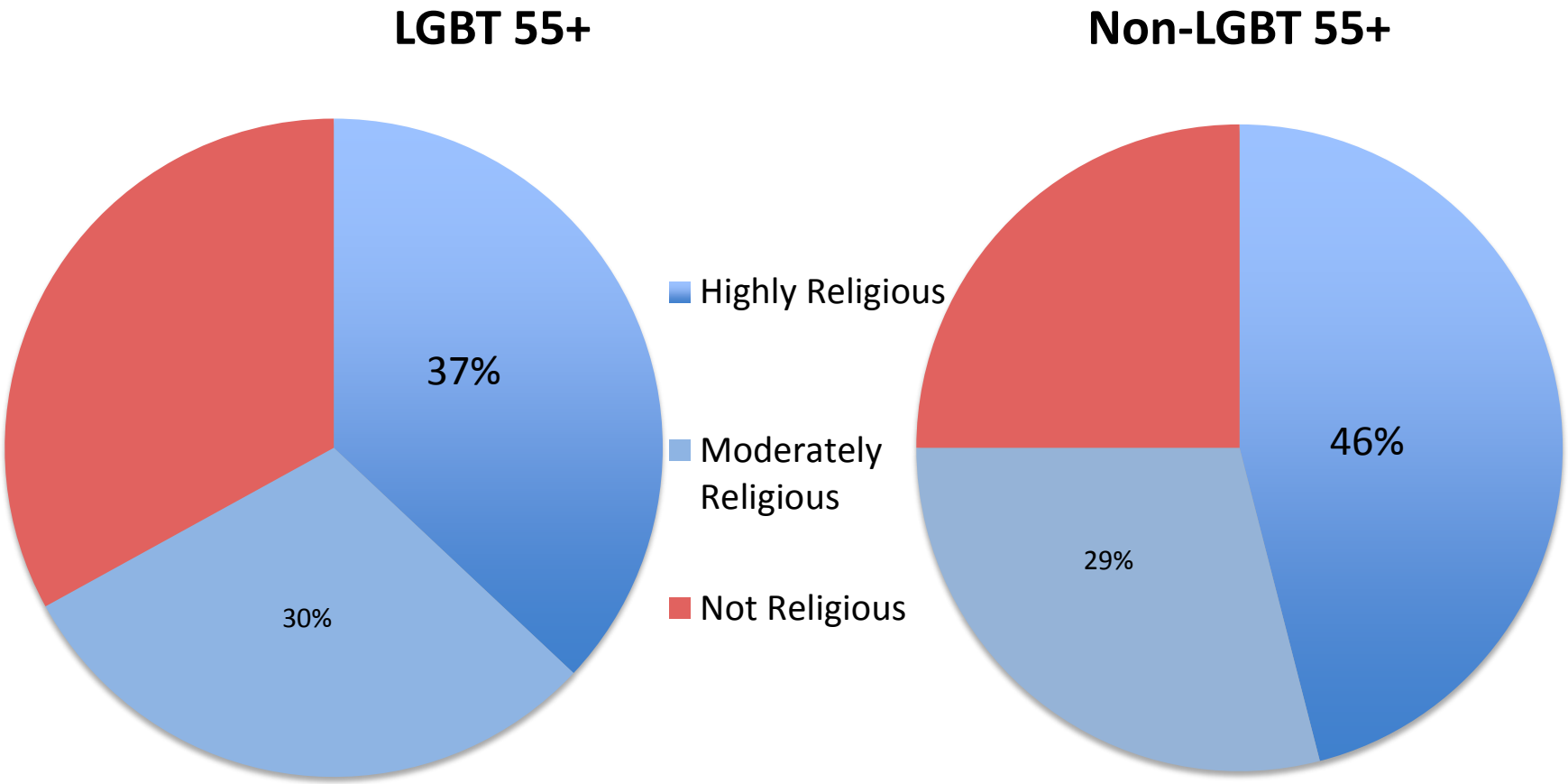
Hindu	
Inclusion HAF: "Given their inherent spiritual equality, Hindus should not socially ostracize homosexuals, but should accept them as fellow sojourners on the path to moksha." (enlightenment) *Attitudes regarding transgender people will vary across different Hindu organizations and society.*	**Marriage Equality** Today, marriage equality enjoys support among Hindu Americans. Same-sex Hindu marriage ceremonies are regularly celebrated in the U.S. The lack of a central Hindu authority or organization means that attitudes can vary greatly.
Unitarian Universalist Association	
Inclusion Opens its doors to people of all sexual orientations and gender identities, values diversity of sexuality and gender, and sees it as a spiritual gift.	**Marriage Equality** 1984 conducted "services of union" for same-sex couples." The UUA has been at the forefront of recent struggles – and victories – for marriage equality.

POSITIVE AND NEGATIVE RELIGIOUS COPING

- Terms coined by Kenneth Pargament
  - **Positive religious coping** (e.g. seeking spiritual support, benevolent religious reappraisals) associated with better health outcomes
  - **Negative religious coping** (e.g. punishing God reappraisal, interpersonal religious conflict) predictive of declines in health*

* Pargament et al. (2004). Religious Coping Methods as Predictors of Psychological, Physical and Spiritual Outcomes among Medically Ill Elderly Patients: A Two-Year Longitudinal Study. Journal of Health Psychology 9(6) 713-730.

Level of Religiosity by 55+ Population (US)



In a 2014 Gallup Poll survey, a smaller percentage of the over-55 LGBT population identified as highly religious (or simply religious) as compared to the over-55 non-LGBTQ population.

U.S. TRANSGENDER SURVEY

- Belonging
  - 66% of respondents were part of a faith community at some point in their lives.
  - 30% of these respondents had been part of a faith community in the past year.
  - 60% have belonged, or do belong, to a faith community in which leaders/ members thought or knew the respondent is transgender.

- Leaving
  - 39% left a faith community due to fear of being rejected because they are transgender.
  - 19% were rejected by a faith community.

- Finding
  - Of those who were rejected by a faith community, 42% found a faith community that welcomed them as a transgender person.

James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). The Report of the 2015 U.S. Transgender Survey. Washington, DC: National Center .for Transgender Equality.

SPIRITUALITY

- Is “a person’s attempt to make sense of his or her world beyond the tangible and temporal.
- “It strives to connect the individual with the transcendent and the transpersonal elements of human existence.
- “It might, but need not include religion.”*
- Experience of connecting to something larger than self—to the sacredness of life as we mature—to religion, art, music, nature—to suffering, altruism
- New resources for defining self, relationships with others, the world, the cosmos, and personal meaning (Richards, 2006)
- Being in touch with our inner-aliveness

*Religion, spirituality, and older adults with HIV: critical personal and social resources for an aging epidemic. Vance, Brennan, Enah, Smith, Kaur 2015

Increasing Spirituality and Resiliency in Aging LGBT Community

- Gerotranscendence Theory (Tornstam, 2005)

  As people age, they:

  – become more spiritual
  – move away from materialism and role-orientation
  – are increasingly comfortable with limited answers to existential questions
  – gain mortality salience

- Study of LGB veterans found that older respondents had lower levels of mental health problems and were more resilient than their younger peers but had smaller social networks.*

*Monin, et al (2017). Older Age Associated with Mental Health Resiliency in Sexual Minority US Veterans. American Journal of Geriatric Psychiatry 25:1 81-90.

RELIGIOUS AND SPIRITUAL COPING

- Crystal Park's work on coping, resilience, and meaning-making
  - In study of cancer patients, spirituality and spiritual coping strongly predicted stress-related growth.*
  - In a study of 83 older adults who reported on their current and lifetime most stressful experience, religiousness was associated with meaning making and adjustment.**

* Park et al. (2009). Religious and non-religious pathways to stress-related growth in cancer survivors: Does faith promote a healthier lifestyle? Journal of Behavioral Medicine 32 582-591.

** Park (2006). Exploring relations among religiousness, meaning, and adjustment to lifetime and current stressful encounters in later life. Anxiety, Stress and Coping 19(1) 33-45.

BENEFITS OF SPIRITUALITY AND RELIGION

- Serve as buffers to life stress, by allowing individuals to interpret their life experiences in the context of their beliefs
- Support finding purpose and meaning in life, as well as promote transcendence over circumstances
- Bolster feelings of inner resources and connection to others
- Provide social support, norms for healthy behaviors, and a sense of well-being that benefits overall mood
- Lessen depressive symptoms/increase optimism
- Yield better health related outcomes
- Slow the progression of illness
- Enhance quality of life

Spiritually supporting LGBTQ Aging in feeling…

- Safe
- To be in their truth/who they are
- Seen and heard/compassionately witnessed
- Validated/ appreciated
- Respected
- The clinician's awe
- Reconciled with relationship with family, God, faith,…
- They matter
- Free of shame
- Their inner aliveness/strength
- Meaningful
- Purposeful
- Gratitude

SEEING THE WHOLE PERSON

- Slowing down
- Taking a pause (when you're with a patient or between patient visits)

- Three Tenets of Zen: Not-knowing, Bearing witness, Compassionate/loving action

- *Not-knowing*
  - Active listening
  - Not judging, not assuming
  - Creating a safe/sacred space for expression of feelings and experience (Is it OK if I ask …?)

- *Bearing witness*
  - Meeting the person/patient where they are at
  - *Being with* instead of doing for
  - Not having an agenda

- *Compassionate/loving action*
  - Acknowledgement/validation
  - Open curiosity

PATIENT DIGNITY QUESTION:

What do I need to know about you as a person to give you the best care possible?

- Harvey Max Chochinov BMJ 2007

MEANING MAKING

"The ability to successfully reconstitute a global meaning of life."*

- Spiritual Review
  - What part of you is strongest right now?
  - What makes you feel alive (inside)?
  - Do you consider yourself spiritual? How is that expressed?
  - Has spirituality been a source of strength?

- Faith Review
  - Has religion been a source of strength? How has it supported you or not?
  - How has your faith impacted your life; who you are: behavior, identity, sexuality?
  - Is there a religious or spiritual community that you are, or would like to be, connected with?

- Life Review
  - Who are the most important people in your life? Who are your supports?
  - What about yourself and your life are you most proud of?
  - Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?"

- Love Review
  - What's your experience with love?
  - What does love mean to you?
  - Do you have loved ones? Who are your loved ones?
  - What are your hopes and dreams for your loved ones?

*Virginia Leea,b, , S. Robin Cohenb,c,d, Linda Edgare, Andrea M. Laiznerb,f, Anita J. Gagnonb, (2006)

MEANING MAKING cont'd

- Writing Therapy
  - Exploring journal, poems, stream of consciousness writing; insightful questions to reflect on: What were the most meaningful parts of my journey? Who am I?...
  - Proprioceptive writing– creating a sacred space

- Art Therapy (getting beyond words)
  - Collage: exploring identity through images
  - Containers, boxes--what's inside and out
  - Masks: what's hidden, unspoken through images?
  - Portraits: of who you are in your most natural setting
  - How have you used art to express yourself?
  - ***Creating a collection (LOOM)- where they and their expression can be in community.***

- Music Therapy
  - Music can deeply connect us to what is universally human
  - The soundtrack of our life: Where were you? Who were you with? What does this song mean to you?
  - How does it make you feel?

- StoryCorps (legacy)
  - Mission: "To preserve and share humanity's stories in order to build connections between people and create a more compassionate world." * www.storycorps.org

KEY POINTS

- Important for care providers to recognize that LGBTQ are aging in a spiritual (both religious and secular) context.

- The context may be turbulent or serene based of the spiritual interpretation of their lives.

- As care providers we can support LGBTQ Aging in feeling safe, seen, loved, and connected by providing open, accepting, non-judgmental presence, witnessing, and compassionate curiosity.

LGBTQ Spiritual/Religious Resources
New Jersey

www.believeoutloud.com

www.jewishlgbtnetwork.com Jewish LGBT Network

www.mccchurch.org Metropolitan Community Church

www.pridecenter.org Pride Center of New Jersey

www.sageusa.org Sage USA

LGBTQ Aging

Nursing Home Care

Caregiver Issues

Community Resources

Jim Palmer, BBA MSW LCSW

Social Work

Department of Geriatrics and Palliative Medicine

Mount Sinai

- *"LGBT Older Adults in Long-Term Care Facilities: Stories from the Field"* is considered a groundbreaking 2011 report that highlights the care challenges that some LGBT older adults may encounter in SNFs

- The reports collected information & stories from 769 individuals who responded to an online survey

- Of the total respondents, 328 people reported 853 instances of abuse, including:
  - Harassment by residents & staff
  - Refusal by staff to accept a medical power of attorney
  - Refusal by staff to use preferred name and/or pronoun
  - Refusal to provide care
  - Wrongful transfer or discharge

LGBT Older Adults in Long-Term Care Facilities: Stories from the Field

April 2011 | National Senior Citizens Law Center in collaboration with Lambda Legal, National Center for Lesbian Rights, National Center for Transgender Equality, National Gay and Lesbian Task Force and Services & Advocacy for GLBT Elders (SAGE)

- Nearly 9 in 10 respondents said that they thought LTC staff would discriminate against someone who ‘came out’ in a facility
- 8 in 10 responded that they would expect mistreatment or bullying from SNF residents

- 1 in 10 reported that SNF staff had disregarded a medical power of attorney when it was assigned to a resident’s partner
- Transgender elders in particular reported that they experienced isolation and staff refusal to recognize their gender identities

A Wake Up Call…Recommendations to Change the Climate in Nursing Homes & Protect Lives

- Staff training is vitally important and should be mandated by management
- LGBTQ advocates can continue to push for laws mandating training for SNF personnel & residents
- Ombudsman programs must take a stronger advocacy role in protecting LGBTQ residents by asking specifically about practices & strategies for dealing with anti-LGBTQ bullying by residents & staff
- Additional research and data collection is needed to uncover additional problems LGBTQ residents face in SNFs
- From this research/date collection, additional focus needed on what strategies, model policies, and programs successfully create welcoming institutional environments (i.e. Eden Alternative; Green House Model)

LGBT Older Adults in Long-Term Care Facilities: Stories from the Field

April 2011 | National Senior Citizens Law Center in collaboration with Lambda Legal, National Center for Lesbian Rights, National Center for Transgender Equality, National Gay and Lesbian Task Force and Services & Advocacy for GLBT Elders (SAGE)

Top 10 Ways **Y-O-U** Can Begin Creating LGBTQ Safety & Inclusivity in your Aging/Health Care Venue

- **DO** presume your agency has LGBT clients
- **DO** ask your clients about their sexual orientations & gender identities in a safe and confidential manner
- **DO** create an opening for LGBT clients to talk about any family members of choice
- **DO** examine current programming to see if it can be modified for LGBT clients
- **DO** train staff in correct pronoun usage for transgender inclusion

"Inclusive Services for LGBT Older Adults", National Resource Center On LGBT Aging, 2011.

