

# The Benefits of LGBTQ+ Affirming Dementia Care

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Nothing to Disclose

# LEARNING OBJECTIVES

## Objective 1

Understand the unique life experiences and historical contexts that shape the health and support needs of LGBTQ+ older adults

## Objective 2

Enhance clinical and cultural competencies to provide respectful, inclusive, and affirming care for LGBTQ+ seniors across healthcare settings

## Objective 3

Identify key concerns and strategies for care partners supporting LGBTQ+ older adults, including navigating family dynamics, chosen families, and access to affirming services

# Objective 1:

Understand the unique life experiences and historical contexts that shape the health and support needs of LGBTQ+ older adults

# LGBTQ+ people experience earlier, more severe disease

1. Substantial disparities in obesity, diabetes, cardiovascular risk, mental health, suicidality, multiple morbidity
2. Evidence suggestive of disparities in aging related diseases, like Alzheimer's and dementia
3. Substantial disparities in cancer risk, especially: cervical, breast, lung, prostate, skin, anal, colorectal, oropharyngeal
4. Greater likelihood of cancer recurrence (3x higher for breast cancer)
5. Higher mortality for certain cancers, varies by population
6. Earlier all cause mortality





# Disparities in cognition/cog decline

1. Sexual minority adults report higher prevalence and more severe cognitive decline
2. Difference in subjective cognitive decline is 17% vs 11% for sexual minority women and 15% vs 10% for sexual minority men compared to nationally representative heterosexual samples
3. This impairment disproportionately impacts their ability to live independently
4. Despite higher need for help with independent activities, 28% of sexual minority women who need help don't get help.



# Stress and biological processes driving health disparities

1. Minority stress, structural stigma, hypervigilance
2. Sleep disruption
3. Biological aging
4. Metabolic dysfunction
5. Vascular changes
6. HIV- and HIV-treatment related cognitive changes
7. Hormone replacement therapy an evolving area – both testosterone and estrogen play a role in cognitive capacity in later life





# Discrimination drives avoidance, discomfort

1. Up to one-third of LGBTQ+ Americans avoid seeing a doctor for fear of discrimination
2. Many LGBTQ+ people are not out to their primary provider
  - Confidentiality
  - Mistreatment
  - Not relevant
3. Nondisclosure can lead to
  - inattention to specific health care needs
  - missed diagnostic screenings and vaccinations
  - higher unmet medical needs





# Sometimes care for LGBTQ+ people is inadequate, inappropriate

1. Sexual minority women are significantly less likely to be offered a Pap test than heterosexual women
2. Transgender people with prostates are less likely to get screened compared to cisgender gay men and heterosexual men
3. Gay and bisexual men who do not disclose their sexual orientation to their provider are less likely to receive HPV vaccine



# When patients feel care is not affirming, we see:

1. Less patient-centered care and patient involvement in medical decision making
2. Greater burden of comorbidities at diagnosis
3. Reduced partner involvement in care decisions
4. Higher social isolation during treatment
5. Survivors have significantly greater physical inactivity, more medical complications, heavy episodic alcohol use, and depression, esp. transgender/gender diverse patients





# Additional challenges contributing to poorer health outcomes for LGBTQ+ populations

1. Structural barriers (like lower rates of health insurance) → missed screenings, later initial presentation for care
2. Laws that allow providers to openly discriminate against LGBTQ+ and other minority populations (Denial of Service Laws)
3. Higher behavioral risk factors for certain diseases (e.g., smoking) not adequately addressed by prevention, intervention, or screening
4. Care fragmentation



# Additional challenges contributing to poorer health outcomes for older LGBTQ+ adults

5. Often referred to as the first out generation
6. Limited/no models of aging
7. Frequently, aging is unexpected, unplanned for (“I never expected to live past 40 and now I’m 60. What do I do?”)
8. Targeted LGBTQ+ supports are limited
9. Mainstream support organizations are sometimes risky, may be faith based, individual staff or clients may be nonaffirming
10. Often aging without a partner, spouse, or adult children. Older gay men especially likely to live alone.
11. Support networks look different, involve more friends, community members, and paid help





## Objective 2:

Enhance clinical and cultural competencies to provide respectful, inclusive, and affirming care for LGBTQ+ seniors across healthcare settings



SUPPORT  
TRANS  
YOUTH

When we have to protect  
children from their government,  
we have failed as a society.

