



ADVANCING EXCELLENCE IN SEXUAL
AND GENDER MINORITY HEALTH

LGBT Aging

Change, Challenge and Resilience



Elizabeth Kass, MD
Fenway Health

Lisa Krinsky, MSW, LICSW
Director, LGBT Aging Project



NATIONAL LGBT HEALTH
EDUCATION CENTER

A PROGRAM OF THE FENWAY INSTITUTE



HARVARD
MEDICAL SCHOOL

How Many LGBT Older Adults?

Today: 1.4 to 3.8 million in U.S.
(Harley & Teaster, 2016)

2030 estimate: 3.6 to 7.2 million in U.S.
(Harley & Teaster, 2016)

MA Estimate: 33,000
(US Census QuickFacts 2019 and MA BRFSS Data
2016-18)

Three Generations: Invisible -- the oldest old
Silenced -- greatest generation
Proud – baby boomers and beyond



What's So Different?

Elder Issues

- Healthcare
- Housing
- Medication Costs
- Social Network: Family, Friends
- Income
- Retirement / Work
- Social / Recreational Activities

LGBT Elder Issues

- Healthcare
- Housing
- Medication Costs
- Social Network: Family, Friends
- Income
- Retirement / Work
- Social / Recreational Activities



Aging Supports



Spouse
Partner



Children
& Grand



Family
Of Origin



Faith
Community



Local
Community



Social
Community



Social
Services



Aging Supports



Spouse
Partner

Children
& Grand

Family
Of Origin

Faith
Community

Local
Community

Social
Community

Social
Services



Aging Supports:

Boomers & Millennials



Spouse
Partner



Children
& Grand



Family
Of Origin



Faith
Community



Local
Community



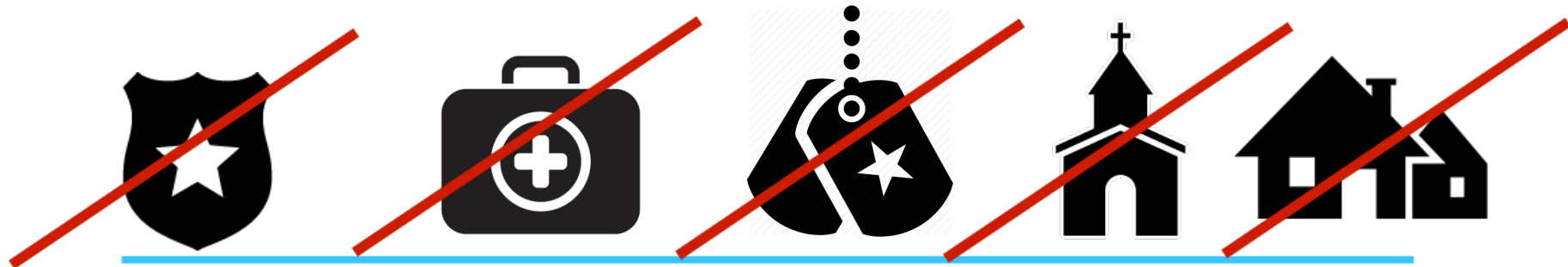
Social
Community



Social
Services



Mainstream Supports



Public Safety

Health Care

Military Service

Faith Community

Housing

Harassment
Entrapment

Mental Illness
(until 1973)
Institutionalization

Dishonorable
Discharge

Sin
Immoral

Eviction
Harassment





Anna

Sarah

Born:	1930	1950
McCarthy Trials (1954)	24	4
Stonewall (1969)	39	19
APA/DSM (1973)	43	23
Harvey Milk Elected (1977)	47	27
Reagan Mentions AIDS (1987)	57	37
“Ellen” Comes Out on TV (1997)	67	47
Marriage Equality in MA (2004)	74	54
Don’t Ask Don’t Tell Repealed (2011)	81	61
DOMA Repealed (2013)	83	63
SCOTUS: Marriage Equality (2015)	85	65
November 2016 ongoing.....Today	90	70



Bisexuality and Aging

- Most invisible element in LGBT spectrum
 - assumption of identity based on current partner
 - community based on current partner
- Bisexual older adults vs. lesbian and gay older adults:
 - significant mental/physical health disparities
 - more internalized stigma/less identity disclosure
 - impacting social network and social support