- **Do** respect gender identity when providing sex-segregated services
- **Do** review your policies and definitions of “family”
- **Do** promote diversity and inclusion
- **Do** create a welcoming environment
- **Do** promote cultural competency training

“Inclusive Services for LGBT Older Adults”, National Resource Center On LGBT Aging, 2011

om • buds • man The National Long-Term Care Ombudsman Resource Center

National Resource Center ON LGBT AGING

Lambda Legal making the case for equality

Residents' Rights and the LGBT Community:

Know YOUR Rights as a Nursing Home Resident

The federal 1987 Nursing Home Reform Law requires nursing homes to "protect and promote the rights of each resident" emphasizing individual dignity and self-determination in the provision of long-term care. Every nursing home accepting Medicare and/or Medicaid must meet federal requirements, including those regarding residents' rights.

Lesbian, Gay, Bisexual or Transgender (LGBT) Older Adults and Long-Term Care

Current estimates state that 9 million Americans identify as lesbian, gay, bisexual or transgender (LGBT).[1] One study found that 27% of LGBT baby boomers had significant concerns about discrimination as they age and there are reports that LGBT older adults encounter violations of their rights when seeking long-term care services and supports.[2] Incidents of abuse are often unreported or unidentified; however, a majority of individuals responding to a recent survey (578 of the 649 respondents or 89%) felt that staff would discriminate against an LGBT elder who was out of the closet.[3] Additionally, negative treatment, including verbal and physical harassment, by other residents was the most commonly reported problem by respondents in this study.[4]

Two friends of mine, Vera and Zayda, had been together for 58 years. When Vera's Alzheimer's became too much, Zayda moved her to an assisted living facility. Zayda could barely trust family or neighbors with the truth, let alone strangers, so she and Vera became "sisters." Much later, after Vera's death, Zayda needed to move into an assisted living facility herself. She had many, many photos of the love of her life, but dared not display them in her new home. The other residents would talk about husbands, children and grandchildren, but she felt too vulnerable to tell the truth. Zayda was in hiding and terribly isolated. *—Nina L., Carlsbad, CA* (LGBT Older Adults in Long-Term Care Facilities: Stories from the Field. www.lgbtlongtermcare.org)

Right to be FREE from ABUSE

All residents have the right to be free from abuse (by any individual - including other residents) and facilities must develop and implement policies and procedures that prohibit mistreatment of residents and investigate and report allegations of abuse. Resident mistreatment includes all types of abuse; such as verbal, sexual, mental and physical abuse, neglect and financial exploitation. For example, facility staff cannot refuse to provide care due to a resident's sexual orientation nor can staff harass a resident due to his/her gender identity.

Right to PRIVACY

Residents have the right to private and unrestricted communication with anyone they choose (e.g. during in-person visits and through letters, telephone and electronic communication) and privacy regarding their medical, personal and financial affairs. Residents also have the right to privacy regarding their bodies, and all care must be given in a manner that maximizes that privacy.

Right to be treated with RESPECT

All residents have the right to be treated with dignity, respect and consideration and have the right to exercise their choice and self-determination. For example, all residents have the right to be addressed how they want to be addressed (e.g. using a resident's preferred pronoun) and the right to be clothed and groomed consistent with their gender identity.

Right to PARTICIPATE in YOUR CARE

Residents have the right to be informed about care and treatment, participate in their own assessment and care planning and make decisions regarding their treatment, including health care choices related to gender transition. Residents also have the right to designate a legal surrogate (or, decision-maker) to act on their behalf. State laws, such as health care power of attorney and guardianship laws, govern how someone (including same-sex partners or spouses or other family of choice) can make decisions on your behalf.

Right to Receive VISITORS

Residents have the right to receive visitors of their choosing. According to the federal government, "residents must be notified of their rights to have visitors on a 24-hour basis, who could include, but are not limited to, spouses (including same-sex spouses), domestic partners (including same-sex domestic partners), other family members, or friends."[7]

Right to Participate in ACTIVITIES

Residents have the right to participate in (or choose not to participate in) social, religious, and community activities both inside and outside of the facility. For example, you have the right to participate in and promote an event, training or resource regarding LGBT equality (e.g. PRIDE parade, PFLAG support group meeting) without fear of discrimination or abuse.

Right to be FULLY INFORMED

Facilities must inform residents of any changes in services, changes in care or treatment, what is covered by Medicare and Medicaid or other health care insurance and of a change in roommate or room. Facilities must provide notice before a change in roommate and be as "accommodating as possible" by considering each resident's preferences.[8] In regards to benefits, the federal government states that Medicare Advantage enrollees are entitled to equal access to services in the same skilled nursing facility their spouse resides in, regardless of sexual orientation. Specifically stating that, "this guarantee of coverage applies equally to couples who are in a legally recognized same-sex marriage, regardless of where they live."[9]

---

[8] Department of Health and Human Services. Centeres for Medicare

Right to CHOICE

Residents have the right to make their own choices, including what to wear, how to express themselves and their daily routine. Residents also have the right to retain and use personal items (e.g. some furnishings, pictures). Additionally, residents have the right to room with a person of their choice, including same-sex spouses or partners, if they live in the same facility and both consent to the arrangement.

Right to REMAIN In the HOME

A nursing home cannot transfer or discharge a resident unless one (or more) of the permissible reasons for transfer or discharge apply. Residents cannot be transferred or discharged due to their sexual orientation or gender identity. (See 42 CFR 483.12 for Admission, transfer and discharge rights, link to federal regulations in “Resources” section).

Advocating for YOUR Rights

You have the right to voice concerns with the staff without fear of reprisal and they must try to resolve grievances promptly. Nursing home staff are required to protect all residents from abuse and report and investigate allegations of abuse. Also, residents have the right to file a complaint regarding abuse, neglect, exploitation or non-compliance with the state licensing and certification agency. There are resources available to support you and agencies responsible for investigating complaints and allegations of abuse.

To locate resources in your state, including the agencies mentioned below, you can contact **Eldercare Locator.** Eldercare Locator is a national public service to help older adults and caregivers connect with local aging and disability services including the Long-Term Care Ombudsman Program, Adult Protective Services and your state licensing and certification agency. You can reach the Eldercare Locator by calling **1-800-677-1116** or visiting www.eldercare.gov.

You have several options in addressing your concerns and you can use these at any time depending on your comfort level with working with the facility staff or the type of concern and outcome you want:

- Share your concerns with the **facility administrator**, **social worker** or another **staff person.** Inquire about the facility policy for grievances and use it, but know that you are not limited to their grievance policy. Document your conversations and keep a written record of your complaint. If necessary, ask for a care plan meeting to discuss your concerns.
- Contact your **Long-Term Care Ombudsman (LTCO) Program**. Ombudsmen are advocates for residents in long-term care facilities and are trained to resolve complaints with you and on your behalf. For additional information about the ombudsman program and to locate your LTCO program, visit www.ltcombudsman.org/ombudsman. Contact information for your ombudsman program should also be posted in your facility.
- Contact your **state licensing and certification agency**. Each state has an agency responsible for the licensing, certification and regulation of long-term care facilities and investigations of complaints. To locate your state licensing and certification agency visit www.ltcombudsman.org/ombudsman.
- Contact **Adult Protective Services** (APS). APS investigates reports of abuse, neglect and exploitation of elders and, in many states, individuals with disabilities. Every state has APS services, but the services vary by state. To locate APS services in your area, visit www.napsa.now.org/get-help/how-aps-helps/.
- Abuse is a crime. If you are a victim of abuse in addition to contacting the investigating agencies contact your **local law enforcement agency**.
- Discrimination against LGBT nursing home residents is illegal. Contact the **Lambda Legal Help Desk** for information and lawyer referrals at 1-866-542-8336 or www.lambdalegal.org.

Long-Term Care Information, Resources and Advocacy

National Consumer Voice for Quality Long-Term Care (Consumer Voice) The Consumer Voice is the leading national voice representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves and provides information and tools for consumers, families, caregivers, advocates and ombudsmen to help ensure quality care for the individual.
www.theconsumervoice.org 202-332-2275

National Long-Term Care Ombudsman Resource Center (NORC) The National Long-Term Care Ombudsman Resource Center provides support, technical assistance and training to the 53 State Long-Term Care Ombudsman Programs and their statewide networks of almost 600 regional (local) programs.
www.ltcombudsman.org 202-332-2275

LGBT Aging Resources and Advocacy

National Resource Center on LGBT Aging The National Resource Center on LGBT Aging is the country's first and only technical assistance resource center aimed at improving the quality of services and supports offered to lesbian, gay, bisexual and/or transgender older adults. http://www.lgbtagingcenter.org 212-741-2247

Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders (SAGE) SAGE is a national organization that offers supportive services and consumer resources for LGBT older adults and their caregivers, advocates for public policy changes that address the needs of LGBT older people, and provides training for aging providers and LGBT organizations, largely through its National Resource Center on LGBT Aging.
www.sageusa.org 212-741-2247

Lambda Legal Founded in 1973, Lambda Legal is the oldest and largest national legal organization whose mission is to achieve full recognition of the civil rights of lesbians, gay men, bisexuals, transgender people and those with HIV through impact litigation, education and public policy work. http://www.lambdalegal.org/ 212-809-8585

National Coalition of Anti-Violence Programs' National LGBTQ Training and Technical Assistance Center The National Coalition of Anti-Violence Programs (NCAVP) coordinates the National Training and Technical Assistance (TTA) Center on Lesbian, Gay, Bisexual, Transgender, & Queer (LGBTQ) Cultural Competency. The NCAVP Training and Technical Assistance Center is available for direct service and advocacy organizations seeking answers, support, and strategies to become inclusive of and accessible to lesbian, gay, bisexual, transgender, and queer (LGBTQ) survivors. http://avp.org/resources/training-center 1-855-287-5428

The National Gay and Lesbian Task Force The mission of the National Gay and Lesbian Task Force is to build the power of the lesbian, gay, bisexual and transgender (LGBT) community from the ground up. We do this by training activists, organizing broad-based campaigns to defeat anti-LGBT referenda and advance pro-LGBT legislation, and by building the organizational capacity of our movement. http://www.thetaskforce.org/ 202-393-2241

National Center for Transgender Equality The National Center for Transgender Equality (NCTE) is a 501(c)3 social justice organization dedicated to advancing the equality of transgender people through advocacy, collaboration and empowerment. http://transequality.org/ 202-903-0112

FORGE: Transgender Aging Network (TAN) FORGE was founded in 1994 in Milwaukee, Wisconsin, and provides peer support to everyone in the transgender community. http://forge-forward.org/aging/

Nursing Home Regulations

Electronic Code of Federal Regulations- Part 483 Requirements for States and Long Term Care Facilities (483.10 Residents' Rights) http://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&tpl=/ecfrbrowse/Title42/42cfr483_main_02.tpl

Search Trained Agencies

The National Resource Center on LGBT Aging recognizes that it is often difficult to find agencies open to LGBT people and their friends, families, and loved ones. Knowing which agencies have received LGBT cultural competency training can be a good place to start connecting to local resources.

Use the form below to search for agencies in your area that have been trained by a National Resource Center Certified Trainer.

You can search by level of training completed, location, or type of agency. For example, searching by state will display a list of every training that has taken place in that state or that has people who have been trained that work in that state. Searching by state and checking "Senior Center" will display all of the senior centers in the state that have staff members who have participated in a National Resource Center training.

Our national training program has reached over 16086 people.

Checking multiples in one field will find agencies with ANY of those checked (broader search).
Entering criteria across multiple fields will find agencies with ALL of those values (narrower search).

Trainings Completed

- ☐ Creating Inclusive Communities for LGBT Older Adults
- ☐ Welcome Home: LGBT Older Adults and Housing
- ☐ LGBT Older Adults: Compliance with the HUD Equal Access Rule
- ☐ Introduction to LGBT Aging
- ☐ Embracing LGBT Older Adults of Color
- ☐ Transgender Aging: What Service Providers Need (and Don't Need!) to Know
- ☐ Respected and Whole: Preventing Anti-LGBT Bias between Constituents, Staff, and across Aging Services
- ☐ Asking Demographic Questions about Sexual Orientation and Gender Identity
- ☐ Supporting Lesbian, Gay, Bisexual, and Transgender Older Adults
- ☐ Improving Aging Services for LGBT Older Adults
- ☐ Hospice and Palliative Care for LGBT Patients and Families
- ☐ Psychosocial Needs of LGBT Veterans
- ☐ Including Older Adults in LGBT Organizations

Agency Name

City

State All States

Search

Alzheimer's Association, Greater New Jersey Chapter - Marlton, NJ
Marlton, NJ 08053

- **5 people** trained on 11/1/2016 by
  Introduction to LGBT Aging

Alzheimer's New Jersey
Denville, NJ 07834

- **1 person** trained on 10/31/2015 by Tim R. Johnston
  Introduction to LGBT Aging

- **19 people** trained on 5/22/2015 by Tim R. Johnston
  Improving Aging Services for LGBT Older Adults

Barnabas Health Hospice and Home Care - Home Care and Health
West Orange, NJ 07052

- **94 people** trained on 10/24/2014 by Tim R. Johnston
  Welcoming LGBT Older Adults

Bear Creek Senior Living Community
West Windsor, NJ 08550

- **1 person** trained on 4/17/2015 by Tim R. Johnston
  Welcoming LGBT Older Adults

Bergen County Area Agency on Aging/Aging and Disability Resource Center
Trenton, NJ 08625

- **6 people** trained on 1/26/2017 by Sadiya Abjani
  Asking Demographic Questions about Sexual Orientation and Gender Identity

- **2 people** trained on 10/18/2016 by Sadiya Abjani
  Supporting Lesbian, Gay, Bisexual, and Transgender Older Adults

- **1 person** trained on 3/30/2016 by Sadiya Abjani
  Respected and Whole: Preventing Anti-LGBT Bias between Constituents, Staff, and across Aging Services

---

Bergen County Board of Social Services
Rochelle Park, NJ 07662-3300

- **4 people** trained on 12/10/2014 by Tim R. Johnston
  Improving Aging Services for LGBT Older Adults

National Resource Center ON LGBT AGING

10 Tips for Finding LGBT-Affirming Services

sage
Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders

National Resource Center
on LGBT Aging
National Headquarters
c/o Services & Advocacy
for GLBT Elders (SAGE)
305 Seventh Avenue
6th Floor
New York, NY 10001

212-741-2247 phone
212-366-1947 fax

info@lgbtagingcenter.org
lgbtagingcenter.org

As an LGBT older adult or a caregiver, you and your loved one might be considering home care or long-term care services. However, you might be concerned about finding services and programs that are LGBT affirming. Inviting someone into your home or revealing personal information can be intimidating at any time, and you may be feeling particularly vulnerable at this point in time. It is important to find service providers who understand LGBT issues and can be trusted to provide you with competent, respectful care. Here are ten helpful tips on finding an LGBT-affirming service provider:

1. The best references come from the people you already know and trust. Ask friends with similar circumstances who they have worked, and whether they felt respected and comfortable.

