

### **Caring for All Elders:**

Integrating Sexual and Gender Minority Elder Health into the Learning Continuum

**November 3, 2016** 

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Moderator John Davis, MD, PhD



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### **Learning Objectives**

By the end of this webinar participants will be able to:

- Understand the demographics of the elder population in the United States who are LGBT and/or born with differences of sex development (DSD).
- Discuss how the social aspects of aging impacts care for patients who are LGBT and/or born with DSD.
- Understand how to tailor the patient history for elders who are LGBT and/or born with DSD.
- Understand the unique psycho-social needs of elders who are LGBT and/or born with DSD and how these needs affect health outcomes.
- Identify 2-3 medical aspects of aging and its impact on care for patients who are LGBT and/or born with DSD.

# Outline

- Terminology Overview
- Demographics of LGBT Elders
- Generational Impact on LGBT and DSD Elders
- Supporting Mental and Physical Health
- Resources
- Case Studies



### Limitations

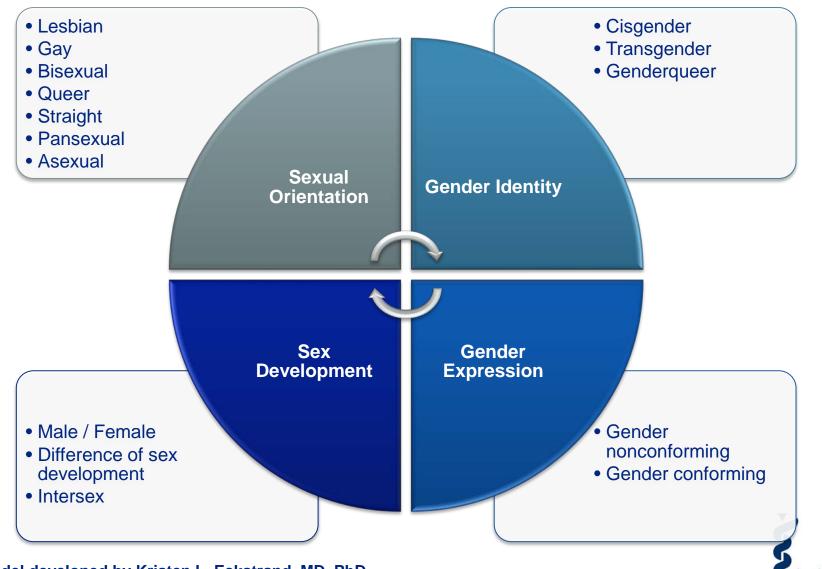
• Limited data is available on DSD aging issues.

Many studies cited have a small n.

 Further research is needed on bisexual, transgender, and DSD populations.



# ALPHABET 101: Respect and utilize the language individuals use to describe themselves



Model developed by Kristen L. Eckstrand, MD, PhD

# **Common Assumptions**

### **Common Assumptions**

- Heterosexuality
- All patients use traditional labels
- Sexual orientation is based on appearance
- Sexual orientation is based on behavior
- Sexual behavior based on orientation
- Identity, attraction, and behavior don't change

- Gender identity = sexual orientation
- Gender identity is based on natal sex
- Gender identity depends on how far along a patient is in transitioning
- All patients are sexually active



# **Demographics of Older LGBT Adults**

	Yes (%)	No (%)	DK/No Answer (%)
18 - 29	6.4	90.1	3.5
30 - 49	3.2	93.6	3.2
50 - 64	2.6	93.1	4.3
65+	1.9	91.5	6.5
1 – 2.8 million older LGBT adults			

Gates & Newport. Special Report: 3.4% of U.S. Adults Identify as LGBT. Gallup. October 18, 2012. http://www.gallup.com/poll/158066/special-report-adults-identify-lgbt.aspx



### **Demographics of Older Adults Born with DSD**

#### Very little available research

- Consensus as to what constitutes DSD
- Estimates based on world population frequencies, elder population frequencies unknown
  - 1.7-2.3%
    - Including mild hypospadias and Late Onset Congenital Adrenal Hyperplasia (LOCAH)
- Klinefelter Syndrome: 0.1-0.2%
- Turner Syndrome: 0.04%
- Mayer-Rokitansky-Kuster-Hauser (MRKH) Syndrome: 0.02%
- Kallman Syndrome: 0.01%
- Classic Congenital Adrenal Hyperplasia (CAH): 0.008%
- Swyer Syndrome: 0.001%
- Complete Androgen Insensitivity Syndrome (AIS): 0.0008%

Blackless, M., Charuvastra, C., Derryck, A., Fausto-Sterling, A., Lauzanne, K., and Lee, E. 2000. How sexually dimorphic are we? Review and synthesis. *American Journal of Human Biology* 12:151-166.