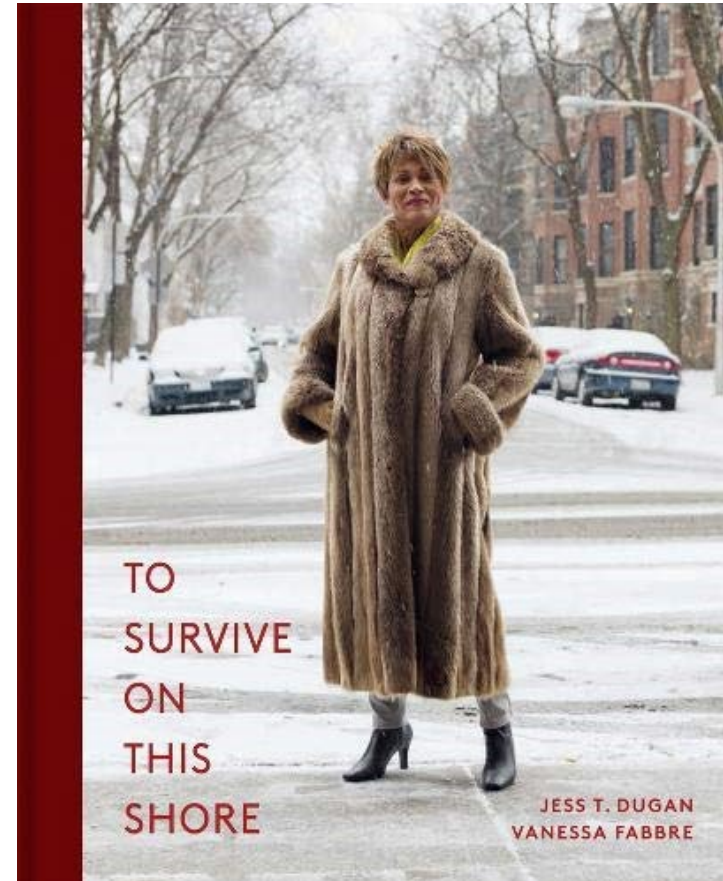
Fredriksen-Goldsen et al, 2017
- Bisexuals 45+ less likely to be “out” with healthcare providers than lesbian/gay peers
- 59% have children/grandchildren
- 74% *do not* live in big cities

AARP, 2018



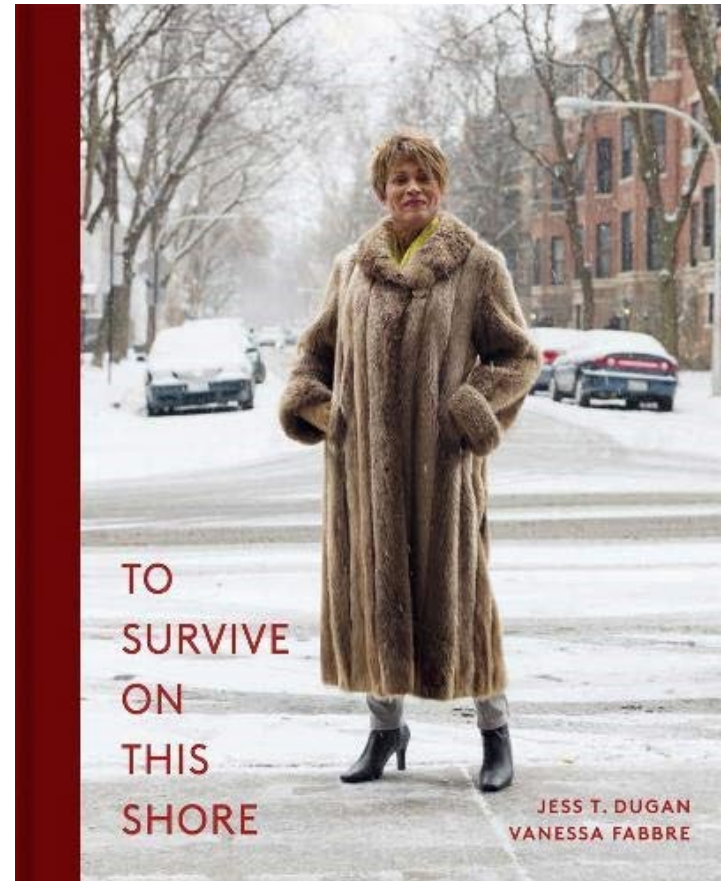
Transgender Aging

- Transition early in life: some lived “stealth” with no history or context; significant losses
- Transition later in life: after milestones
 - Retirement, family grown, deaths
- Selective authenticity: maintaining different identities in different settings



Transgender Aging

- High rates of unemployment, underemployment, violence, denied healthcare
- Reluctance & fear of health & long term care
 - Lack of trans inclusive care
 - Lack of knowledge about long term hormone use
- Isolation from LGB older adults



LGBT Elders of Color and Aging



- Estimated 20% of LGBT community are people of color; double to 40% by 2050
Adams, Generations 2016 in MAP 2017
- Intersectionality of experiences with multiple minority identities and stressors
 - What does it mean to be LGBT in one's racial/ethnic/faith community?
 - What does it mean to be old?
 - What does it mean to be a person of color in the LGBT community?
 - What does it mean to be old?
- LGBT Elders of Color/Flashback Sunday: community to welcome all identities