2. Contact your local SAGE Affiliate or LGBT aging provider, LGBT Community Center, PFLAG chapter or other LGBT organizations and ask for referrals to providers they have worked with in their networks.

3. Look to see if there are service providers that advertise in your local LGBT newspapers and magazines (either print or online) or have signed up as sponsors, members, etc. with local LGBT groups.

4. Reach out to your local HIV/AIDS service providers, who often have close connections to LGBT-affirming home care agencies and other services.

5. Ask or look for information about whether an agency's staff have been trained on how to provide culturally competent care to LGBT people.

6. Check the SAGECare website (listed below) for agencies that have received the SAGECare Credential for completing training by SAGE.

7. Ask providers directly if they serve LGBT individuals, and if so, find out whether that answer is concrete (current or past clients) or hypothetical ("we welcome everyone").

8. Most providers have non-discrimination policies—check to see if these policies specifically include sexual orientation and gender identity, and whether they post or distribute their policies openly. You can also ask how those policies are enforced.

9. Review the provider's pamphlets, brochures or websites. Are LGBT individuals represented in these materials? Do they use LGBT-inclusive language—such as partner, domestic partner, and significant other—on their websites, in their print materials or on their intake forms?

10. Most importantly, always trust your instincts! Only you and your loved one know what's right for you.

SAGE LGBT ELDER **HOTLINE**

Toll-free 1-888-234-SAGE

(1-888-234-7243)

[illegible] is the world's largest organization devoted to improving the lives of LGBT older people.
For nearly forty years, SAGE has prioritized the needs of our most vulnerable LGBT elders and continues to do so.
That is why the SAGE LGBT elder hotline was launched with the LGBT-related help center in order as part of a national effort to take care of our own.

Now, no matter where they live, LGBT elders have a place to call when they need peer counseling, information and local resources.
Operated by the SAGE national help center, this hotline offers peer support to callers who are often very isolated sometimes still closeted,
and in need of a caring, non-judgmental person to talk with. The folks on the hotline don't give advice, instead they listen and they care.

HOURS:

Monday thru Friday from 1pm to 9pm, *pacific time*

(Monday thru Friday from 4pm to midnight, *eastern time*)

Saturday from 9am to 2pm, *pacific time*

(Saturday from noon to 5pm, *eastern time*)

Email: [illegible]@SAGEhotline.org

This hotline is broadly defined as inclusive of people ages 50 and over.

No matter where you live, LGBT seniors now have a place to call when you need peer-support, information and local resources.

The SAGE LGBT Elder Hotline provides gay, lesbian, bisexual and transgender seniors the ability to talk with our trained peer-counselor volunteers about issues including isolation, relationship concerns, bullying, HIV/AIDS, and much more.

We also provide local senior resource information for cities and towns across the United States.

All services are free and confidential.

National LGBT Caregiver Support Group

The caregiver support group provides a safe and nurturing space for caregivers in our community to build relationships, share information and resources, vent frustrations and gain emotional support.

Whether you are caring for a parent, partner or friend, your well-being is essential to those you care for.

If you are interested in joining SAGE's National Caregiver Support Group please contact SAGE at 212-741-2247.

All members of the group and issues discussed in the group will be treated with the utmost confidentiality.

This support group is offered free of charge.

Visit us on the web at www.sageusa.org

SAGECAP
{Caring and Preparing}

LGBTQ Aging

Palliative Care

Hospice/End of Life Care

Advance Care Planning

Jim Palmer, BBA MSW LCSW

Mount Sinai

EDUCATIONAL OBJECTIVES

- To identify barriers to providing palliative care & hospice care to LGBTQ older adults
- To provide guidance on how to enhance & enrich our work with this population and to provide inclusive delivery of care
- To discuss the importance of Advance Care Planning with LGBTQ individuals

Whenever I see new health care providers, I have to deal with invisibility. My life is invisible to them. I constantly have to decide if it's safe to come out to new providers. I wish that my life was reflected at the doctor's office or the clinics where I receive health care, in their questions and forms. I wish I didn't have to decide to disclose my sexual orientation and the context in which I live my life. I wish I didn't have to explain about my family of choice. Straight people don't have to do that….Why do I?

-37 year old lesbian patient

Smolinski, K. & Colon, Y. '*Palliative Care with Lesbian, Gay, Bisexual, and Transgender Persons'.* Oxford Textbook of Palliative Social Work, 2011.

Palliative Care

to Palliate:

Alleviate (a symptom)

Moderate (the intensity of a condition)

Reduce *(the suffering from a disease)*

Palliative Care

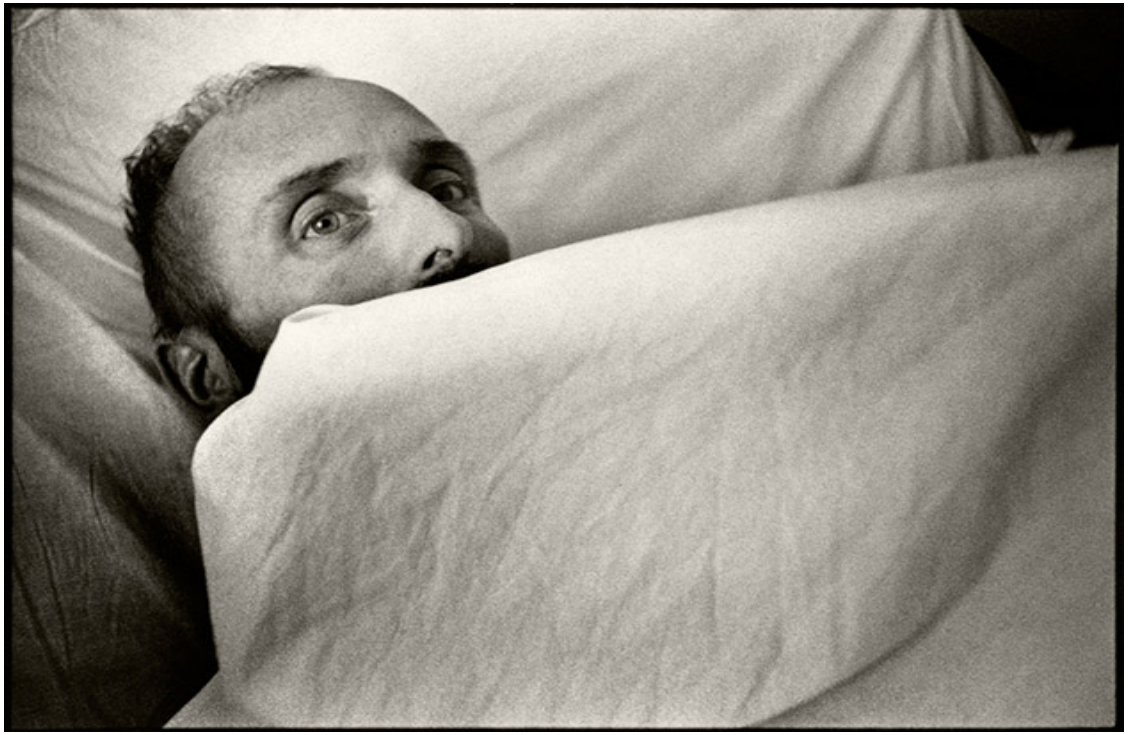
To ***Cure*** Sometimes

To ***Relieve*** Often

To ***Comfort*** Always

Hospice Care

All hospice is palliative care, but not all palliative care is hospice



"How we treat people who are dying is a test of our understanding, acceptance and compassion. Becoming seriously ill and knowing you are dying is distressing enough without the added stress of worrying that your caregivers may not accept you if they know you are lesbian, gay, bisexual, or transgender"

-Peter Tatchell, Human Rights Advocate

- A long history of stigma, prejudice & discrimination against LGBTQ people in the U.S. results in many LGBTQ individuals being hesitant to seek health care, especially palliative care (PC) & hospice care

- Other factors/issues affecting acceptance of PC & hospice:
  - Greater risk for physical /mental illness
  - Social Isolation/Many reside alone
  - Family of Choice v. Biological Family
  - Caregiver status
  - Depression/Anxiety
  - Poverty
  - Delayed care seeking
  - Poor nutrition
  - Premature mortality
  - Chronic Illnesses
  - Legal inequalities creating barriers to access to services

Acquaviva, K. LGBTQ-Inclusive Hospice And Palliative Care, 2017.
"Iinclusive Services for LGBT Older Adults: A Practical Guide to Crating Welcoming Agencies", National Resource Center for LGBT Aging, 2011

"LGBT seniors are less likely than their heterosexual counterparts to have children or other nuclear family members to support their aging and they are more likely to be caring for a friend or family member. Many in our region feel extremely vulnerable as they age and many return to the 'closet' for fear of being mistreated by health and other professionals"

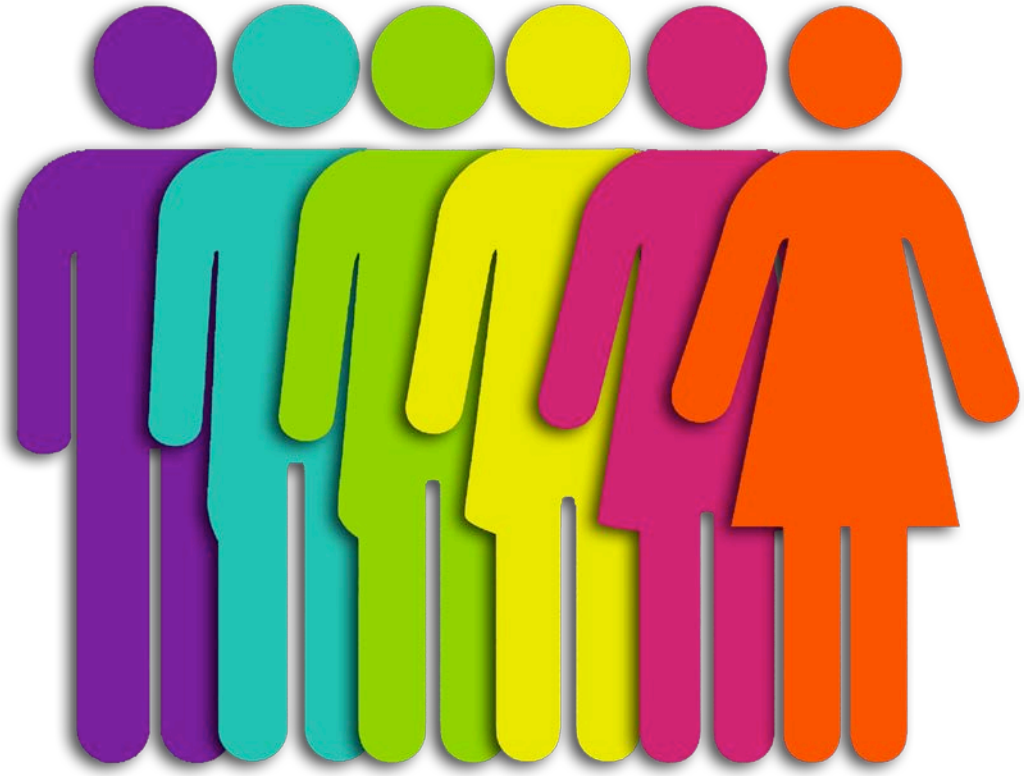
--Kathleen LaTosch

Affirmations, Metro Detroit's Community Center for LGBT People

Quote from "Inclusive Services for LGBT Older Adults: A Practical Guide To Creating Welcoming Agencies", National Resource Center On LGBT Aging, 2011

Additionally, for LGBTQ individuals, barriers to PC & hospice care fall into 3 general categories:

- Perceptual Barriers
- Financial Barriers
- Institutional Barriers



Acquaviva, K. LGBTQ-Inclusive Hospice And Palliative Care, 2017

Overcoming Barriers…

- For PC & hospice programs to address these barriers to care, it is recommended that a two pronged approach be developed:
  - Outward Facing
  - Inward Looking

Acquaviva, K. LGBTQ-Inclusive Hospice And Palliative Care, 2017

Home Care & Hospice Association of NJ

The Home Care & Hospice Association of NJ is the non-profit Association which represents and advocates for home care and hospice agencies in our state. The Association was founded in 1973 by a group of New Jersey home health agencies. Since that time it has continued to grow, while still providing the same advocacy and education for which it was founded.

Our Mission is to serve as ***the catalyst for excellence in home care and hospice.***

Our Goals are to inform, educate, assist and advocate for home care and hospice providers and the patients and families they serve throughout New Jersey.