GENDER AFFIRMING  
HEALTHCARE  
IS  
NECESSARY.



PROTECT  
TRANS  
KIDS





# What is LGBTQ+ affirming care?



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Cultural and clinical competencies

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Respectful communication with  
LGBTQ+ individuals

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Understanding, addressing specific  
health needs of LGBTQ+ individuals

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Visible and explicit inclusion

# Levels of Affirming Care

## Interpersonal Level

- Gender inclusive language, rainbow pins, sharing information about increased and earlier risk of cognitive decline among LGBTQ+ older adults

## Institutional Level

- Implementing LGBTQ+ competence in medical education, providing continuing education for providers, supporting LGBTQ+ trainees, showing up for colleagues

## Structural Level

- Advocating for health insurance expansion, coverage of gender affirming care





# Measures

## Has an Affirming Care Provider

Do you have an LGBT-affirming health care provider?

- Yes, they are my primary health care provider
- Yes, I see them in addition to another health care provider
- No, I don't need or want an LGBT-affirming health care provider
- No, I cannot find an LGBT-affirming health care provider in my area
- I don't know

## Preventative Screenings

- Have you seen a doctor or healthcare provider in the past year?
- Have you ever had any of the following preventative care screenings or tests? In the last three years?
  - Flu shot
  - Breast cancer screening/mammogram
  - Pap test
  - Colorectal cancer screening/colonoscopy
  - HIV test

## Chronic Disease Management

If condition:

Is your [high blood pressure, diabetes, heart condition, respiratory condition, mental health condition] pretty much under control (1) or is it still a problem (0)?



# Who Has An Affirming Provider?

About two-thirds of sample reports an LGBTQ+ affirming provider.

Compared to participants with a usual source of care, those with an LGBTQ+ affirming provider are more likely to:

- Be lesbian or gay (vs bisexual or something else)
- Be transgender or gender diverse (vs cisgender)
- Be living with HIV (vs not)
- Have a college degree or higher (vs less than college)
- Be insured (vs not)





# Association of Affirming Care with Chronic Disease and Preventative Care Outcomes LGBTQ Older Adults

- Seen a doctor, last 12 months
- Flu shot
- HIV test
- Cancer screenings
- Management of chronic conditions



# Mechanisms?

## **Less Avoidance**

- Patients anticipate less discrimination, lowering barriers to engagement and decreasing delays in care.