HIV/AIDS and Aging

- Disproportionally LGBT/MSM and People of Color
- Nationally: 50% of all people in the U.S. living with HIV & AIDS are over 50 years old

CDC

- Massachusetts: 62% of all people living with HIV/AIDS are over 50 years old
MA Department of Public Health, 2018



HIV and Aging

- Long Term Survivors
 - as long as 25 years or more with HIV infection
 - almost 70% live alone
 - impact of stigma persists
 - impact of losses of late 1980s/early 1990s persists
 - HIV supports of early era now gone
 - increased poverty(early disability)
 - Importance of LTS peer groups



HIV and Aging

- New Infections/New Diagnoses in older adults
 - more likely to present with advanced disease
 - less likely to achieve CD4/immune recovery with ARVs
 - more rapid progression to AIDS and shorter survival
 - increased risk of IRIS(immune reconstitution)



HIV and Aging

- New and newly identified infections - late diagnosis
- providers underestimate risk: ageism, lack of knowledge about past and present risk history
- patient lack of risk and prevention knowledge, increased risk behavior due to stigma, substance use



HIV and Aging

- stigma leading to: failure to engage in care, fear of disclosure
- missed diagnosis: symptoms which would be striking in younger adults attributed to other aging conditions
- CDC recommends annual testing age 13-64
- Under ACA, annual testing covered until age 65



HIV and Aging

- HIV Longterm Survivors
 - increased inflammation even with viral load control
 - immune senescence
 - controversy about whether HIV itself accelerates aging process

Co-morbidities/Multimorbidity

- for many conditions, older people with HIV have greater incidence of co-morbidities but not at an earlier age
- Polypharmacy
 - 55% of people with HIV over 50 are on at least 5 medications



HIV and Co-Morbidity/Multimorbidity

- Lipodystrophy /Metabolic Issues: due to HIV, antivirals
- Cardiovascular Disease
- Chronic Kidney Disease
- Osteoporosis



HIV and Co-Morbidity/Multimorbidity

- Liver Disease
- Non-HIV Malignancies:
 - HPV related - especially anal squamous cell cancer
 - Liver/cirrhosis related(due to hepatitis, EtOH, (fatty liver)
 - Lymphoma and other hematologic illness
 - Smoking related
- Depression/Anxiety/PTSD
- Substance Use



HIV and Co-Morbidity/Multimorbidity

- Neurocognitive dysfunction
 - Risks of HIV Associated Neurocognitive Disorders(HAND) increase with age
 - HIV dementia in effective antiretroviral era much less common
 - HAND prevalent and has impact on attention, working memory, processing speed and motor skills
 - HAND therefore has significant impact on medication adherence and other activities of daily living essential to independence (medication management, finances, shopping and cooking)



Dementia & LGBT Patients/Loved Ones

- Diagnosis – When and by whom?
 - Diagnosis could be delayed due to lack of socialization/family support and/or fear of doctor visits

- Care – Primary contact? Who manages? Who is informed?
 - Family may be estranged = partner may be ousted
 - May not have family or emergency contact information



Dementia & LGBT Patients/Loved Ones

- Legal Issues – “next of kin” vs. “family of choice”
 - Estranged/unaccepting family member may not respect relationship or wishes
 - LGBT friends may end up being HCP or POA
 - Legal Documents for Providers



Aging and Cognitive Decline

- Fear of loss of autonomy and fears of vulnerability/abuse are more acute: “I have taken care of myself my entire life!”
- Early stages of cognitive decline affect instrumental ADLs:
 - managing medication
 - managing finances
 - managing shopping and cooking
 - Driving/transportation
- --> can easily be missed in an office visit ←
- --> highest risk for people living alone without supports <--



Aging and Cognitive Decline

Useful Interventions Which Do Not Require a Neurologist!

- Assess for safety: driving, cooking, finances, wandering
- Assess for social isolation and potential sources of support
- Assess for sensory problems: hearing and vision



Aging and Cognitive Decline

Useful Interventions Which Do Not Require a Neurologist!

- Assess particularly for modifiable contributors to cognitive decline:
 - polypharmacy - de-prescribe when possible
 - medication adherence/confusion
 - medication interactions and side effects
 - sleep disorders
 - STIs(syphilis, HIV)



Aging and Cognitive Decline

Useful Interventions Which Do Not Require a Neurologist!