Our Members include licensed home health agencies, licensed health care service firms, licensed hospices, and organizations that offer services and products that support home care and hospice.

Our Services to members include:

- **Members only email network** to keep home care and hospice providers well-informed about issues, regulations, legislation, emergency alerts, and new developments at both the state and national levels.
- **State and Federal lobbying representation** advocating for the advancement of home care and hospice.
- **Discounted educational seminars and an Annual Conference & Exhibition** to bring the latest financial, clinical, legislative, regulatory, and industry information to the administrators, managers and professionals responsible for home care and hospice in NJ. A Hospice Team Conference each fall is focused on the hospice interdisciplinary team. The Hospice Volunteer Conference each summer offers education and networking opportunities to hundreds of hospice volunteers
- **Participation on health care coalitions, committees and work groups** with state and federal departments, consumer groups, and other health care organizations to promote improvements in regulations, legislation, outreach, and access to home care and hospice in New Jersey and the nation.

www.homecarenj.org

Look here for:

- **Lists of licensed home health agencies, by county** ("Find Provider" tab)
- **Lists of licensed hospice programs, by county** ("Find Provider" tab)
- Calendar of education programs ("Education & Events" tab)
- Membership Directory & Referral Guide ("Find Provider" tab)
- "Consumer" tab:
  - What Is Home Care?
  - What Is Hospice?
  - Patient Rights
  - Consumer Guidance on seeking a health care service form

ADVANCE CARE PLANNING

- In health care, an individual's autonomy is best protected through Advance Care Planning (ACP): the process of Identifying, Discussing, & Executing plans for future health care decisions

ACP

- There are several ethical principles & legal issues that affect LGBTQ individuals in the ACP process

Advance Care Planning

The Home Care & Hospice Association of NJ also serves as a leading advocate for advance care planning. Fewer than 1/3 of New Jerseyans have written documents expressing the kind of care they would like if they become incapable of expressing those preferences.

Those preferences can be expressed through advance directives, healthcare proxy forms, "Five Wishes" forms and Practitioners Orders for Life Sustaining Treatment forms. We encourage all New Jerseyans to express their caregiving wishes to loved ones and complete documents that can be used when healthcare decisions must be made.

Further information is available at www.caringinfo.org and www.nhdd.org, the website for National Healthcare Decisions Day.

Home Care & Hospice Association of NJ
485D Route 1 South, Suite 210, Iselin, NJ 08830
732-877-1100 / fax 732-877-1101 / www.homecarenj.org

PROXY DIRECTIVE--(Durable Power of Attorney for Health Care)
Designation of Health Care Representative

I understand that as a competent adult, I have the right to make decisions about my health care. There may come a time when I am unable, due to physical or mental incapacity, to make my own health care decision. In these circumstances, those caring for me will need direction and they will turn to someone who knows my values and health care wishes. By writing this durable power of attorney for health care I appoint a health care representative with the legal authority to make health care decisions on my behalf and to consult with my physician and others. I direct that this document become part of my permanent medical records.

A) CHOOSING A HEALTH CARE REPRESENTATIVE:

I, _____, hereby designate _____,
of _____
_____,
(home address and telephone number of health care representative)

as my health care representative to make any and all health care decisions for me, including decisions to accept or to refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition and decisions to provide, withhold or withdraw life-sustaining measures. I direct my representative to make decisions on my behalf in accordance with my wishes as stated in this document, or as otherwise known to him or her. In the event my wishes are not clear, my representative is authorized to make decisions in my best interest, based on what is known of my wishes.

This durable power of attorney for health care shall take effect in the event I become unable to make my own health care decisions, as determined by the physician who has primary responsibility for my care, and any necessary confirming determinations.

B) ALTERNATE REPRESENTATIVES: If the person I have designated above is unable, unwilling or unavailable to act as my health care representative, I hereby designate the following person(s) to act as my health care representative, in the order of priority stated:

1. *name* _____
   address _____
   city _____ *state* _____
   telephone _____

2. *name* _____
   address _____
   city _____ *state* _____
   telephone _____

C) SPECIFIC DIRECTIONS: Please initial the statement below which best expresses your wishes.

_____ My health care representative is authorized to direct that artificially provided fluids and nutrition, such as by feeding tube or intravenous infusion, be withheld or withdrawn.

_____ My health care representative does not have this authority, and I direct that artificially provided fluids and nutrition be provided to preserve my life, to the extent medically appropriate.

(If you have any additional specific instructions concerning your care you may use the space below or attach an additional statement.)

_____

_____

_____

_____

D) COPIES: The original or a copy of this document has been given to my health care representative and to the following:

1. *name* _____
   address _____
   city _____ *state* _____ *telephone* _____
2. *name* _____
   address _____
   city _____ *state* _____ *telephone* _____

E) SIGNATURE: By writing this durable power of attorney for health care, I inform those who may become entrusted with my care of my health care wishes and intend to ease the burdens of decision making which this responsibility may impose. I have discussed the terms of this designation with my health care representative and he or she has willingly agreed to accept the responsibility for acting on my behalf in accordance with my wishes as expressed in this document. I understand the purpose and effect of this document and sign it knowingly, voluntarily and after careful deliberation.

Signed this _____ **day of** _____, **20**_____.

signature _____

address _____

city _____ *state*_____

F) WITNESSES: I declare that the person who signed this document, or asked another to sign this document on his or her behalf, did so in my presence, that he or she is personally known to me, and that he or she appears to be of sound mind and free of duress or undue influence. I am 18 years of age or older, and am not designated by this or any other document as the person's health care representative, nor as an alternate health care representative.

1. *witness* _____
   address _____
   city _____ *state* _____
   signature _____
   date _____

2. *witness* _____
   address _____
   city _____ *state* _____
   signature _____
   date _____

INSTRUCTION DIRECTIVE

I understand that as a competent adult I have the right to make decisions about my health care. There may come a time when I am unable, due to physical or mental incapacity, to make my own health care decisions. In these circumstances, those caring for me will need direction concerning my care and they will require information about my values and health care wishes. In order to provide the guidance and authority needed to make decisions on my behalf:

A) I, _____, hereby declare and make known to my family, physician, and others, my instructions and wishes for my future health care. I direct that all health care decisions, including decisions to accept or refuse any treatment, service or procedure used to diagnose, treat or care for my physical or mental condition and decisions to provide, withhold or withdraw life-sustaining measures, be made in accordance with my wishes as expressed in this document. This instruction directive shall take effect in the event I become unable to make my own health care decisions, as determined by the physician who has primary responsibility for my care, and any necessary confirming determinations. I direct that this document become part of my permanent medical records.

Part One: Statement of My Wishes Concerning My Future Health Care

*In **Part One**, you are asked to provide instructions concerning your future health care. This will require making important and perhaps difficult choices. Before completing your directive, you should discuss these matters with your doctor, family members or others who may become responsible for your care.*

*In **Section B and C**, you may state the circumstances in which various forms of medical treatment, including life-sustaining measures, should be provided, withheld or discontinued. If the options and choices below do not fully express your wishes, you should use **Section D**, and/or attach a statement to this document which would provide those responsible for your care with additional information you think would help them in making decisions about your medical treatment. **Please familiarize yourself with all sections of Part One before completing your directive.***

B) GENERAL INSTRUCTIONS: To inform those responsible for my care of my specific wishes, I make the following statement of personal views regarding my health care:

Initial ONE of the following two statements with which you agree:

1. ____ I direct that all medically appropriate measures be provided to sustain my life, regardless of my physical or mental condition.

2. ____ There are circumstances in which I would not want my life to be prolonged by further medical treatment. In these circumstances, life-sustaining measures should not be initiated and if they have been, they should be discontinued. I recognize that this is likely to hasten my death. In the following, I specify the circumstances in which I would choose to forego life-sustaining measures.

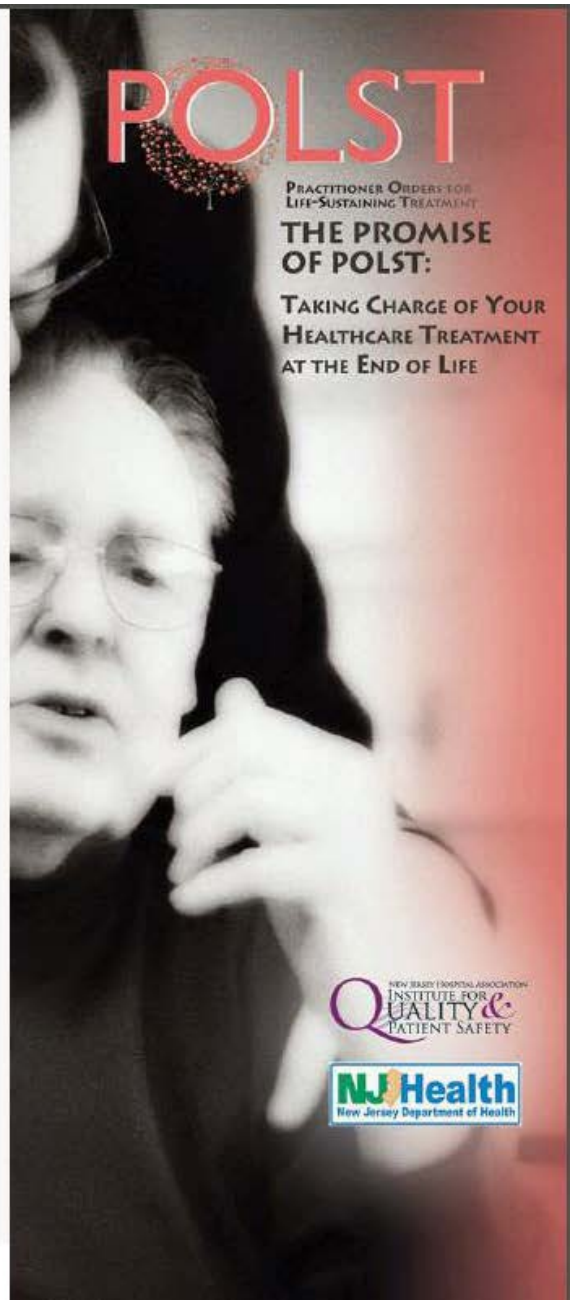
HOW IS POLST DIFFERENT FROM AN ADVANCE DIRECTIVE?

POLST complements an Advance Directive and does not totally replace that document. You may still need an advance directive to appoint a legal healthcare administrator. It is recommended that all adults have an advance directive regardless of their health status. If there is a conflict between the documents, have a conversation with your practitioner as soon as possible to determine the most current preferences.

The promise of POLST is that it empowers you to make the important decisions about your end-of-life care. Have the POLST conversation with your medical professional.

New Jersey Hospital Association Institute for Quality & Patient Safety

NJ Health New Jersey Department of Health



THE PROMISE OF POLST:

TAKING CHARGE OF YOUR HEALTHCARE TREATMENT AT THE END OF LIFE

Talking about your wishes during a serious, life-altering illness can be difficult, emotional and, and for some of us, is a conversation we would rather avoid. But it's a conversation you must have as an important and necessary part of good medical care. You have the right to participate fully in all your healthcare decisions – and that's even more important near the end of life.

The best way to make your preferences known is by talking with your healthcare provider and filling out the Practitioner Orders for Life-Sustaining Treatment form, or POLST. POLST is a medical order form that empowers individuals by carefully detailing their personal wishes regarding end-of-life care.

POLST can help you make meaningful personal choices regarding your care – and ensure that every member of the healthcare teams understands and respects those choices. Individuals fill out the POLST form together with their physician or advance practice nurse. It's signed by all of you and then becomes a permanent part of your medical record. Your POLST form will travel with you and must be honored in all his/her healthcare settings. And you can modify your POLST form at any time.

YOU SHOULD HAVE A POLST FORM IF YOU ARE:

- Seriously ill with a life-limiting advanced illness
- Frail and weak and have trouble performing routine daily activities
- Afraid of losing the capacity to make your own healthcare decisions in the near future
- Living in a nursing home or hospice.

MAKE YOUR WISHES KNOWN: CHOICES TO DISCUSS WITH YOUR HEALTHCARE PROFESSIONAL

There are two very important parts of the POLST form for you to describe your goals and wishes at the end of life: your "goals of care" and the medical interventions that you do and do not want.

GOALS OF CARE

This section details how you want to live your life in the time you have left. What is most important to you as you deal with a life-limiting illness? Do you have personal goals or family milestones you would like to reach? How much do you want to know about your illness? How much does your family know about your priorities and wishes? These are all issues you should consider. Your POLST form will allow you to make known any personal, cultural or spiritual practices related to your care.

MEDICAL INTERVENTIONS

The form also will allow you to work with your medical professional to clearly define the types of medical interventions you want – or don't want. For example, you may specify that you want comfort measures only, which is medical treatment intended to eliminate pain and suffering. You may specify an array of other treatment options such as intravenous fluids or antibiotics. Or you may state your wishes for full treatment, including all options available to sustain your life which could include a feeding tube and cardio pulmonary resuscitation.

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

NEW JERSEY PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

Follow these orders, then contact physician/APN. This Medical Order Sheet is based on the current medical condition of the person referenced below and their wishes stated verbally or in a written advance directive. Any section not completed implies full treatment for that section. Everyone will be treated with dignity and respect.

Person Name (Last, first, middle) Date of Birth

A GOALS OF CARE
(See reverse for instructions. This section does not constitute a medical order.)

B MEDICAL INTERVENTIONS: *Person is breathing and/or has a pulse*

- ☐ **Full Treatment**: Use all appropriate medical and surgical interventions as indicated to support life. If in a nursing facility, transfer to hospital if indicated. See section D for resuscitation status.
- ☐ **Limited Treatment**: Use appropriate medical treatment such as antibiotics and IV fluids as indicated. May use non-invasive positive airway pressure. Generally avoid intensive care.
  - ☐ Transfer to hospital for medical interventions.
  - ☐ Transfer to hospital only if comfort needs cannot be met in current location.
- ☐ **Symptom Treatment Only**: Use aggressive comfort treatment to relieve pain and suffering by using any medication by any route, positioning, wound care and other measures. Use oxygen, suctioning and manual treatment of airway obstruction as needed for comfort. Use Antibiotics only to promote comfort. Transfer only if comfort needs cannot be met in current location.