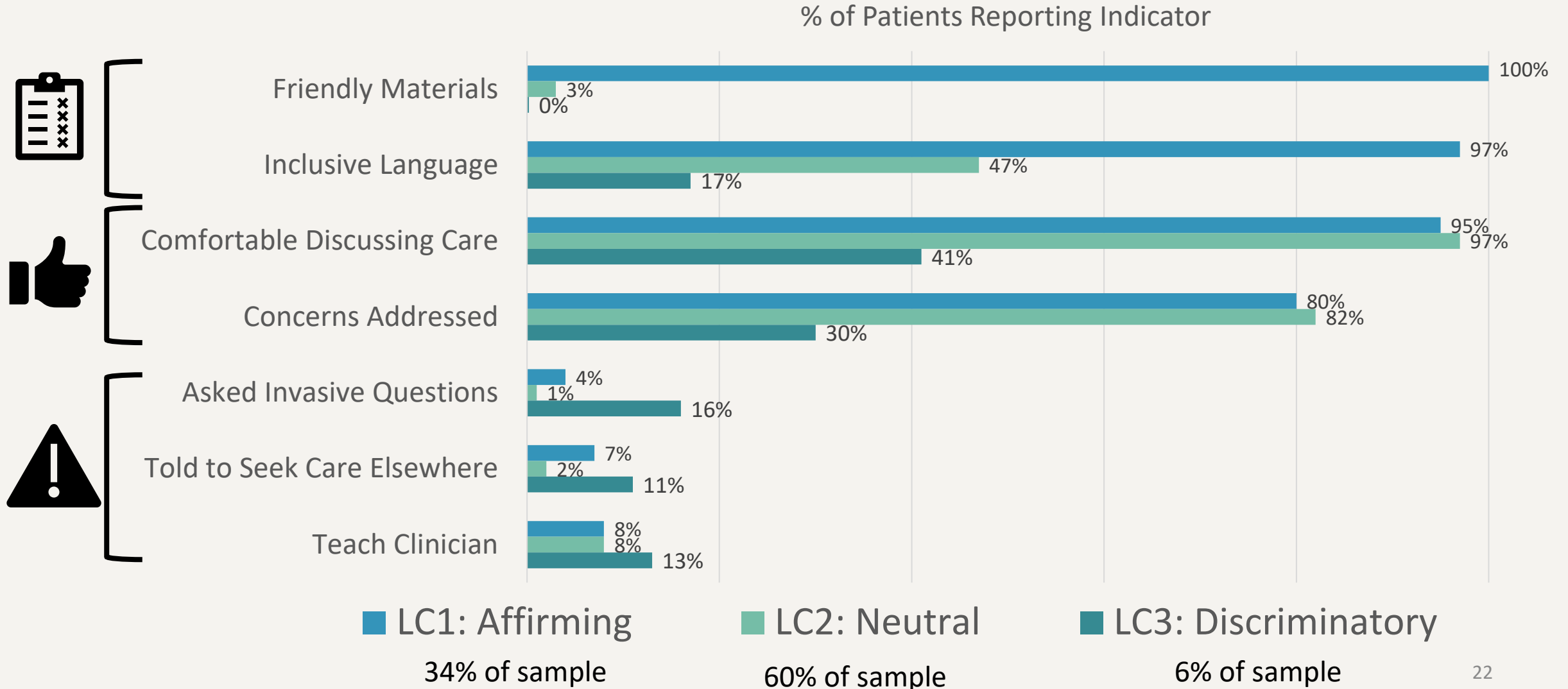
## **More Trust**

- Affirming providers engender more trust, increasing openness about problems and action on recommendations.

