Sexual and Gender Minorities & Dementia Caregiving

Jason Flatt, PhD, MPH
Pronouns: He/They
- Terminology
- Historical & Social Context
- Dementia & Caregiving Research
- Collecting Sexual Orientation, Sex Assigned at Birth, and Gender Identity
- Future Research
- Q&A
Sexual minority – individuals who self-identify as asexual, bisexual, gay, lesbian, queer, as well as those who do not self-identify with these terms but whose sexual orientation varies from heterosexual.

Gender minority – individuals who self-identify as transgender & non-binary, as well as those with a gender identity and/or expression that does not conform to social & cultural expectations based on the sex assigned to them at birth.

Cisgender - a term used to describe people whose gender identity aligns with the sex assigned to them at birth.

Sexual orientation & gender identity may evolve over the lifespan.
The Gender Unicorn

Gender Identity
- Female/Woman/Girl
- Male/Man/Boy
- Other Gender(s)

Gender Expression
- Feminine
- Masculine
- Other

Sex Assigned at Birth
- Female
- Male
- Other/Intersex

Physically Attracted to
- Women
- Men
- Other Gender(s)

Emotionally Attracted to
- Women
- Men
- Other Gender(s)

To learn more, go to: www.transstudent.org/gender

Design by Landyn Pan and Anna Moore
1970
To commemorate Stonewall, one of the first gay pride parades occurs in NYC.

1993
"Don't Ask, Don't Tell" policy was signed into law. Forbidding openly gay people from serving in the military.

2015
Same-sex marriage legalized nation-wide after a 5-4 decision by the United States Supreme Court.

1969
Stonewall Riots take place in NYC, sparking the modern LGBTQ+ movement.

1978
The rainbow flag is designed by Gilbert Baker to create a symbol of pride for the LGBTQ+ community.

2011
"Don't Ask, Don't Tell" policy is repealed. Gay community allowed to openly serve in the military.

2020
Supreme Court rules that 1964 Civil Rights Act protects LGBTQ+ workers from workplace discrimination.
- Historical & current pathologizing of sexual & gender identities in DSM
- Lack protections for basic human rights (e.g., housing, employment, healthcare)
- Compounded for intersecting marginalized identities (gender, race/ethnicity, serostatus, disability)
2.7 MILLION LGBT ADULTS AGED 50 AND OLDER

1.1 MILLION ARE 65 AND OLDER

APPROXIMATELY ONE IN FIVE (20%) LGBT OLDER ADULTS ARE PEOPLE OF COLOR

ONE-THIRD OF LGBT OLDER ADULTS LIVE AT OR BELOW 200% OF THE FEDERAL POVERTY LEVEL

- Barriers to healthcare access & use
- Lifetime exposure to discrimination & trauma

Unique concerns:
- Intersect with race/ethnicity
- Less likely to be married or have children
- 2-3X as likely to live alone
- Little to no caregiver support
SGM DEMENTIA & CAREGIVING RESEARCH
Subjective Cognitive Decline among Lesbian, Gay, Bisexual, Transgender (LGBT) Adults

1 in 7 people aged 45 years and older are experiencing Subjective Cognitive Decline.

36% of people with SCD had to give up day-to-day activities.

One in three of people with SCD say it interfered with social activities, work or volunteering.

Less than half of people with SCD have discussed their symptoms with a healthcare provider.

36% of people with SCD need help with household tasks.

16% SGM vs 11% Non-SGM

Study supported by NIA - K01AG056669 (Flatt)
LGBT OLDER ADULTS AND DEMENTIA

LGBT people have greater health disparities, many of which are risk factors for dementia, including:

- Depression
- Obesity
- Alcohol and tobacco
- Lower rates of preventive screenings
- Cardiovascular disease
- HIV/AIDS

7.4% of the lesbian, gay and bisexual older adult population is living with dementia.

LGBT adults living with dementia face unique challenges in accessing support:

40% report that their support networks have become smaller over time
34% live alone
30% experience lower rates of access to care

Alzheimer’s is the most expensive disease in the nation

51% of LGBT older people report being very concerned about having enough money to live on

Fear of discrimination can delay access to care
40% say their health care providers don’t know their sexual orientation

Visit alz.org for additional information, support and resources.