Additional Orders: _____

C ARTIFICIALLY ADMINISTERED FLUIDS AND NUTRITION:
Always offer food/fluids by mouth if feasible and desired.

- ☐ No artificial nutrition.
- ☐ Defined trial period of artificial nutrition.
- ☐ Long-term artificial nutrition.

D CARDIOPULMONARY RESUSCITATION (CPR)
Person has no pulse and/or is not breathing

- ☐ Attempt resuscitation/CPR
- ☐ Do not attempt resuscitation/DNAR
- Allow Natural Death

AIRWAY MANAGEMENT
Person is in respiratory distress with a pulse

- ☐ Intubate/use artificial ventilation as needed
- ☐ Do not intubate - Use CO, manual treatment to relieve airway obstruction, medications for comfort
- ☐ Additional Order (for example defined trial period of mechanical ventilation): _____

E
If I lose my decision-making capacity, I authorize my surrogate decision maker, listed below, to modify or revoke the NJ POLST orders in consultation with my treating physician/APN in keeping with my goals. ☐ Yes ☐ No
☐ Health care representative identified in an advance directive ☐ Other surrogate decision maker

Print Name of Surrogate (address on reverse) Phone Number

F SIGNATURES:
I have discussed this information with my physician/APN.

Print Name_____

Signature_____

- ☐ Person Named Above
- ☐ Health Care Representative/Legal Guardian
- ☐ Spouse/Civil Union Partner
- ☐ Parent of Minor
- ☐ Other Surrogate

Has the person named above made an anatomical gift
☐ Yes ☐ No ☐ Unknown

These orders are consistent with the person's medical condition, known preferences and (best known) information.

PRINT Physician/APN Name Phone Number

Physician/APN Signature (Mandatory) Date/Time

Professional License Number

4/12/17 SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

PRINT PERSON'S NAME (LAST, FIRST, MIDDLE) DATE OF BIRTH

PRINT PERSON'S ADDRESS

CONTACT INFORMATION

PRINT SURROGATE HEALTH CARE DECISION MAKER ADDRESS PHONE NUMBER

DIRECTIONS FOR HEALTH CARE PROFESSIONAL

COMPLETING POLST

- Must be completed by a physician or advance practice nurse.
- Use of original form is strongly encouraged. Photocopies and faxes of signed POLST forms may be used.
- Any incomplete section of POLST implies full treatment for that section.

REVIEWING POLST

POLST orders are actual orders that transfer with the person and are valid in all settings in New Jersey. It is recommended that POLST be reviewed periodically, especially when:

- The person is transferred from one care setting or care level to another, or
- There is a substantial change in the person's health status, or
- The person's treatment preferences change.

MODIFYING AND VOIDING POLST - *An individual with decision making capacity can always modify/void a POLST at any time.*

- A surrogate, if designated in Section E on the front of this form, may, at any time, void the POLST form, change his/her mind about the treatment preferences or execute a new POLST document based upon the person's known wishes or other documentation such as an advance directive.
- A surrogate decision maker may request to modify the orders based on the known desires of the person or, if unknown, the person's best interest.
- To void POLST, draw a line through all sections and write "VOID" in large letters. Sign and date this line.

SECTION A

What are the specific goals that we are trying to achieve by this treatment plan of care? This can be determined by asking the simple question: "What are your hopes for the future?" Examples include but not restricted to:

- Longevity, care, remission
- Better quality of life
- Live long enough to attend a family event (wedding, birthday, graduation)
- Live without pain, nausea, shortness of breath
- Eating, driving, gardening, enjoying grandchildren

Medical providers are encouraged to share information regarding prognosis in order for the person to set realistic goals.

SECTION B

- When "limited treatment" is selected, also indicate if the person prefers or does not prefer to be transferred to a hospital for additional care.
- IV medication to enhance comfort may be appropriate for a person who has chosen "symptom treatment only."
- Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), or bi-level positive airway pressure (BiPAP).
- Comfort measures will always be provided.

SECTION C

Oral fluids and nutrition should always be offered if medically feasible and if they meet the goals of care determined by the person or surrogate. The administration of nutrition and hydration whether orally or by invasive means shall be within the context of the person's wishes, religion and cultural beliefs.

SECTION D

Make a selection for the person's preferences regarding CPR and a separate selection regarding airway management. A defined trial period of mechanical ventilation may be considered, for example, when additional time is needed to assess the current clinical situation or when the expected need would be short term and may provide some palliative benefit.

SECTION E

This section is applicable in situations where the person has decision making capacity when the POLST form is completed. A surrogate may only void or modify an existing POLST form, or execute a new one, if named in this section by the person.

SECTION F

POLST must be signed by a practitioner, meaning a physician or APN, to be valid. Verbal orders are acceptable with follow-up signatures by physician/APN in accordance with facility/community policy. POLST orders should be signed by the person/surrogate. Indicate on the signature line if the person/surrogate is unable to sign, declined to sign, or a verbal consent is given. Remind the person/surrogate that once completed and signed, this POLST will void any prior POLST documents.

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED

MODEL POLICY FOR HOSPICES

Practitioner Orders for Life-Sustaining Treatment (POLST)

PURPOSE

This policy defines a process for hospice providers to follow when a patient who is enrolled in hospice, or is considering enrollment, has a Practitioner Orders for Life-Sustaining Treatment (POLST) form. This policy also outlines procedures regarding the completion of a POLST form and the steps necessary when reviewing or revising a POLST form.

POLST

PREAMBLE

The Practitioner Orders for Life-Sustaining Treatment (POLST) is a physician or nurse practitioner (NP) order that complements an advance directive by converting an individual's wishes regarding life-sustaining treatment and resuscitation into physician/NP orders. It is used statewide for individuals to communicate their wishes about a range of life-sustaining and resuscitative measures. It is a portable, authoritative and immediately actionable physician/NP order consistent with the individual's wishes and medical condition, which shall be honored across treatment options.

THE POLST FORM:

- Is a standardized form that is brightly colored and clearly identifiable;
- Can be revised or revoked by an individual with decision-making capacity at any time;
- Is legally sufficient and recognized as a physician/NP order;
- Is recognized and honored across treatment settings;
- Provides statutory immunity from criminal prosecution, civil liability, discipline for unprofessional conduct, administrative sanction or any other sanction to a healthcare provider who relies in good faith in honoring a POLST;
- Can be an alternative to some other forms, although POLST is more comprehensive than a Out-Of-Hospital DNR in that it addresses other life-sustaining treatment in addition to resuscitative measures; and
- Should be made available for patients who wish to execute a POLST form while enrolled in hospice.

The original form in its most current version must remain physically with the patient across all care settings.

A health care provider is not required to initiate a POLST form, but is required to treat an individual in accordance with his/her POLST form. This does not apply if the POLST requires ineffective medical care.

A legally recognized health care decision-maker may execute, revise or revoke the POLST form for a patient only if the patient lacks decision-making capacity and if the action is consistent with the expressed preferences of the patient. This policy does not address the criteria or process for determining or appointing a legally recognized health care decision-maker, nor does it address the criteria or process for determining decision-making capacity.

While a health care provider such as a hospice nurse or a hospice social worker can explain the POLST form to the patient and/or the patient's legally recognized health care decision-maker, the patient's physician/NP or nurse practitioner or the hospice physician/NP or nurse practitioner is responsible for

MODEL POLICY FOR

NURSING HOMES & ASSISTED LIVING RESIDENCES

Practitioner Orders for Life-Sustaining Treatment (POLST)
SUBJECT: Practitioner Orders for Life-Sustaining Treatment (POLST)

PURPOSE

This policy defines a process for nursing homes and assisted living residences to follow when a person who resides in the nursing home or assisted living residence, or is considering residency, has a Practitioner Orders for Life-Sustaining Treatment (POLST) form. This policy also outlines procedures regarding the completion of a POLST form and the steps necessary when reviewing or revising a POLST form.

POLICY

It is the policy of ___(facility name)_____ to support the rights of residents in making decisions regarding their care and treatment.

POLST is the Practitioner's Physician's Orders for Life-Sustaining Treatment. The POLST form is used by the physician or advance practice nurse to write orders that indicate what types of life-sustaining treatment the resident wants or does not want.

PROCEDURES

1. At the time of admission the facility will determine whether the individual has completed a POLST form.
2. The facility will review the existing POLST for completeness and confirm with the individual and/or with the individual's legally recognized health care decision-maker that the POLST form in hand has not been revoked or superseded by a subsequent POLST form. A completed, fully executed POLST is a legal physician/NP order, and is immediately actionable. The facility will place the POLST form in the clinical record, along with the patient's advance directive if he/she has one. If the individual has an electronic health record, the POLST should be scanned in and placed in the appropriate section of the health care record per facility/agency policy.
3. If the individual does not have a POLST form at the time of admission, the facility will introduce POLST within 14 days of admission.
4. The attending physician or advance practice nurse will complete the POLST with the individual or the legally recognized health care decision maker, after discussing options for care.
5. The original POLST form will remain in the individual's clinical record
6. As the patient moves from one health care setting to another, the original POLST form and copies of the patient's advance directive should always accompany the patient.
7. POLST forms will be reviewed annually and at the time of any significant change in the individual's condition, and at the individual's request.

LGBTQ AGING

POLICIES & REGULATIONS

Matthew Gayton, BSN MSN GNP

Mobile Acute Care for the Elderly Team (MACE)

Department of Geriatrics and Palliative Medicine

Mount Sinai

LGBTQ LAW and POLICY in NJ Healthcare

- Objectives:
- NJ Specific Laws and Policy
- Compare NJ Tristate Area
- Context of National LGBTQ History, a nursing perspective
- Human Rights Campaign's Healthcare Equality Index
- HEI Facilities and other Resources

- "All providers should remember that the presence of illness does not diminish the right or expectation to be treated equally. Stated another way, illness does not in and of itself change a patient's legal rights or permit a physician to ignore those legal rights." (ACP, 2012).

GLMA, 2013. Compendium of Health Profession Association LGBT Policy & Position Statements.

NJ LAW Against Discrimination

- **LEGAL:**
  - **Homosexuality**
  - **Marriage – issues marriage licenses to same sex couples**
- **PROHIBITS:**
  - **Housing discrimination**
  - **Employment discrimination**
  - **Hate or bias crimes**
  - **Discrimination in public accommodation**
  - **Harassment and/or bullying**
  - **Discrimination against students**
  - **Provides protections on the basis of "gender identity or expression."**

…based on sexual identity *and gender identity*

Vespa-Papaleo, FJ. (2007). Recent Legislative Amendments to the LAD & FLA. Division on Civil Rights Director's Report. The State of New Jersey Department of Law and Public Safety. http://www.nj.gov/oag/dcr/report.html

Additionally in NJ

- Changing gender is legal, surgery not required
- Adoption is legal
- Conversion therapy is banned (2013)
- Men who have sex with men (MSM) donating blood banned
- LGBTQ serving openly is legal
- Has neither a ban on insurance exclusions for transgender healthcare nor does it provide transgender-inclusive health benefits to state employees
- One Eleven Liquors, Inc. vs. Division of Alcoholic Beverage Commission

Human Rights Campaign, 2017. http://www.hrc.org/local-issues/new-jersey

Equaldex, (2017). LGBT rights in New Jersey.
http://www.equaldex.com/region/united-states/new-jersey

NJ Law Against Discrimination NJSA 10:5-1

As of June, 2007, NJ was one of the most progressive in the nation for LGBT people by prohibiting discrimination in employment, housing and public accommodation on the basis of sexual orientation, gender identity or expression, and civil union or domestic partnership status.

Family Leave Act (FLA) 34:11B-1 protecting gay and lesbian individuals on the basis of civil union status.

Vespa-Papaleo, FJ. (2007). Recent Legislative Amendments to the LAD & FLA. Division on Civil Rights Director's Report. The State of New Jersey Department of Law & Public Safety. http://www.nj.gov/oag/dcr/report.html

NJ Law Against Discrimination
Who Is Protected?

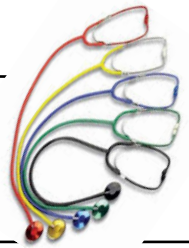
- All sexual orientations: heterosexual, homosexual, bisexual and transsexual persons who fall into one of these orientations.
- Protects whether actually a member of a sexual minority or are perceived to be LGBTQ.
- Unlawful to discriminate in employment - paid or volunteer.
- Unlawful for labor unions to discriminate.

Vespa-Papaleo, FJ. (2007). Recent Legislative Amendments to the LAD & FLA. Division on Civil Rights Director's Report. The State of New Jersey Department of Law & Public Safety. http://www.nj.gov/oag/dcr/report.html

NJ Law Against Discrimination
What forms of discrimination?