Generitcs Home Reference: your guide to understanding genetic conditions. U.S. National Library of Medicine. https://ghr.nlm.nih.gov/condition



# **Generational Impact and Health**

### Many older LGBT individuals:

- have lived entirely or partially in the closet
  - >20% of LGBT elders do not disclose their sexual or gender identity to their physician
- (almost two-thirds) have been victimized three or more times
  - have experienced emotional, physical, and psychological trauma

### **Greater risk for isolation and loneliness:**

- 50% less likely to have a significant other, children, or close relative for help
- more likely to be rejected from their children and families
- live alone

### **Display many signs of resilience:**

- strong sense of community involvement
- multiple sources of social support
- attendance in religious and spiritual activities

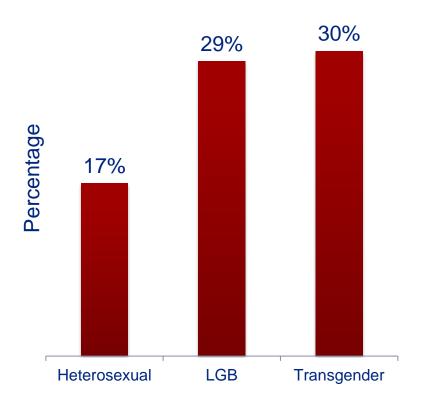
Fredriksen-Goldsen, K.I., Kim, H., Emlet, C.A., Muraco, A., Erosheva, E.A., Hoy-Ellis, C.P., Goldsen, J., & Petry, H. (2011). *The aging and health report.* Retrieved from http://depts.washington.edu/agepride/wordpress/wp-content/uploads/2011/05/Ful-Report-FINAL.pdf



### Impact on Health by Sexual Orientation— Disparities

- Risk Behaviors
  - Smoking
  - Excessive Drinking
- Screening
  - Mammograms
  - Pap testing
- Chronic Conditions
  - Obesity
  - Cardiovascular Disease
  - Disability

# Adults delaying or not seeking healthcare





# Impact on Health by Sexual Orientation

### **Anal Cancer**

- 43 times more common in GB men
- 88 times more common in HIV+ GB men

### **Cervical Cancer**

- LB women have lower rates of lifetime and routine Pap testing
- No current data on rates of cervical cancer

### **Breast Cancer**

- LB women have a greater prevalence of risk factors for breast cancer<sup>1-3</sup>
- No difference in overall risk for mortality



2. Case P, Austin SB, Hunter DJ, et al.. Journal of women's health. Nov 2004;13(9):1033-1047.







### Impact on Health by Gender Identity and Sex Development

Very little available research

#### **Gender Identity**

- Trans women have higher rates of HIV, hepatitis C, and substance abuse
- More likely to use non-medically prescribed hormones
- Less likely to receive preventive care or have mental health needs met
- More research required to understand long-term impact of cross-gender hormone therapy

Institute of Medicine (U.S.). Committee on Lesbian Gay Bisexual and Transgender Health Issues and Research Gaps and Opportunities. The health of lesbian, gay, bisexual, and transgender people : building a foundation for better understanding. Washington, DC: National Academies Press; 2011.