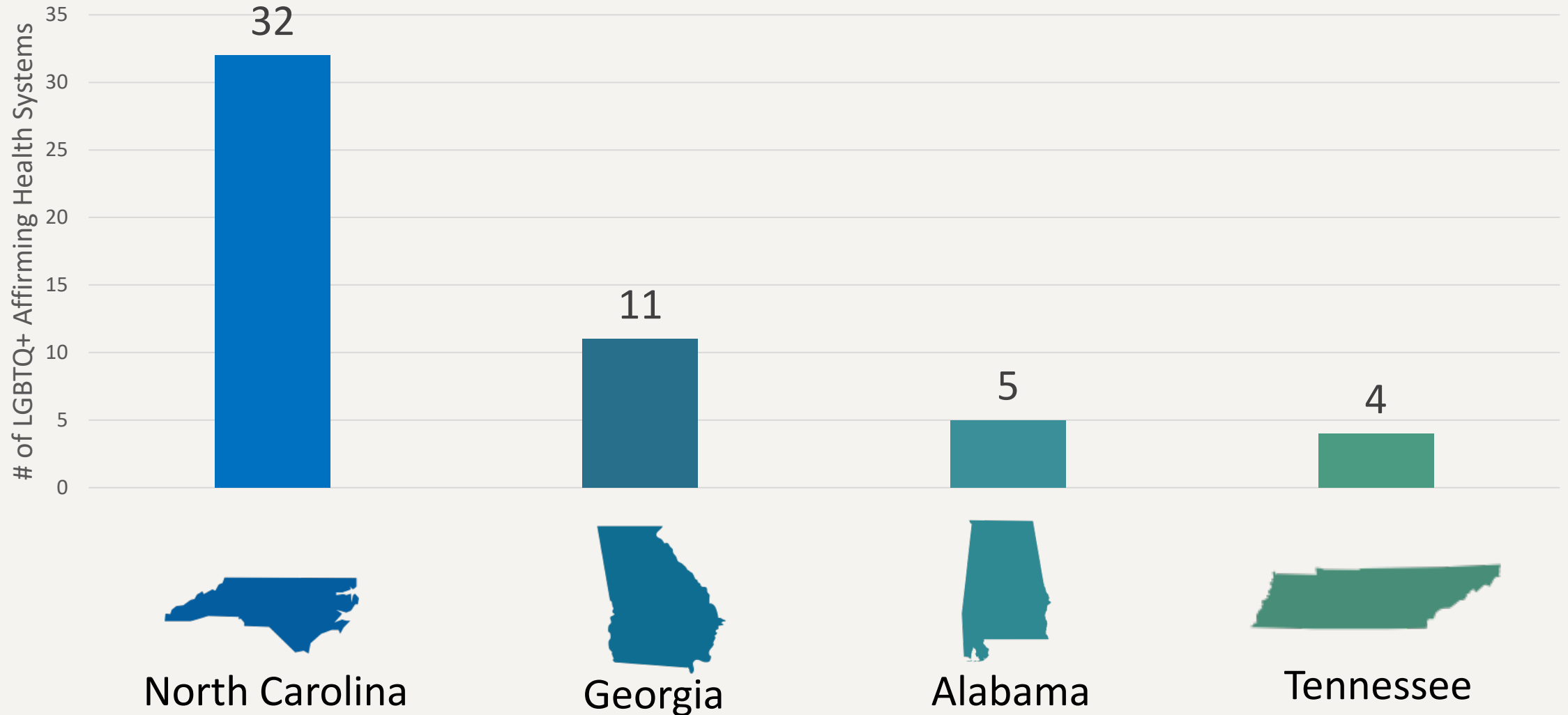
## **Integration of Care**

- Greater engagement with primary care, less healthcare fragmentation

# What Kinds of Experiences Create an Affirming Environment?



# # of LGBTQ+ Affirming Health Systems by State



Data come from the 2022 LGBTQ+ Healthcare Equality Index

# Take Aways from Our Research

- Not everyone has access to LGBTQ+ affirming care
- Without explicitly affirming care, LGBTQ+ older adults are less likely to be up to date with US Preventive Task Force recommendations
- Patients in more affirming health systems report higher satisfaction overall, not just LGBTQ+ patients
- Expanding access to LGBTQ+ affirming providers across the health system may
  - Decrease healthcare avoidance and delay for LGBTQ+ populations
  - Help narrow health disparities for LGBTQ+ older adults through increased and more timely screening, uptake of provider recommendations, earlier detection
  - Intervene in the poorer health trajectories of LGBTQ+ people in many Southern states



**Given clear  
benefits, why  
aren't more  
providers  
LGBTQ+  
affirming?**

**Actually, they  
are!**

Most healthcare  
providers have very few  
reservations about  
caring for LGBTQ+  
populations

But they feel  
unprepared

Limited engagement  
with LGBTQ+ health in  
medical curriculum

Limited interaction with  
LGBTQ+ patients

# How do I start?



## Awareness:

- Attend a training focused on LGBTQ+ health topics
- Know your workplace policies
- Join/start an LGBTQ+/Allies affinity group at your workplace