- **Housing**, places of public accommodation, contracts, employment
- **Employment**: hiring, promotions, retirement, salary, wages, privileges etc.
- **Hostile work environment** is prohibited: homophobic or transphobic comments, or actions.
- FLA - permits employees to take time off for **taking care of a sick family member including [civil union] spouses**
- School district could be held liable for not adequately responding to student-on-student sexual harassment against a student perceived to be gay. **A school must prevent and eliminate "a hostile school environment."**

Vespa-Papaleo, FJ. (2007). Recent Legislative Amendments to the LAD & FLA. Division on Civil Rights Director's Report. The State of New Jersey Department of Law & Public Safety. http://www.nj.gov/oag/dcr/report.html



COMPARE AND CONTRAST

FACTOR	NEW JERSEY	NEW YORK	PENNSYLVANIA
Homosexuality	LEGAL	LEGAL	LEGAL
Marriage	LEGAL	LEGAL	LEGAL
Housing Protection	YES	PARTIAL	NO
Employment Protection	YES	PARTIAL	NO
Hate/Bias Crime Legislation	YES	PARTIAL	NO
Public Accommodation	YES	YES	NO
Harassment/Bullying	YES	YES	NO
Change Gender	YES	LEGAL	YES
Adoption	YES	LEGAL	YES
Conversion Therapy	BANNED	AMBIGUOUS	AMBIGUOUS
MSM Donate Blood	BANNED	BANNED	BANNED
LGBTQ Serve Openly	YES	YES	YES
Trans Healthcare	YES/NO	YES/YES	YES/NO

Equaldex, (2017). LGBT rights in New Jersey. http://www.equaldex.com/region/united-states/new-jersey Human rights campaign, 2017. Score card on the issues. http://www.hrc.org/local-issues

	65 YO b. 1952	75 YO b. 1942	85 YO b. 1932
20 YO	**1972 Stone Wall.** Anita Bryant. **Religious Right. Harvey Milk assassinated.** Gay Olympics. **Watergate** (cracks in US govt.) **The First Pride Parade.**	**1962 Arrests.** Bar Raids. Don't stand too close (**solicitation**.) **Women's Movt.** No word for "gay." **Sick!** Things start to change. **Compton riots**. Society for individual rights. The **Transexual Phenomenon**.	**1952 Lose job.** Lose custody. Prison. **Forced ECT.** Police Raids. **Mattachine Society.** Lose a scholarship. **Bilitis. Institutionalized.** ONE Inc. vs. Oleson. **Coopers Donuts.** Executive order **10450.**
30 YO	**1982 GRID.** Act Up. Larry Kramer. **White Night Riots.** Gerry Studds. **Rock Hudson** dies. **Bowers vs. Hardwick.**	**1972 Stonewall**. Community Centers. **APA** removes from DSM. Michigan **Women's Festival**. **Studio 54** (gay is chic.) The **Castro 14.**	**1962 MLK.** Hippies. Arrests. **Vietnam.** FBI investigates **"subversive groups."** Berkeley freedom of speech. **JFK.** Bar raids. **The Advocate**.
40 YO	**1992 DOMA.** Protease Inhibitors. **DADT.** 1st Lesbian Kiss on television. **Ellen**. **March on Washington**. Col. M. **Cammermeyer.** Red Ribbon. **Althea Garrison.**	**1982 HIVAIDS.** Cleve Jones. The Names **Mem Quilt. Reagan. AZT.** Domestic Partnership in Berkeley. **Barney Frank.**	**1972 Youth** led movement. **A symbol**. Salsa soul sisters. **Being out = activism. Community centers.**

Human Rights Campaign Healthcare Equality Index

"...national LGBTQ benchmarking tool that evaluates healthcare facilities' policies and practices related to the equity and inclusion of their LGBTQ patients, visitors, and employees...."

- **Scored on 8 separate criteria**
- **100 points = "Leader in Healthcare Equality."**
- **SEARCH HEI http://www.hrc.org/hei/search**
- **SEARCH HEI NJ http://www.hrc.org/hei/search/new-jersey**

Human Rights Campaign Healthcare Equality Index
HRC HEI Inclusive Policies and Practices

1. LGBTQ-inclusive patient non-discrimination policy
2. LGBTQ-inclusive visitation policy
3. LGBTQ-inclusive employment nondiscrimination policy and
4. Staff training in LGBTQ patient-centered care
5. Patient Services and Support
6. Employee Benefits and Policies
7. Community Engagement
8. Responsible Citizenship (negative points)

Rank	Facility Name	City	1				2	3	4		
			Patient Non-Discrimination	Equal Visitation	Employment Non-Discrimination	Training in LGBTQ Patient Centered Care	Patient Services and Support	Employee Benefits and Policies	Patient & Community Engagement	Responsible Citizenship	Grand Total (Sum)
			10 pts	10 pts	10 pts	10 pts	30 pts	20 pts	10 pts	-25 pts	
	NEW JERSEY										
■	AtlantiCare Regional Medical Center	Atlantic City	●	●	●	●	●	●	●		100
●	Reproductive Medicine Associates of New Jersey	Basking Ridge	●	●	●	●	◐	●	◐		80
	Cape Regional Medical Center	Cape May Court House	○	○	○	○	○	○	○		0
▬	VA New Jersey Health Care System	East Orange	●	●	●	●	●	●	●		100
▬	Hackensack University Medical Center	Hackensack	●	●	●	●	●	●	●		100
●	Bayshore Community Hospital	Holmdel	●	●	●	●	◐	●	◐		80
▬	Jersey City Medical Center	Jersey City	●	●	●	●	●	●	●		100
	Saint Barnabas Medical Center	Livingston	●	●	●	◐	◐	●	◐		75
▬	Goryeb Children's Hospital	Morristown	●	●	●	●	●	●	●		100
■	Morristown Medical Center	Morristown	●	●	●	●	●	●	●		100
●	Jersey Shore University Medical Center	Neptune	●	●	●	●	◐	●	◐		80

Saint Barnabas: Participant, 75/100

Criteria 1 Staff Training 35/40: Y LGBTQ staff training option; N staff training requirement

Criteria 2 Patient Services and Support 15/30: have implemented 5-9 best practices, need 10.

Criteria 3 Employee Benefits and Policies 20/20 !!!!

Criteria 4 Patient and Community Engagement 5/10 has implemented 2-3 of best practices, need to implement 4.

Criteria 5 Responsible Citizenship 0/-25

NEW JERSEY HEI 2017 Leaders in LGBTQ Healthcare Equality: 100/100 score!

- **AtlantiCare Regional Medical Center Atlantic City**
- **VA New Jersey Health Care System East Orange**
- **Hackensack University Medical Center Hackensack**
- **Jersey City Medical Center Jersey City**
- **Goryeb Children's Hospital Morristown**
- Morristown Medical Center **Morristown**
- **Robert Wood Johnson University Hospital New Brunswick**
- **Newton Medical Center Newton**
- **Chilton Medical Center Pompton Plains**
- **Overlook Medical Center Summit**

- **Partnering with LGBTQ Elders**
- **Qspot LGBT Community Center - http://qspot.org/**
- **Buddy Program for Older LGBT Adults in Association with Monmouth University Schools of Social Work and Nursing**
  - **Dr. Laura Kelly**
- **https://www.monmouth.edu/school-of-nursing-health/lgbt-older-adult-project.aspx**
- **Buddy Program and Cultural Competency Training**

Other LGBTQ Resources in NJ

- **RWJ PROUD Family Health Clinic – first full LGBT Health clinic in NJ**
- **The Pride Center of NJ, Highland Park – www.pridecenter.org**
- **Newark LGBTQ Community Center – http://newarklgbtqcenter.org/**
- **Hudson Pride Connections Center, Jersey City – http://hundsonpride.org/**
- **The Lesbian, Gay, Bisexual & Transgender Community Center, NYC – https://gaycenter.org**

NEWARK LGBTQ
COMMUNITY CENTER

EQUALITY FRIENDSHIP COMMUNITY
The Pride Center of New Jersey
www.pridecenter.org

HUDSON pride
CONNECTIONS CENTER
JOURNAL SQUARE, JERSEY CITY

Professional Resources

- National Resource Center on LGBT Aging – http://lgbtagingcenter.org/
- Fenway Health – web based interactive modules - http://fenwayhealth.org/
- UCSF Center of Excellence for Transgender Health - http://www.transhealth.ucsf.edu/trans?page=lib-00-00
- World Professional Association for Transgender Health http://www.wpath.org/site_home.cfm

- GLMA, 2013. Compendium of Health Profession Association LGBT Policy & Position Statements. Retrieved from: http://www.glma.org/_data/n_0001/resources/live/GLMA%20Compendium%20of%20Health%20Profession%20Association%20LGBT%20Policy%20and%20Position%20Statements.pdf

- Equaldex, (2017). LGBT rights in New Jersey. http://www.equaldex.com/region/united-states/new-jersey

- Human rights campaign, 2017. Score card on the issues. http://www.hrc.org/local-issues/new-jersey

- Human rights campaign. (2017). Healthcare equality index scoring criteria. http://www.hrc.org/hei/hei-scoring-criteria

- Vespa-Papaleo, FJ. (2007). Recent Legislative Amendments to the LAD & FLA. Division on Civil Rights Director's Report. The State of New Jersey Department of Law & Public Safety. http://www.nj.gov/oag/dcr/report.html

LGBTQ Aging

CULTURALLY COMPETENT STRATEGIES

An Open-Minded Approach

Try to avoid
•Making assumptions about the gender of the patient's partner (even if married)
•Assuming that patients sexuality is fixed, absolute, and/or lifelong
•Assuming that being gay, lesbian, or bisexual is not a difficult issue for many patients
•Forcing labels or outing a patient if they are not ready
•Assuming that all transgender patients want full reconstructive surgery or complete hormonal transformation

Culturally Competent Approach to LGBTQ Care

•Share some personal history about yourself before inquiring into the social history of your patient
•Join a referral program
•Adapt forms to be inclusive (for example spouse/partner rather than husband/wife)
•Talk with your registration staff and clinic director
•Encourage cultural competency training by your colleagues and staff
•Place an LGBT-friendly symbol, sticker or sign in a visible location
•Have an LGBT-specific magazine or newspaper in the reception area
•Have an open dialogue with patients about their life

Best Practices: Creating A Welcoming Environment

Visible Indicators:

Promo Materials/Web Site/Post Policies/ Openly LGBT Staff/Providers/Rainbow Flags/unisex bathrooms/brochures etc.

Respect:

Names/Pronouns/Partner Status/ Record Keeping and Data Collection/Intake Forms

Confidentiality:

Other providers, other staff, other patients

Patient/Provider Relationship

Key to enhanced adherence and better patient outcomes

Intake Forms (con't)

- **Legal name**
- **Name I prefer to be called (if different)**
- **Preferred pronoun?**
  - ❑ She
  - ❑ He
- **Gender: Check as many as are appropriate**
  - ❑ Female
  - ❑ Male
  - ❑ Transgender
  - ❑ Female to Male
  - ❑ Male to Female
  - ❑ Other *(leave space for patient to fill in)*

GLMA Guidelines

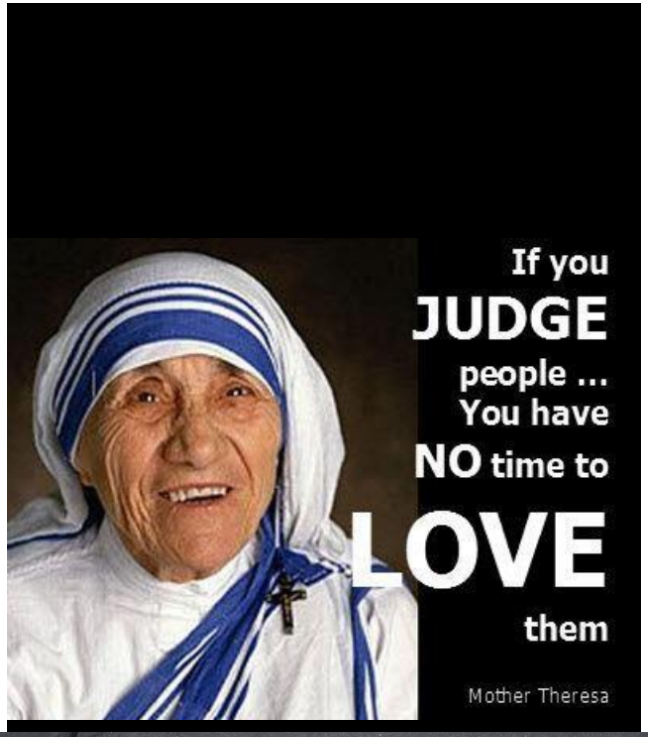
sage℠

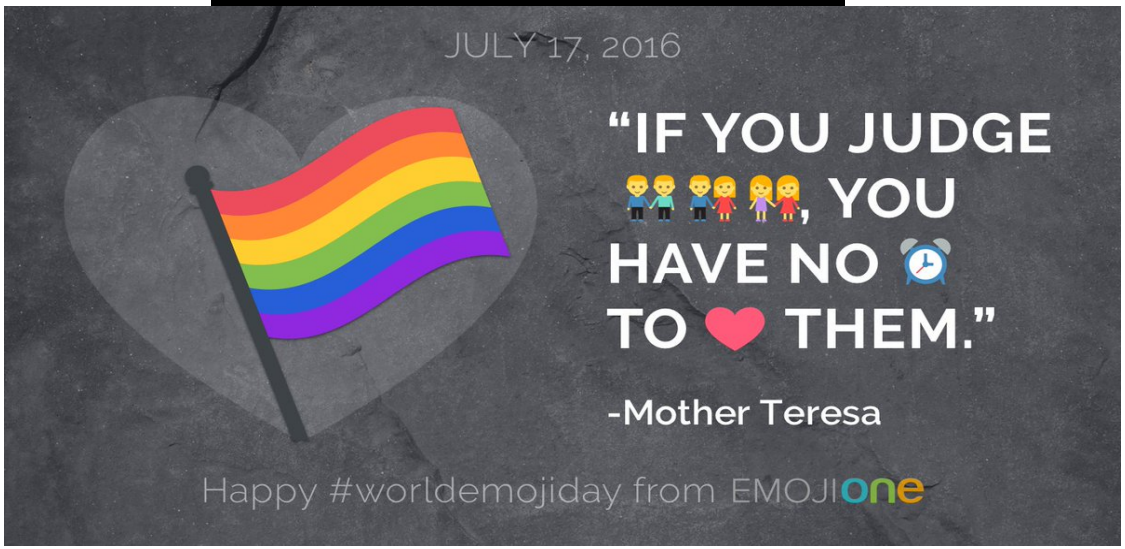
Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders

TAKE-HOME POINTS

KEY POINTS

- Don’t assume your patient/client is heterosexual: Ask politely.
- Reflect on your own attitudes toward aging and the aged.
- Reflect on your own attitudes toward LGBTQ older persons: An older LGBTQ person is not just old and not just another minority.
- Seek consultation with colleagues as needed.
- Have some knowledge of LGBT Services for Older Adults: SAGE, WPATH, Callen Lorde, Fenway etc. Knowledge is Power.
- Normalize conversation around data collection and history taking.
- Create a welcoming environment.
- Apply a multidimensional approach to caring for an older LGBTQ adult.