SOURCES
- Alzheimer’s Association and SAGE, Issues Brief LGBT and Dementia
- American Medical Association, 2015, 1 in 5 Older Adults Have Dementia and 1 in 10 Will Develop Alzheimer’s
- National Institute on Aging
- The American Federation for Aging Research
- The Gerontological Society of America
- The American Psychological Association
- The Alzheimer’s Association
- The National Institute on Aging
- The National Institute on Disability, Independent Living, and Rehabilitation Research
- The National Institute on Aging
- The National Alliance on Mental Illness

Alzheimer’s caregivers provide care for a longer time than other caregivers of older adults without Alzheimer’s.

- 35% of Alzheimer’s caregivers report their health has gotten worse.

- SGM people become caregivers at a higher rate than the general population (1 in 5 vs. 1 in 6).
CAREGIVING AMONG LESBIAN, GAY, BISEXUAL, TRANSGENDER (LGBT) ADULTS

2015–2018 Behavioral Risk Factor Surveillance System (BRFSS) Data from Lesbian, Gay, Bisexual, Transgender (LGBT) Adults in 20 States

1 in 4 adults are caregivers

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

WHO ARE CAREGIVERS?

LENGTHY
Over 40% have provided care for at least two years

INTENSE
30% are providing care for at least 20 hours per week

43% are women

less than 10% are 65 years old or older

43% are caring for a parent or parent-in-law

Nearly 10% are providing care for someone with dementia

HOW DO CAREGIVERS HELP?

8 in 10 manage household tasks

Over half assist with personal care

FUTURE CAREGIVERS

1 in 5 NON-CAREGIVERS expect to BECOME CAREGIVERS within 2 years

CDC.gov/aging

www.rainbowsofaging.org

76%
are concerned about having adequate family and/or social supports to rely on as they age.

LGBT Concerns About Long Term Care

67%
neglect

61%
limited access to services

60%
verbal or physical harassment

52%
will be forced to hide/deny identity

LGBT Adults Want Welcoming Long-Term Care Services Designed for Them

88%
want LGBT trained providers

85%
want providers that are also LGBT

86%
want advertising for LGBT friendly services

82%
want LGBT signs displayed onsite

63%
have provided caregiving to an adult loved one such as a relative, friend, spouse or partner

61%
think it is likely they will be a caregiver to a loved one in the future

23%
have received caregiving as an adult from a loved one such as a relative, friend, spouse or partner

66%
think it is likely they will need caregiving from a loved one in the future

The three most common concerns for LGBTQ caregivers are:

64%
feeling emotionally stressed

60%
finding it difficult to exercise

57%
finding it difficult to get enough rest

Contact: Angela Houghton, AARP Research, ahoughton@aarp.org

Dignity 2022: The Experience of LGBTQ Older Adults, June 2022
https://www.aarp.org/LGBTQ/dignity
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Characteristics of Sexual and Gender Minority Caregivers of People With Dementia

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- 1 in 3 living in a small town/rural area
- 63\% providing care to SM person living with dementia
- 1 in 5 were providing care to a GM person living with dementia
- 1 in 3 found it difficult to afford the very basics
- Most cared for their spouse/partner
- Average of 2 years providing care
- More than half did not live with their care recipient
- Most did not use respite or transportation services
- 1 in 3 had below average health status
  - Greater for lesbian & transgender caregivers
  - Queer caregivers - more discrimination, victimization, and microaggressions
- 73% reported moderate to high levels of stress
  - Higher bisexual & queer caregivers
- 78% reported probable depression
  - Higher for queer & African American LGBTQIA+ caregivers
- LGBTQIA+ caregivers of color had lower family quality of life than Whites
Conclusions

1. Similar or higher risk of Alzheimer’s disease in SGM community & unique caregiving/care partner needs

2. Promote resilience, cultural humility, consider trauma-informed care approaches, & give back!

3. We need more SOGI data
Collecting SOGI – Sexual Orientation & Gender Identity

• NASEM report (2022) provided foundation for recommendations

• National Alzheimer’s Coordinating Center - UDS 4.0


Collecting Sexual Orientation

The next questions ask about your gender identity, sex assigned at birth, and sexual orientation. This information will be used to help us improve health, well-being, and quality of care. By gender identity, we mean the inner sense that you have of yourself as being a man, woman, or a different gender. Gender identity can be different from your sex assigned at birth or your sexual orientation, and it can change over time.