## • Signaling

- Add a rainbow pin/lanyard/badge sticker
- Review your
  - Intake forms
  - Promotional materials
  - Decorations around your office
  - Website
- Consider the impact of gendered program titles on inclusion
  - “Men’s support group”

## • Staying Current

- Connect with a local or national training program in LGBTQ+ Health





# Level Up!

- Check your assumptions → if you're not sure how a patient identifies or what pronouns they use, ASK!
- Use inclusive language like spouse or partner in patient interactions
- Pay attention to health disparity areas, but also the whole person
  - gender-related medical misattribution ("trans broken arm syndrome") and invasive questioning are recurring complaints from LGBTQ+ patients
- Ask → many workplaces have a space for this in medical record, but most don't use it
- Openly engage care partners, esp. nontraditional ones like close friends or community members





# Do I really need to do this?

- 2.4 million Americans aged 65+ identify as LGBTQ+
- Substantial disparities in disease risk, stage of diagnosis, rates of cancer recurrence and survival, earlier mortality
- Increasing evidence that the care partners of LGBTQ+ older adults are being left behind, isolated, struggling

A rectangular sign with a light-colored wooden frame is mounted on a bright yellow wall. The sign has a black background with the words "YOU CAN DO THIS" written in a teal, sans-serif, all-caps font. The text is arranged in three lines: "YOU" on the top line, "CAN DO" on the middle line, and "THIS" on the bottom line.

YOU  
CAN DO  
THIS

# Do patients really want to talk about this?

**PLOS ONE**

 OPEN ACCESS  PEER-REVIEWED

RESEARCH ARTICLE

## Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers

Sean Cahill , Robbie Singal, Chris Grasso, Dana King, Kenneth Mayer, Kellan Baker, Harvey Makadon

Published: September 8, 2014 • <https://doi.org/10.1371/journal.pone.0107104>

# I need more information:

- Vanderbilt University Medical Center [Program for LGBTQ Health](#)
- Alzheimer's Association [LGBTQ+ Resources for Dementia](#)
- American Medical Association on [LGBTQ Health Issues](#)
- [National LGBT Cancer Network](#)
- [American Association for Cancer Research](#)



## Objective 3:

Identify key concerns and strategies for care partners supporting LGBTQ+ older adults, including navigating family dynamics, chosen families, and access to affirming services

# The Role of Family Care Partners and "Chosen Families"

Family care partners may include, but are not limited to:

- Partners and/or spouses
- Parents, siblings, and other immediate family members
- Neighbors or community members
- Clergy or spiritual leaders
- Friends
- Other members of one's "chosen family"



# Key Mechanisms of Disparities in Dementia Care and Caregiving for LGBTQ+ People

- Higher risk of living alone & lacking traditional family caregiver networks
- Lack of LGBTQ+ nondiscrimination protections in care settings
- Exclusion of chosen family in care decisions
- Limited provider training
- Pressure to conceal LGBTQ+ identity or relationships to receive better care
- Underrepresentation in research, clinical trials, and dementia care models