If you
JUDGE
people ...
You have
NO time to
LOVE
them
Mother Theresa

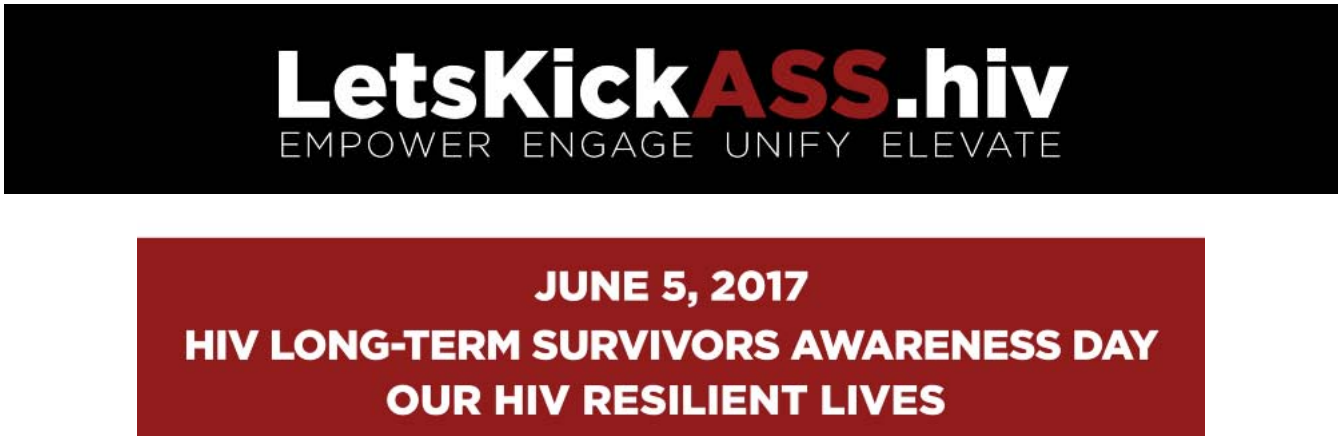

JULY 17, 2016
"IF YOU JUDGE
👫👫👭, YOU
HAVE NO ⏰
TO ❤ THEM."
-Mother Teresa
Happy #worldemojiday from EMOJIone

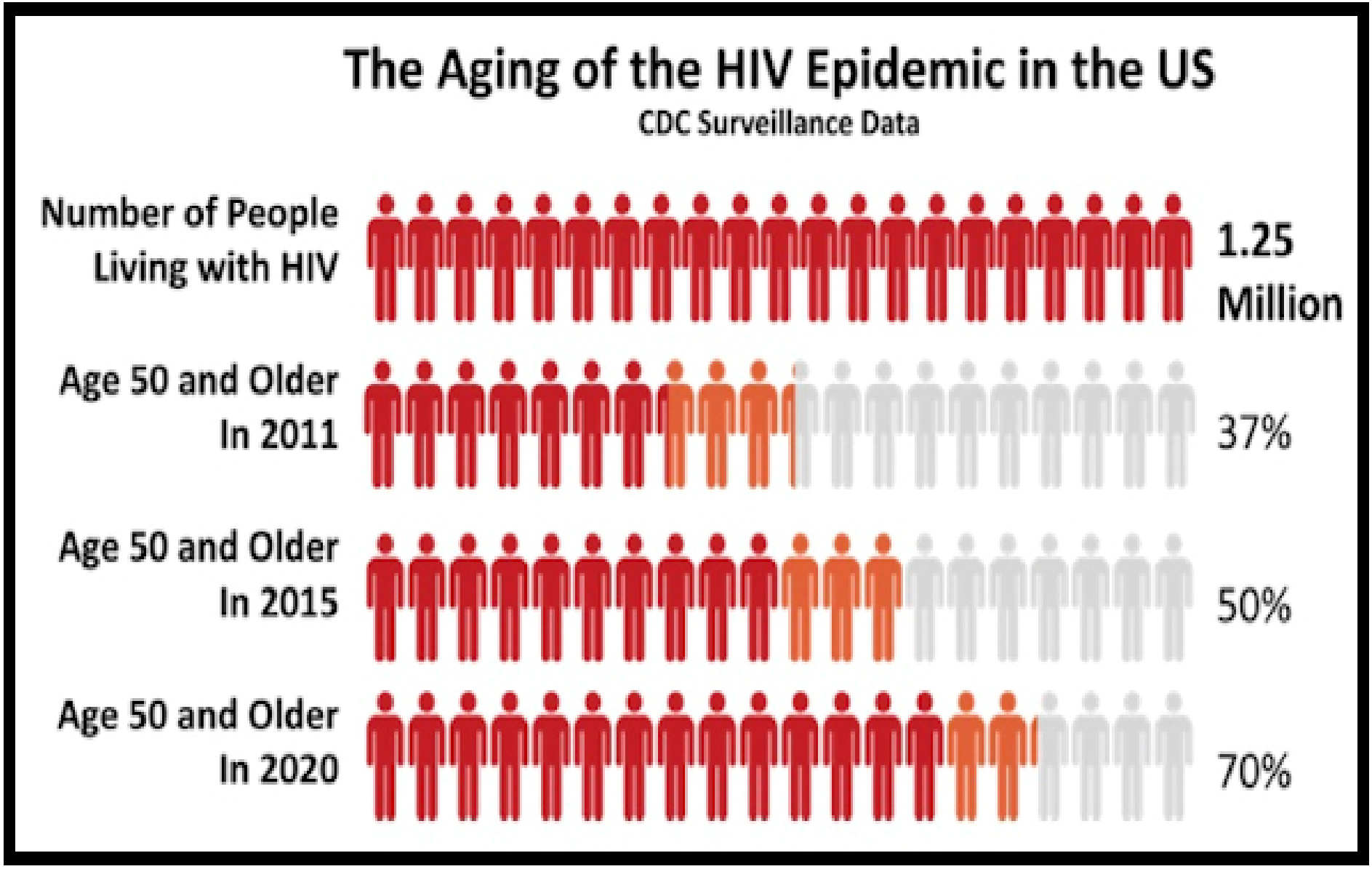

THANK YOU!
- THROUGH HER EYES -
See the world, from a different perspective
Transgender Film - December 2013

HIV & Aging

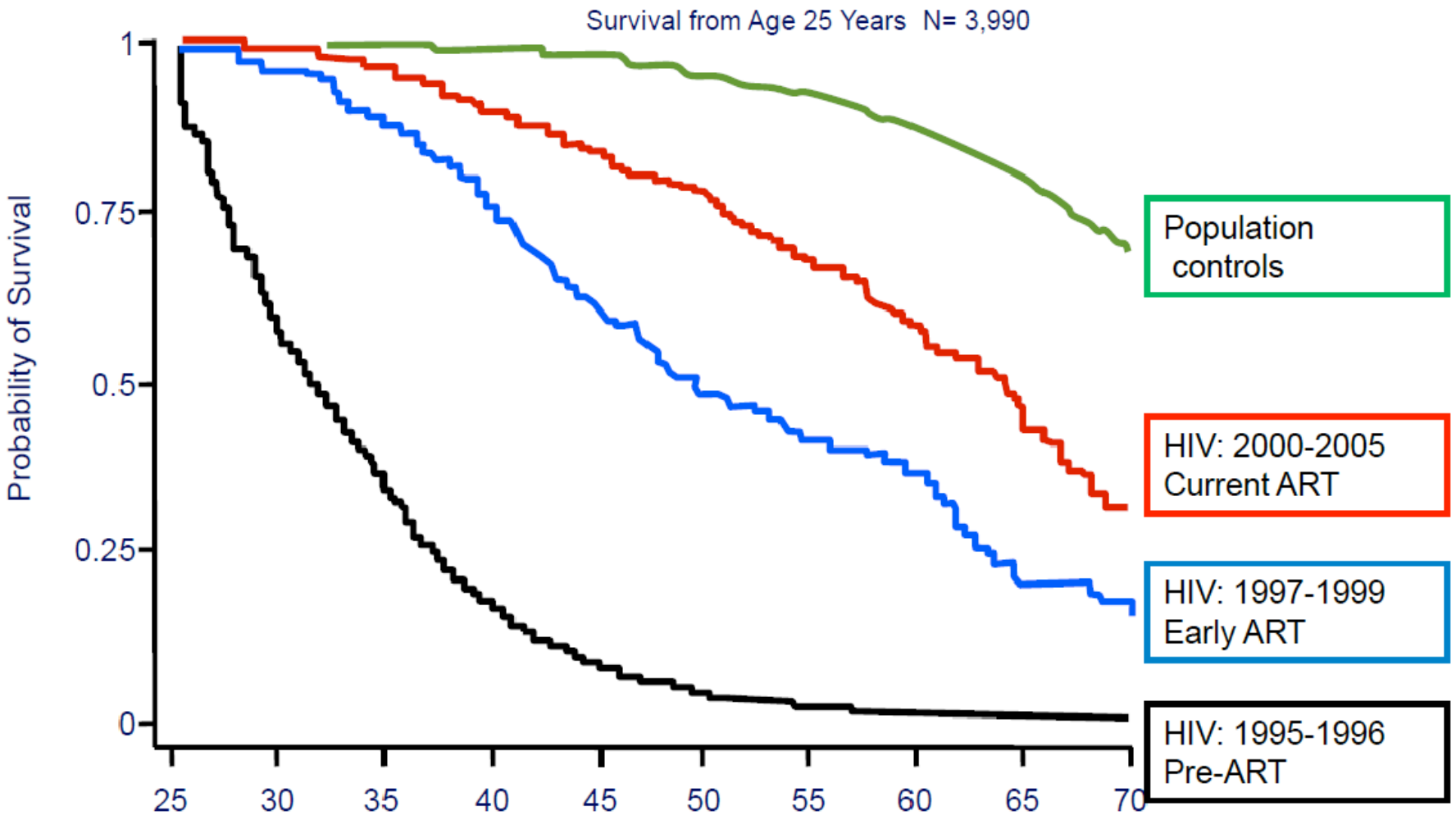
Jeffrey J. Weiss, PhD, MS
Associate Professor
Division of General Internal Medicine
Department of Medicine
Icahn School of Medicine at Mount Sinai

Let's Kick ASS (AIDS Survivor Syndrome)




The Aging of the HIV Epidemic in the US
CDC Surveillance Data
Number of People Living with HIV
1.25 Million
Age 50 and Older In 2011
37%
Age 50 and Older In 2015
50%
Age 50 and Older In 2020
70%

ART on HIV Survival



Lohse N et al. Ann Intern Med. 2007

Overton, ET (2016). Aging and HIV [slides]

Improved life expectancy of people living with HIV: who is left behind?
Katz & Maughan-Brown, The Lancet HIV 2017

- Cohort studies show a small but persistent gap in the lifespan between HIV-positive and HIV-negative individuals.

- A 20-year old HIV positive adult on ART in the USA or Canada has a life expectancy approaching that of the general population.

- Individuals who are not white, have a history of injection drug use, or begin ART with low CD4 cell counts have no reduction in mortality or improvements in life expectancy.

Quality vs. Quantity

Health Adjusted Life Expectancy (HALE)

Adjusts overall life expectancy by the amount of time lived in less than perfect health.

Diseases More Common in persons with HIV over 50

- Cancer
- Cardiovascular Disease
- Cognitive Problems
- Diabetes Mellitus
- Frailty
- Kidney Problems
- Low Testosterone
- Osteoporosis
- Depression

50% increased risk of AMI

HIV Infection and the Risk of Acute Myocardial Infarction

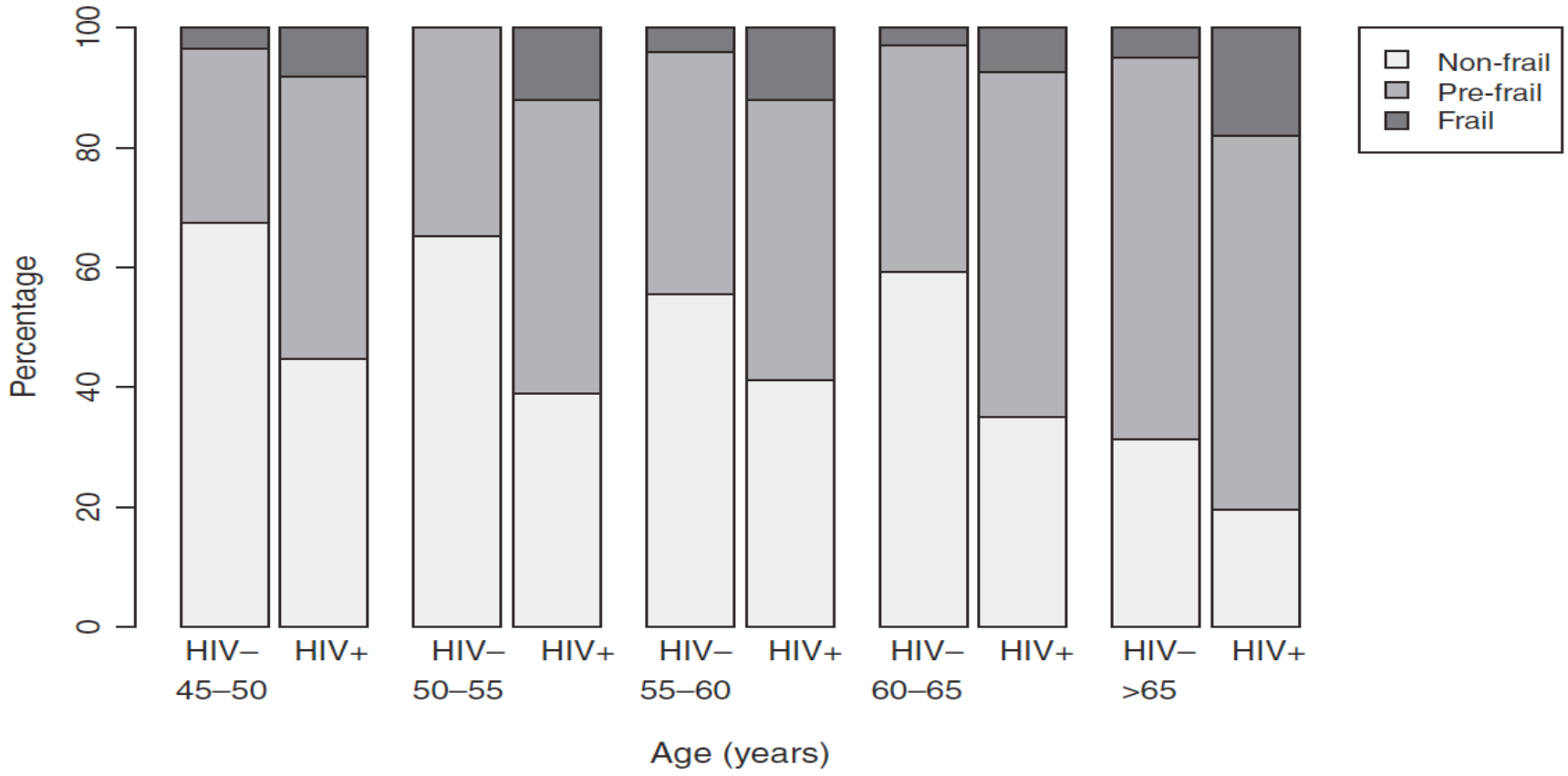
Matthew S. Freiberg, MD, MSc; Chung-Chou H. Chang, PhD; Lewis H.