#### Sex Development

- Some treatments may involve longterm steroid use
- Increased risk of germ-cell tumors development in some conditions
- Multiple surgeries throughout childhood and adulthood
- Lower sexual quality of life
- Higher psychological distress

Gupta, D., Bhardwaj, M., Sharma, S., Ammini, A. C., & Gupta, D. K. (2010). Long-term psychosocial adjustments, satisfaction related to gender and the family equations in disorders of sexual differentiation with male sex assignment. *Pediatric surgery* 

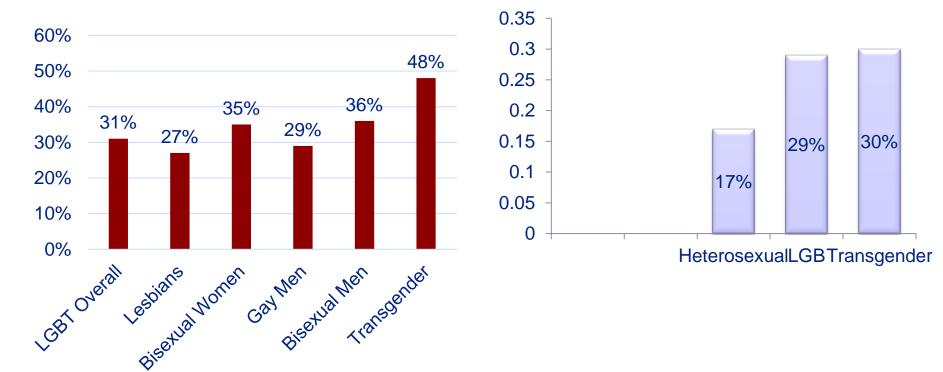
Schober, J., Nordenström, A., Hoebeke, P., Lee, P., Houk, C., Looijenga, L., ... & Woodhouse, C. (2012). Disorders of sex development: summaries of long-term outcome studies. *Journal of Pediatric Urology*, 8(6), 616-623., 26(10



# **Impact on Mental Health**

#### Rates of Depression among LGBT older adults

#### Rates of Suicidal Ideation among LGBT older adults





### **Case 1: Julian**



# **Case Objectives**

• Describe the care of the older patient with HIV and other co-morbidities

• Compare and contrast accelerated vs. accentuated aging, multi-morbidity



### Case 1: Julian

Julian is a 62 year-old man infected with HIV for 25 years seen for follow up. His last HIV RNA was < 20 copies/ml and CD4 count 525.

- Current medical conditions: Hypertension, type 2 DM, hyperlipidemia
- Medications: Dolutegravir + tenofovir alafenamide/emtricitabine, metformin/sitagliptin, lisinopril, aspirin, atorvastatin
- FH: Brother lives in another city, no children. Father died of MI at age 52, mother is in a nursing home with Alzheimer Disease



### **Case 1: Julian**

 SH: Lives alone, MSM but rarely sexually active. Former smoker, social EtOH, occasional poppers and marijuana, no injection drugs, works at a local bank. Has few friends outside of work.

 ROS: Some chest tightness when he runs, occasional ankle edema at the end of the day, has ED and decreased libido, has insomnia—reports early morning awakening



### Exam

- Overweight male, looks stated age
- BP 152/92, P 76, RR 12, afebrile
- HEENT: no thrush, no adenopathy
- Lungs: clear
- Heart: S4 S1 S2 grade 1/6 systolic murmur at upper RSB, no radiation
- Abdomen: no tenderness, no organomegaly
- Ext: good pulses, 1+ edema bilaterally



### **Baseline labs**

CD4 655 cells/mm<sup>3</sup> HIV RNA <20 copies/mL CBC, CMP normal TC 225 mg/dL, HDL-C 35 mg/dL HBA1C 7.8%

Total testosterone 156 ng/dL (normal > 250 ng/dL)



### **Polling Question**

More than half of those infected with HIV are now over the age of 50, soon over 60.

Why do you think that almost 20% of NEW HIV infections occur in people over the age of 50?

- a. Lack of provider awareness
- b. Decreased screening
- c. Lack of targeted prevention strategies
- d. Perceived lack of risk factors
- e. All of the above



### **Does Julian have CAD?**

- He has multiple risk factors
- Can we calculate his cardiac risk?
  - Both FRS and ACC/AHA underestimate risk in patients with HIV
  - ACC/AHA 10-yr risk of CAD would be 37.2%
- How would you approach the evaluation and treatment of his chest pain?
- What about his ART-would you make any changes?