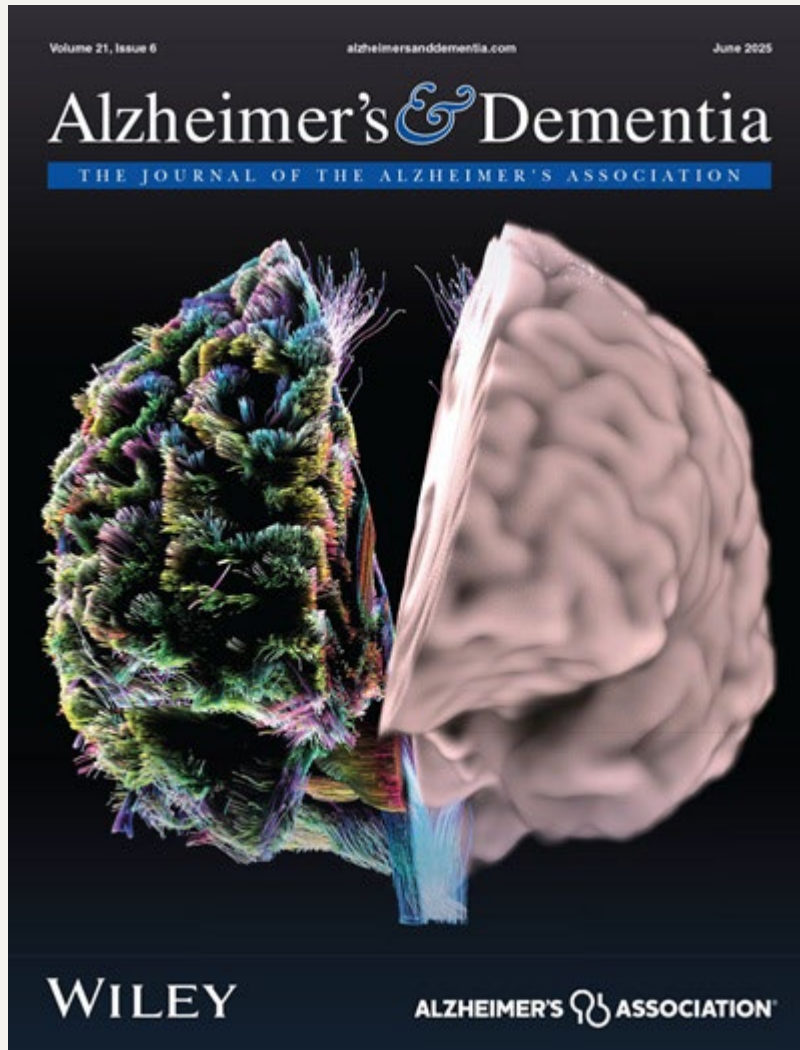


What are the key concerns for family  
care partners of LGBTQ+ persons  
living with dementia?

# Care partners of LGBTQ+ individuals often face gaps in support and care access

- 27-45% of LGBTQ+ adults are providing care to an older adult
- LGBTQ+ older adults and their care partners face structural barriers in accessing LGBTQ+ social support
- LGBTQ+ caregivers also encounter substantial barriers in accessing care for themselves





## **LGBTQ+ Identity Social Support and Care Access among LGBTQ+ Caregivers of Individuals Living with Mild Cognitive Impairment, Alzheimer's Disease, and Related Dementias**

*Data source: Wave 3 (N = 982) of QSNAPS*

- Description of LGBTQ+ MCI/ADRD caregiver and care recipient characteristics relative to other LGBTQ+ caregivers and non-caregivers
- LGBTQ+ identity social support from family, friends, coworkers, and neighbors
- Access to LGBTQ+ affirming care services and environments



**1 out of 12 respondents (8.1%) care for individuals with mild cognitive impairment (MCI) or dementia**

Compared to other groups, MCI/dementia caregivers were more likely to:

- **Be transgender or gender diverse** (10.0% vs 9.7% vs 5.4%,  $p < 0.1$ )
- **Report household income lower than the US median** (16.3% vs 13.5 vs 7.6%,  $p < 0.05$ )



# LGBTQ+ Identity Social Support among Caregivers of Individuals Living with MCI/Dementia

MCI/dementia caregivers more frequently reported having:

- **Unsupportive immediate family members** (44.3% vs 28.5% vs 33.1%,  $p < 0.1$ )
- **Unsupportive neighbors** (63.3% vs 46.3% vs 53.4%,  $p < 0.1$ )
- **Received practical help from others** (65.0% vs 52.6%,  $p < 0.01$ )



# LGBTQ+ Affirming Care Access among Caregivers of Individuals Living with MCI/Dementia

MCI/dementia caregivers more frequently reported that they received healthcare in settings that:

- **Did not display LGBTQ affirming materials** (86.3% vs 77.2%,  $p < 0.1$ )
- **Did not use gender-inclusive or affirming language** (51.3% vs 41.7,  $p < 0.1$ )
- **Did not feel comfortable discussing aspects of their health and care** (25.0% vs 11.3% vs 18.9%,  $p < 0.05$ )





What are some evidence-based strategies for care partners supporting LGBTQ+ adults with dementia?