Table 2. Rates of AMI by HIV Status and Age Group[a]

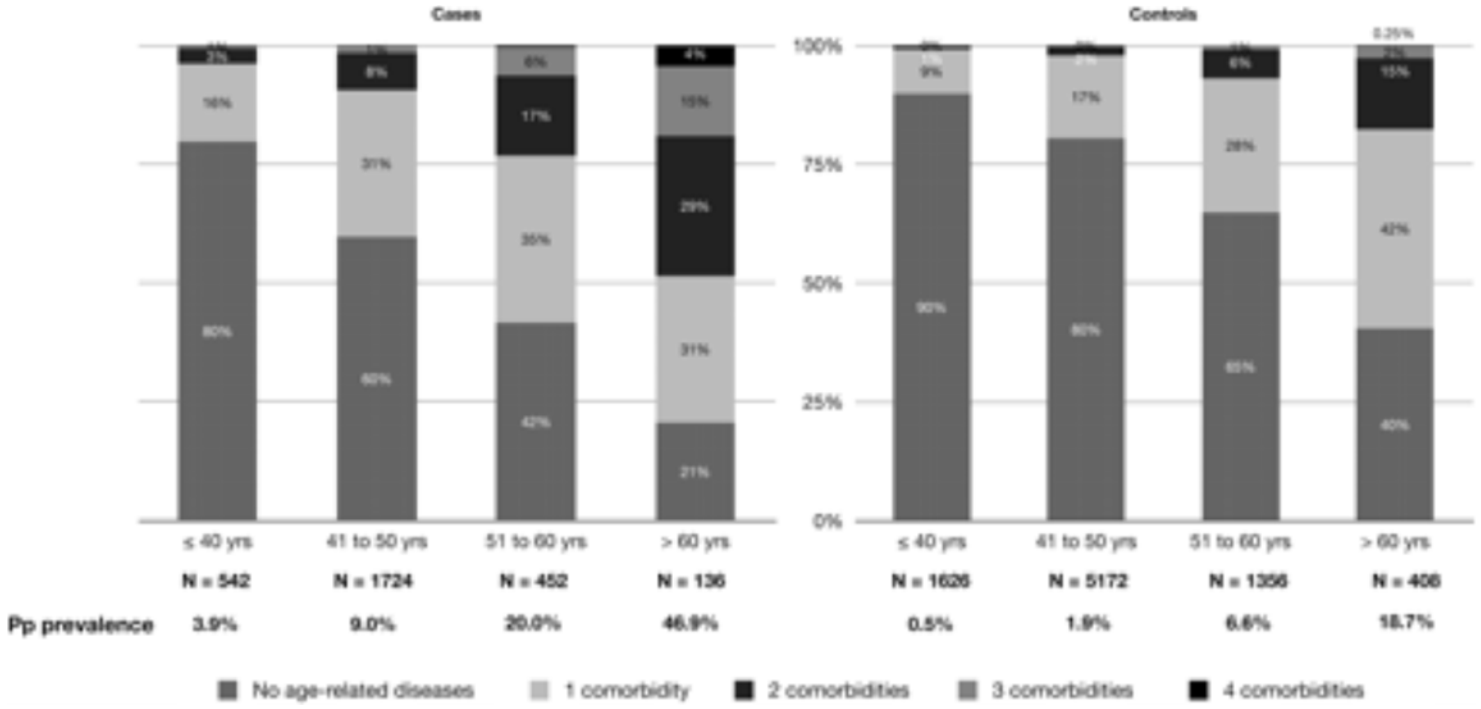
	Age Group, y							
Status	**<30**	**30-39**	**40-49**	**50-59**	**60-69**	**70-79**	**80-89**	**>89**
				Uninfected				
No. of participants	1175	6783	21 866	19 805	4209	1120	148	3
No. of AMI events	0	10	164	218	66	36	14	0
AMI rates per 1000 person-years (95% CI)	. . .	0.3 (0.2-0.6)	1.5 (1.3-1.7)	2.2 (1.9-2.5)	3.3 (2.6-4.2)	6.7 (4.8-9.2)	21.5 (12.7-36.4)	. . .
				HIV Infected				
No. of participants	725	3848	10 575	9342	2065	557	56	0
No. of AMI events	0	13	105	171	46	25	3	0
AMI rates per 1000 person-years (95% CI)	. . .	0.7 (0.4-1.2)	2.0 (1.6-2.4)	3.9 (3.3-4.5)	5.0 (3.8-6.7)	10.0 (6.7-14.7)	13.5 (4.3-42.0)	. . .
Incidence rate ratio (95% CI)	. . .	2.19 (0.89-5.58)	1.34 (1.04-1.72)	1.80 (1.47-1.21)	1.53 (1.03-2.26)	1.50 (0.86-2.57)	0.63 (0.12-2.25)	. . .

2013

HIV infection is independently associated with frailty in middle-aged HIV type 1-infected individuals compared with similar but uninfected controls



Kooij et al. (2016)



From: Premature Age-Related Comorbidities Among HIV-Infected Persons Compared With the General Population

Clin Infect Dis. 2011;53(11):1120-1126. doi:10.1093/cid/cir627

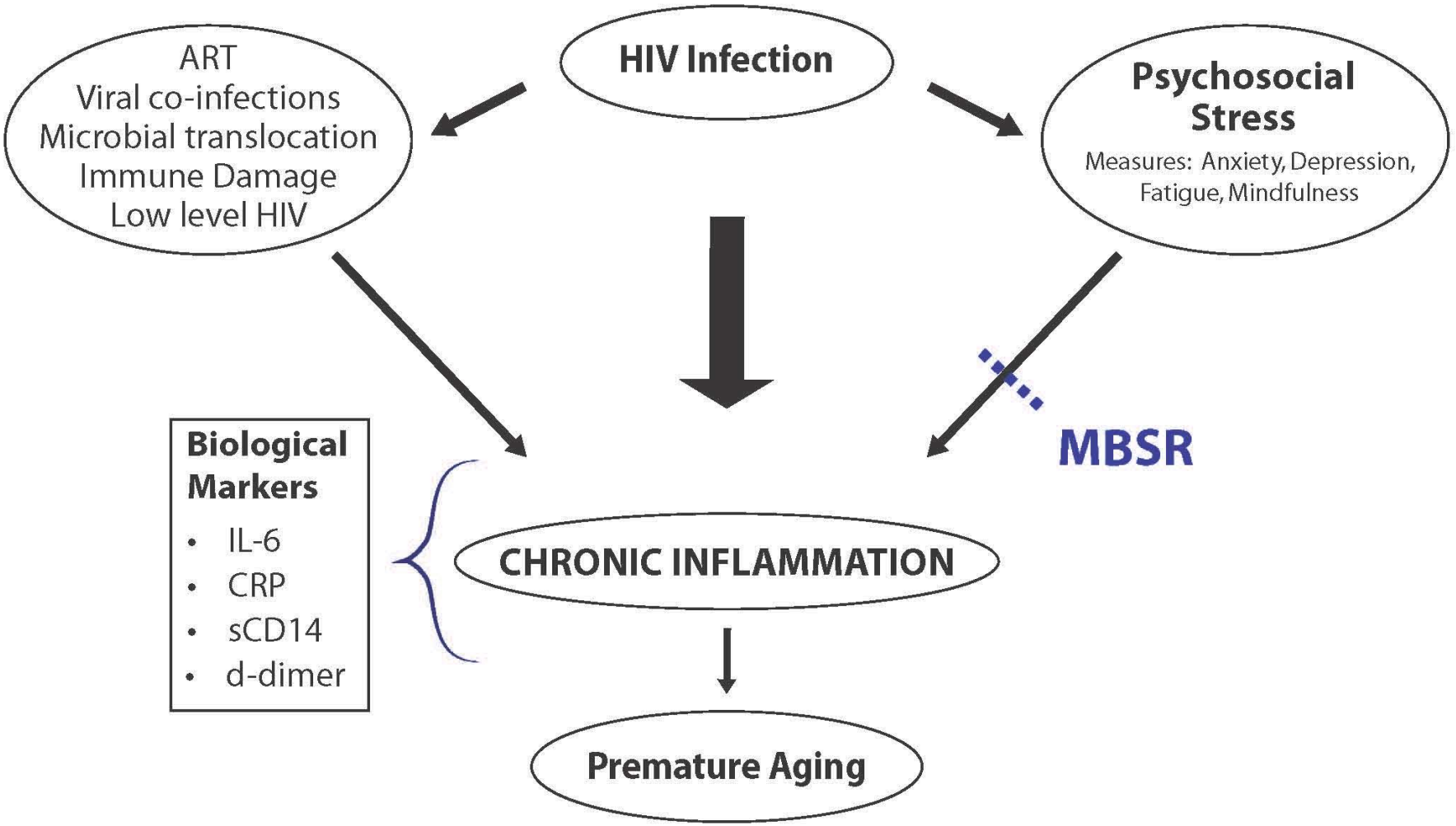
Has been described as…

- Premature Aging
- Accelerated Aging
- Increased Comorbidity Score

Likely involved mechanism…

- Chronic Inflammation

Working Model



DEPRESSION

- Most common mental health problem in older adults living with HIV: 25%-39%
- Depression associated with loneliness, isolation, and HIV stigma
- Greater medical comorbidities associated with greater depression
- Engagement with mental health care associated with less depression
- Depression associated with nonadherence to medication and medical care
- Depression associated with decrease in life expectancy

Illicit Drug Use in Older Adults with HIV/AIDS

Skalski, Sikkema, Heckman & Meade

Psychology of Addictive Behaviors 2013

202 males and 99 females living with HIV
Ages 50-76 (average 55.5)
New York City (79%); Ohio (21%)

75 (24.9%) characterized as drug users in past 60 days
Cocaine – 36
Marijuana – 36
Other (opioids and benzos) – 33

53.3% of drug users were gay/bisexual vs. 43.4% of nonusers

National Survey on Drug Use and Health – age 50-59
9.4% reported drug use in last year

Drug use 2-3 times higher in HIV-positive vs. HIV-negative older adults

UCSF Ward 86

Beginning in January 2017, Ward 86 launched the Golden Compass program. The program will focus on 4 “points” (related to compass directions) that will serve both the medical and psychosocial needs of people over 50 living with HIV.
The program will provide multidisciplinary medical care on-site along with other comprehensive services some of which are outlined below.
NORTH — Heart and Mind: A cardiologist with expertise in HIV will join Ward 86; Memory concerns will be evaluated; a class to learn about brain and memory with some practical tips starts in February.
EAST — Bones and Strength: Exercise classes for PLWH Age 50 or older are offered; focus on preventing falls and supporting bone health.
WEST — Dental, Hearing and Vision: Ward 86 will help link people to the appropriate screenings and services.
SOUTH — Network and Navigation: A monthly support group will provide an opportunity to come together and share experiences.

Strategies to Improve the Health of Older Adults Living with HIV: National Center for Innovation in HIV Care

CHALLENGES:

- Intersection of age-related stigma, HIV=stigma, anti-gay stigma, racism and other forms of prejudice
- Lack of cultural competence on the part of health care, social service, and elder service providers to serve older adults with HIV
- Sexual health promotion and HIV/STI prevention among older adults
- Social isolation and lack of social support networks
- Medical comorbidities, depression, and cognitive decline
- Substance use, including tobacco use

Strategies to Improve the Health of Older Adults Living with HIV: National Center for Innovation in HIV Care

KEY ORGANIZATIONAL STEPS:

1. Train all staff in the unique needs and experiences of older people living with HIV
2. Screen and treat for comorbidities, depression, and cognitive decline
3. Screen for substance use, including tobacco use, and promote treatment
4. Promote sexual health and HIV/STI prevention with this population
5. Strenthen social support networks and reduce isolation

New HIV infections

- 1 in every 6 new HIV diagnoses in New York State occurs in persons 50 years or older
- Condom use decreases with age
- Ageism, fear, and HIV stigma are barriers to testing in older adults

RESILIENCE

- Self-acceptance
- Optimism
- Will to live
- Generativity
- Self-management
- Relational living
- Independence

Emlet et al. Gerontologist 2011

Resilience is both a trait (hardiness) and a dynamic adaptive process

It can be increased through behavioral interventions (including psychotherapy)

Resilience processes (coping self-efficacy, active coping, social support) reduce the negative impact of life stressors

CONTACT INFORMATION

Speakers

- Matthew Gayton – matthew.gayton@mountsinai.org
- Noelle Marie Javier – noelle.javier@mssm.edu
- Jim Palmer III – jim.palmer@mountsinai.org
- Jeffrey Weiss – jeffrey.weiss@mountsinai.org
- Evan Zazula – evan.zazula@mssm.edu