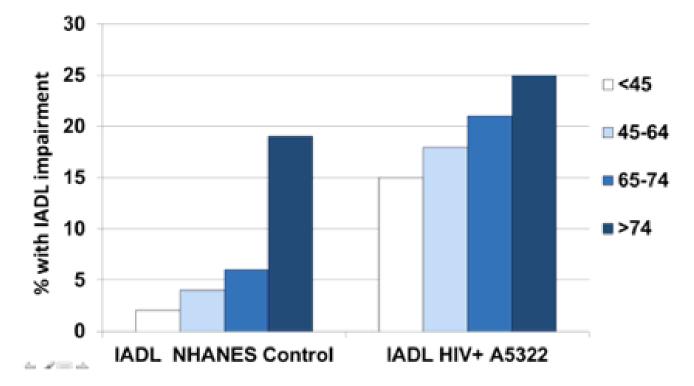


# Multimorbidity

- Definition: multiple chronic conditions that interact to worsen health outcomes
  - More common in older patients with HIV due to intersection of disease, lifestyle risk factors, polypharmacy, chronic inflammation and immune activation
  - Associated with increased mortality, frailty
  - Impact of single disease treatment impacts overall health of patients with multimorbidity



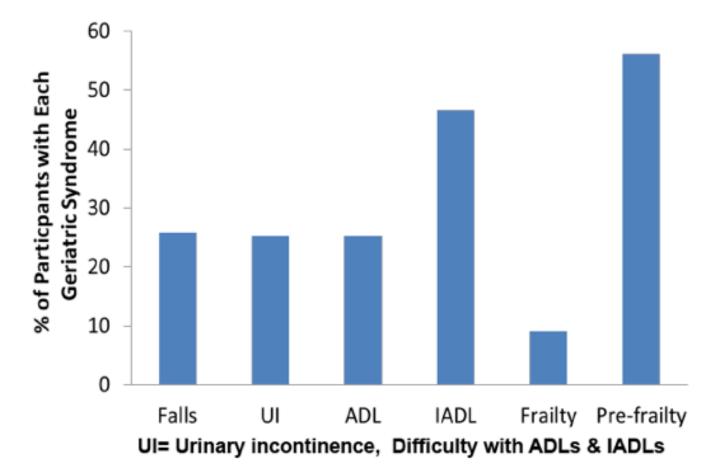
# Impairment by Age, Compared to NHANES Controls



KM Erlandson, K Wu, R Kalayjian, S Koletar, B Taiwo, FJ PalellaJr, K Tassiopoulos and the A5322 Team 7th International Workshop on HIV and Aging, September 26-27, Washington, DC









John,M et al JAIDS 2016

# **Does HIV accelerate aging?**

Conditions: CAD, osteoporosis, frailty, dementia

- For (accelerated)
  - Multivariate analysis indicates HIV is an independent risk factor

- Against (accentuated):
  - Higher excess and age-adjusted rates, but did not occur earlier than general population



### **Behavioral Health**

- His PHQ-2 screen positive
  - Complete PHQ-9
- Depression associated with HIV, hypogonadism, diabetes
- What factors contribute to this:
  - Social isolation
  - Stigma: HIV, internalized homophobia
  - Age
  - SES, education?



### **Prevention**

- Colon cancer screening (A): over age 50, with at least 10 year life-expectancy
- Vaccinations: PCV13, PPSV 23, influenza, zoster, Tdap, hepatitis
- AAA screening: Not until age 65
- Lung cancer (B): > Age 50, more than 30 pack-yr
- Osteoporosis: FRAX will underestimate, HIV is a secondary cause of osteoporosis
- Prostate: Controversial
- HCV (B), syphilis (A)
- Advance directive



### How to approach the care of Julian

Biopsychosocial approach to his care

- Consider multimoribidity
- Prioritize his care:
  - Evaluate his CAD and depression before multiple preventative procedures
  - Engage community services
- Evaluate and balance the risk-benefit of interventions:
  - Treatment of hypogonadism balanced against increase risk of CAD



### **Case 2: Marie**



### **Case 2: Marie**

Marie collapsed in front of her neighbor's home while on her morning walk. She was transported to the ED by ambulance. Providers noted that she has adrenal insufficiency from her medical alert bracelet. After a hydrocortisone injection, her vitals returned to normal.