- Assess particularly for modifiable contributors to cognitive decline:
 - substance use:
 - smoking which is higher in LGBT adults
 - alcohol: higher in LGBT adults, increase after retirement
 - marijuana???
 - methamphetamine
 - benzos/sleep medications
 - opioids



Caregiving and Care receiving

Most LGBT Caregiving is HORIZONTAL

General Population

women

90% birth/marriage

10% non relative

LGBT Population

men/women

35% partner/spouse

16% parent

9% other relative

32% friend

7% non relative/neighbor

*The Aging and Health Report: Disparities and Resilience in
Lesbian, Gay, Bisexual and Transgender Older Adults, 2011*

LGBT Caregiver Support: Safe space for unique experience

LGBT Bereavement Group: Current & Previous Losses; Broader range of losses



Aging and Autonomy: Advanced Directives

- People express concern about autonomy and control of end of life care
- Over half of people with advanced illness have not completed advanced directives
- Many people who complete advanced directives do not share these with their physician



Aging and Autonomy: Advanced Directives

- Health care proxy may not be sufficient if proxy not aware of wishes and comfortable respecting these wishes
- Health care proxy needs to be reviewed regularly especially when same aged peer is the proxy
- MOLST/POLST sometimes helpful
- LGBT individuals may have complicated relationships with family of origin and detailed advance directive may be enormously helpful to the health care proxy



Case Example: Emily Blake*

- 76 year old retired elementary school teacher
- Never married, came out as lesbian late in life, never had a same sex partner
- Lives alone, managing well, large and supportive network of friends
- Medical history: breast cancer, asthma, coronary artery disease, heart failure
- Last year: ovarian cancer with surgery and chemotherapy (atrial fibrillation and heart failure)
- Follow up scans: no cancer

- Currently: friends concerned about forgetfulness and disorganization and safety at home



Case Example: Emily Blake*

- Bloodwork: unrevealing for reversible causes of cognitive decline
- CNS imaging: some small vessel disease
- Medication regimen reviewed and simplified to eliminate any potential medication contributors to her cognitive changes

- Increasing:
 - Frequent EMT assistance for falls at home
 - Difficulty with self-care, finances
 - Repeatedly changing mind about whom she names as health care proxy

- Emily is aware that she is having difficulty managing, and she appreciates her friends help, but she is not sure that she needs as much assistance as they are telling her.



Individual Practice

- **Challenge heterosexual/cisgender assumptions about older adults**

- **Language of the times:**
 - Homosexual vs. Gay/Lesbian
 - Lifestyle vs. Orientation; Gender Identity/Expression
 - Friend, lover, partner, spouse, husband/wife
 - Euphemisms -- friend, roommate, cousin

- **Newer language:**
 - Queer
 - Ally
 - Non-binary; Gender non conforming; Gender diverse



Individual Practice

- **Open ended questions:**
 - Who else lives in your home? Who do you consider your family?
 - What else would be helpful for me to know?
 - Anything about your body you would like us to know about?

- **Affirming environment without naming it:**
 - You two make a great team
 - How long have you lived together/know each other?
 - We work with all kinds of people and it's important to us that you feel comfortable here, please let us know if we can do anything differently for you



SPECIAL
LEGISLATIVE
COMMISSION ON
LESBIAN, GAY,
BISEXUAL AND
TRANSGENDER
AGING



An Act Relative to LGBT Awareness Training for Aging Service Providers

SECTION 1. Chapter 19A of the General Laws is hereby amended by inserting after section 41 the following section:

Section 42. The department shall **develop a curriculum and training program** on the prevention and elimination of discrimination based on sexual orientation, gender identity and expression and on improving access to services for lesbian, gay, bisexual and transgender elders and caregivers. The training program shall be completed by **all providers of services who contract with or receive funding from the department, Aging Service Access Points or the MassHealth Office of Long Term Care**, or whose services are certified by the department.

July 2018



Resources for LGBT Older Adults and Caregivers

- Social Organizations
 - The Prime Timers, OLOC, RALLY, LGBT Elders of Color, Griot Circle
- LGBT Friendly Community Cafes - 23 statewide in MA
- LGBT Friendly Senior Housing - 10 currently; 20 pending in US
- LGBT Bereavement Groups
- LGBT Senior Pride Coalition
- LGBT Aging Project Newsletter (lgbtagingproject.org)

- SAGE – NY and national affiliates
- National Resource Center on LGBT Aging (lgbtagingcenter.org)



What Supports Resilience?

Ability to be Authentic

LGBT inclusive and affordable health care

Safe and affordable housing

Social network and community

Meaningful engagement

Livable income



Resilience



able to return to an original shape after being pulled, stretched, bent or pushed

Merriam Webster Learners Dictionary



Q & A

Are there any questions that
you would like to ask?

Elizabeth Kass, MD

Ekass@fenwayhealth.org

Lisa Krinsky, MSW, LICSW

Lkrinsky@fenwayhealth.org