# Strategies for Care Partners Who Support LGBTQ+ Adults Living with Dementia

1. Use LGBTQ+ culturally responsive care communication
2. Offer psychosocial support and assist with resource navigation
3. Protect your own health and quality of life



# Strategies for Care Partners Who Support LGBTQ+ Adults Living with Dementia

1. **Use LGBTQ+ culturally responsive care communication**
2. Offer psychosocial support and assist with resource navigation
3. Protect your own health and quality of life





# Tips for Using LGBTQ+ Culturally Responsive Care Communication

1. Use the person's affirmed name, pronouns, and relationship terms.
2. Advocate the person's care preferences and decisions (e.g., continuing hormone therapy).
3. Encourage early conversations about legal, medical, and identity-related wishes to protect chosen family roles and preferences.
4. Discuss who they want informed about their LGBTQ+ identity, relationships, or dementia diagnosis—and under what circumstances.
5. Dementia may affect how a person expresses gender or talks about relationships; try to remain supportive and nonjudgmental.

"It is very important to have to be sure that gender is understood and that the proper pronouns are used. Because good Lord, it's hard enough dying without having all this other stuff going on with respect by gender."

- **Yvette**

# Strategies for Care Partners Who Support LGBTQ+ Adults Living with Dementia

1. Use LGBTQ+ culturally responsive care communication
- 2. Offer psychosocial support and assist with resource navigation**
3. Protect your own health and quality of life





# Tips for Offering Psychosocial Support and Assist with Resource Navigation

1. Connect the person and yourself with LGBTQ+-affirming, age- and dementia-friendly support groups and providers
2. Help access caregiver support services, transportation, housing assistance, and financial resources
3. Assist in navigating insurance coverage and reducing financial barriers
4. Support safe disclosure of care partner needs to ensure affirming, coordinated support

“The [LGBTQ+ center] is three blocks from my apartment, so they used to have social functions there, which I would attend, but they've now shifted them to [church], which would be like a \$40 taxi ride. And so, I don't attend any of their social functions anymore...” - **Ben**

# Strategies for Care Partners Who Support LGBTQ+ Adults Living with Dementia

1. Use LGBTQ+ culturally responsive care communication
2. Offer psychosocial support and assist with resource navigation
3. **Protect your own health and quality of life**



# Tips to Stay Healthy and Resilient as a Family Care Partner

1. Take care of your own health by staying current with medical visits, managing stress, and getting enough rest
2. Build LGBTQ+-affirming resilience and support networks through caregiver groups, community organizations, or online spaces
3. Ask for help and take breaks to prevent burnout—respite care and shared responsibilities are essential
4. Plan ahead with inclusive advance care planning and affirming daily routines

“What happened was my wife was sick for a long time, she had severe dementia and, you know, I was the primary caregiver. . . And I did a deep introspective into myself and how I felt my entire life. . . [A]nd it just came to the conclusion that, hey, this [medically transitioning] is something you know, I got to look into. . .” - **Helen**



# Policy Implications for Supporting LGBTQ+ Older Adults and Their Care Partners



# I need more information:

- Alzheimer's Association
  - <https://www.alz.org/help-support/resources/alzheimers-and-dementia-resources-for-lgbtq-commun>
  - **24/7 Helpline: (800) 272-3900**
- SAGE
  - <https://www.sageusa.org/your-rights-resources/>
  - <https://lgbtagingcenter.org/library/item/recommendations-for-supporting-lgbt-people-living-with-dementia/>
- PFLAG
  - <https://pflag.org/find-resources/>
- LGBT Caregiver Center
  - <https://lgbtqcaregivers.org/>