- Marie
  - 65 y.o.
  - Lives by herself, no children, never married
  - First reported adrenal crisis since childhood
- Current medical conditions: XX 21-hydroxylase deficiency, UTI
- Medications: none; past medications inc. long-term use of glucocorticoids and mineralocorticoids—stopped "cold turkey" at age 45.



### Living with Classic CAH

- Marie
  - Multiple surgeries in infancy
  - Not interested in sex
  - Marie's life had reportedly improved since she "stopped going to the doctor"
  - Marie stopped taking her medications because, "those drugs were killing"



### **Polling Question**

Although diagnosed as a child with the salt-wasting form of CAH, Marie showed no adrenal crises for the past 20 years (without mineralocorticoid treatment). This is most likely because:

- a. There was an original misdiagnosis of salt-wasting CAH
- b. There are long-term changes of adrenal function from prolonged use of corticosteroids
- c. Living in a humid climate protects against heat intolerance and salt craving in CAH
- d. In contrast to children, many adults with XX 21hydroxylase deficiency maintain adrenal functional capacity without any treatment

### Are DSD's uniform across the lifespan?

### Long-term tx considerations are necessary

- Adulthood
  - CAH adults don't have salt-wasting
- Long-term use of glucocorticoids
  - Osteopenia
  - Cushingoid phenotype
  - Adherence issues
    - Many adults maintain normal BP and function without treatment, unlike children



# Living with DSD in advancing age

- Reproductive, genito-urinary and psychosexual health
  - Surgeries → Complications (UTI, fistulas)
  - Dyspareunia
  - Dissatisfaction with genital appearance
  - Less sexual activity
  - Infertility
  - Sexual dysfunction
- Other health concerns
  - Bone mineral density
  - Metabolic and cardiovascular screening
  - Adrenal tumors



### Who determines the proper care for DSD?

Transition of care to adult providers is still uncommon

- Care doesn't end by puberty
- Standards predominantly target the pediatric population
- Patient-centered care, shared decision-making critical



#### Case 3: Abigail and Elizabeth



## The first visit

- Abigail & Elizabeth (ages 62 and 64) present to your office for a new patient visit
- Relocated to your community seeking warmer weather
- Readily share with you their long-term relationship of 20 years



# Negotiating an agenda

- Abigail wants to discuss her right knee pain
  - Knee pain
  - Weight management

- Elizabeth has no particular complaints
  - hypertension and dyslipidemia
  - history of smoking

 Abigail wants to discuss some concerns she has about Elizabeth



#### **Reflection Question**

How would you approach this situation?



# What should be your focus?

• USPSTF recommendations

• Lifestyle modifications for Abigail

• Elizabeth's new diagnosis and related issues

 Supporting your new patients and their relationship



## Just like any other woman

- Breast cancer screening
- Cervical cancer screening
- Colon cancer screening
- HIV testing
- Cardiovascular health (blood pressure, lipids)
- Depression
- Hepatitis C



# Impact on Health by Sexual Orientation

LB women have a greater prevalence of risk factors for breast cancer<sup>1-3</sup>

- Nulliparity, lower rates of abortion, fewer pregnancies, lower rates of breastfeeding, and older age at first childbirth
- Higher rates of obesity, smoking, and alcohol

#### **Rates of breast cancer<sup>4</sup>**

- Greater age-adjusted risk for fatal breast cancer (RR=3.2, CI 1.01-10.21)
- No difference in overall risk for mortality