Which term(s) best describes your sexual orientation?
(Check all that apply)

- Lesbian or gay
- Straight/heterosexual
- Bisexual
- Two-Spirit (if respondent is AIAN)
- I use a different term (Please specify. Ex: asexual, queer, questioning) __________________________
- Don't know
- Prefer not to answer

AIAN = American Indian and Alaska Native population
Collecting Sex Assigned at Birth and Gender Identity: Two-Step Method

What sex were you assigned at birth, on your original birth certificate?
- [ ] Male
- [ ] Female

Which term(s) best describes your current gender identity? (Select all that apply)
- [ ] Man
- [ ] Woman
- [ ] Transgender man
- [ ] Transgender woman
- [ ] Non-binary/Genderqueer
- [ ] Two-Spirit (*if respondent is AIAN*)
- [ ] I use a different term (*Please specify*) ___________
- [ ] Don't know
- [ ] Prefer not to answer

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Collecting Sex Assigned at Birth and Gender Identity: Two-Step Method

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☐ Female

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☐ Woman

☐ Transgender man

☐ Transgender woman

☐ Non-binary/Genderqueer

☐ Two-Spirit (if respondent is AIAN)

☐ I use a different term (Please specify) ___________

☐ Don't know

☐ Prefer not to answer

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www.rainbowsofaging.org
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Which term(s) best describes your current gender identity? (Select all that apply)

☐ Man
☑ Woman
☐ Transgender man
☐ Transgender woman
☐ Non-binary/Genderqueer
☐ Two-Spirit (if respondent is AIAN)
☐ I use a different term (Please specify) ___________
☐ Don't know
☐ Prefer not to answer

AIAN = American Indian and Alaska Native population
Intersex/DSD status

Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a “Difference of Sex Development (DSD)” or were you born with (or developed naturally in puberty) genitals, reproductive organs, and/or chromosomal patterns that do not fit standard definitions of male or female?

☐ Yes
☐ No
☐ Don't know
☐ Prefer not to answer
Conclusions

1. Similar or higher risk of ADRD & cognitive impairment in SGM populations & unique caregiving/care partner needs
2. Promote resilience, cultural humility, consider trauma-informed care approaches, & give back!
3. We need more SOGI data
4. More research (e.g., RISE, Stonewall Generations Study)
Aim 1: Identify & explore domains of ADRD caregiving for SGM ADRD caregivers

Aim 2: Develop & refine new measures of ADRD caregiving for SGM ADRD caregivers

Aim 3: Test the new and existing measures with SGM and non-SGM ADRD caregivers

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www.theriseregistry.org

Join the registry -
https://is.gd/RISE_REGISTRY

Supported by NIH/NIA R24AG066599 (Wharton, Flatt, Anderson)
Goals of the Study

• Recruit 500 diverse LGBTQ+ (n=250) and non-LGBTQ+ (n=250) older adults
• Compare differences in memory and thinking skills between LGBTQ+ and non-LGBTQ+ older adults
• Identify health and social factors linked with memory and thinking skills among LGBTQIA+ adults
Conclusions

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5. Advocacy: Support SGM caregivers, families of choice, and ensure inclusive services for all people

6. Mentoring others and funding to support new programs, services and research
LGBTQ senior day program launches
Since moving back to San Francisco in the mid-1990s after relocating to...
Welcome

The LGBTQ Caregiver Center is a developing virtual resource hub that aims to raise awareness of the unique needs, challenges and experiences of LGBTQ Caregivers and those who care for LGBTQ individuals. We engage in advocacy and research activities, provide training and deliver services that promote caregiver well-being and cultivate belonging.

https://lgbtqcaregivers.org/
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Thank you!

Questions?

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