1. Cochran SD, Mays VM, Bowen D, et al.. American journal of public health. Apr 2001;91(4):591-597.

2. Case P, Austin SB, Hunter DJ, et al.. Journal of women's health. Nov 2004;13(9):1033-1047.

3. Brandenburg DL, Matthews AK, Johnson TP, Hughes TL Women & health. 2007;45(4):109-130.

4. Cochran SD, Mays VM. Journal of women's health. May 2012;21(5):528-533.



# Improving Abigail's diet

#### Patient concerns

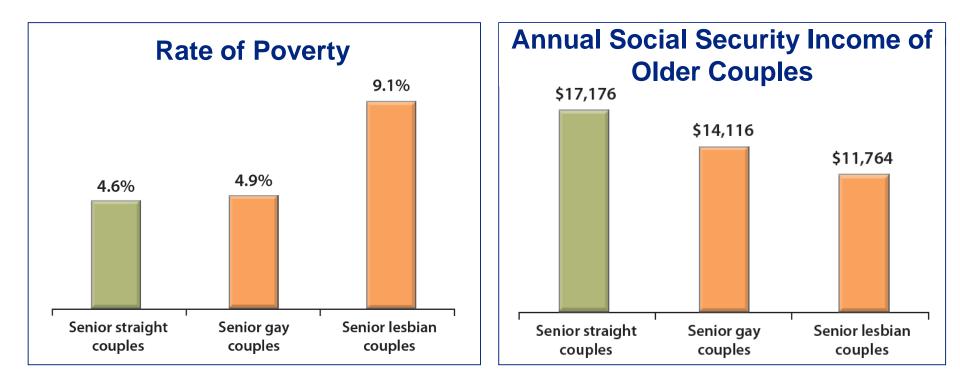
- Neither woman is working now
- Finances are tight
- Meals often consist of frozen meals or fast food
- Express concerns about affording fresh fruits and vegetables, healthy proteins, and whole grains

#### **Provider perspective**

 Understand local resources and appeal to multidisciplinary team



# **Demographics of Older Adults**





### Elizabeth's new diagnosis

 Abigail shares concerns about Elizabeth's impaired memory and disorientation

• Screening test shows "cognitive impairment"

• You suspect early vascular dementia

• Family support is lacking



#### **Reflection Question**

How should transitions of care be addressed?



# The health implications of legal protections

- Abigail and Elizabeth are not legally married
- Deprived of many health-related benefits of this recognition
  - Helps protect and promote the mental & physical health of lesbians and gay men
  - Helps protect and promote the health of children being raised by gay men & lesbians
  - Helps protect and promote the health of aging gay & lesbian individuals

Gay and Lesbian Medical Association. Same-Sex Marriage and Health. <u>http://glma.org/document/docWindow.cfm?fuseaction=document.viewDocument&documentid=146&documentFormatId=236</u>. Accessed 11/1/2016.



#### Resources







## **Accord Alliance**

better care. better outcomes. better lives.

National Resource Center ON LGBT AGING

NSCLC



**SERVICES & ADVOCACY** FOR GAY, LESBIAN, BISEXUAL & TRANSGENDER ELDERS



Access resources and the webinar recording: www.aamc.org/axis.

# **Takeaway Points**

#### Questions

- Who are the important people in your life?
- Are you in a relationship?
- What name and pronouns would you like me to use?
- What is your billing name on your insurance?

#### History

- Reassert confidentiality
- Include partner if present
- Use of hormones (medically supervised, medically unsupervised, herbal)
- Remember to inquire about suicide risk factors
- Conduct a patient-centered history, inclusive of an organ inventory



# **Takeaway Points**

#### **Physical Exam**

- Based on organs present, if needed for chief complaint
- Reflect patient's language regarding their body
- Sensitivity given high rates of trauma and victimization

#### **Shared Decision Making**

- Provider creates a safe environment
- Patient understands risks/benefits
- Provider modifies suggestions based upon patient's goals



# **Questions?**



Jonathan Appelbaum

John Davis

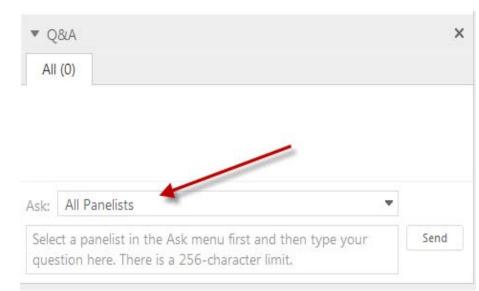
Please use the **Q&A panel** located on the right side of your screen to submit your questions. Send your questions to "All Panelists."



Jason Schneider



Andrew Vosko





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