

First dementia prevalence data in lesbian, gay and bisexual older adults

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The first dementia prevalence data from a large population of lesbian, gay and bisexual older adults was reported today at the 2018 Alzheimer's Association International Conference in Chicago.

Researchers from University of California, San Francisco and Kaiser Permanente Division of Research, Oakland, CA, examined the prevalence of dementia among 3,718 sexual minority adults age 60+ who participated in the Kaiser Permanente Research Program on Genes, Environment, and Health (RPGEH). Dementia diagnoses were collected from medical records.

Over 9 years of follow-up, the overall crude prevalence of dementia was 7.4 percent for sexual minority older adults in this study population. For comparison, Alzheimer's Association 2018 Alzheimer's Disease Facts and Figures reports U.S. prevalence of Alzheimer's disease dementia and other dementias for age 65+ at approximately 10 percent. According to the researchers, significant rates of depression, hypertension, stroke and cardiovascular disease in the study population may be contributing factors to the level of dementia.

"Current estimates suggest that more than 200,000 sexual minorities in the U.S. are living with dementia, but—before our study—almost nothing was known about the prevalence of dementia among people in this group who do not have HIV/AIDS-related dementia," said Jason Flatt, Ph.D., MPH, Assistant Professor at the Institute for Health & Aging, School of Nursing, University of California, San Francisco.



"Though our new findings provide important initial insights, future studies aimed at better understanding risk and risk factors for Alzheimer's and other dementias in older sexual minorities are greatly needed."

"With the growing prevalence of Alzheimer's disease dementia and the swelling population of LGBT older adults, we place a high priority on examining the intersections of Alzheimer's disease, sexual orientation, and gender identity and expression," said Sam Fazio, Ph.D., Alzheimer's Association Director of Quality Care and Psychosocial Research. "A more thorough and thoughtful understanding of this intersection will enable us to better meet the needs of LGBT elders living with dementia and their caregivers."

"Encouraging people to access healthcare services and make healthy lifestyle changes can have a positive impact on both LGBT and non-LGBT communities. Effective outreach to LGBT communities that is sensitive to racial, ethnic, and cultural differences could result in earlier diagnosis, which has been linked to better outcomes," Fazio added.

"Our findings highlight the need for culturally competent healthcare and practice for older sexual minorities at risk for, or currently living with, Alzheimer's disease or another dementia. There are also important implications for meeting the long-term care services and caregiving needs of this community. Given the concerns of social isolation and limited access to friend and family caregivers, there is a strong need to create a supportive healthcare environment and caregiving resources for sexual minority adults living with dementia," Flatt said.

The LGBT Community and Dementia

According to "Issue Brief: LGBT and Dementia," a co-publication of the Alzheimer's Association and SAGE (Services and Advocacy for GLBT



Elders), there are 2.7 million LGBT people over age 50, and that number will likely double over the next 15 years. While the LGBT community faces similar health concerns as the general public, the LGBT population who receive a dementia diagnosis face uniquely challenging circumstances.

- Even with recent advances in LGBT rights, LGBT older adults are often marginalized and face discrimination.
- They are twice as likely to age without a spouse or partner, twice as likely to live alone and three to four times less likely to have children—greatly limiting their opportunities for support.
- There's also a lack of transparency as forty percent of LGBT older people in their 60s and 70s say their healthcare providers don't know their sexual orientation (Out and Visible).

The Institute of Medicine identified the following pressing health issues for LGBT people: lower rates of accessing care (up to 30%); increased rates of depression; higher rates of obesity in the lesbian population; higher rates of alcohol and tobacco use; higher risk factors of cardiovascular disease for lesbians; and higher incidents of HIV/AIDS for gay and bisexual men (Brennan-Ing, Seidel, Larson, and Karpiak, 2014). Risk factors for heart disease—including diabetes, tobacco use, high blood pressure and high cholesterol—are also risk factors for Alzheimer's and stroke-related dementia.

Due to the healthcare-related challenges they and others have faced, an LGBT person may not reach out for services and support because they fear poor treatment due to their LGBT identity, because they fear the stigma of being diagnosed with dementia, or both. Several studies document that LGBT elders access essential services, including visiting nurses, food stamps, senior centers, and meal plans, much less frequently than the general aging population.



Among the 16 recommendations for organizations and service providers in their Issue Brief, the Alzheimer's Association and SAGE suggest:

- Expand your definition of family.
- Educate yourself and your staff on LGBT cultural competency.
- Find or create support groups specifically for LGBT people.
- Partner with local LGBT community groups and political organizations.
- Help LGBT people and their families with legal and financial planning.

Dementia Survival Time is Short, Regardless of Age at Onset

Previous studies of survival times in persons with dementia have varied considerably, reporting between three and 12 years in elderly populations with either general dementia or Alzheimer's disease dementia. To better understand survival time in individuals of a relatively young age and with different types of dementia, Hanneke Rhodius-Meester, MD, Ph.D., of VU University Medical Center in Amsterdam, and colleagues investigated survival time of 4,495 early-onset dementia patients in a memory clinic (aged 66 ±10 years; 45 percent female) enrolled in the Amsterdam Dementia Cohort between 2000-2014, with any type of dementia (n=2,625), mild cognitive impairment (n=739) or subjective cognitive decline (n=1,131).

The study found that the median survival time across all groups was six years and varied based on dementia type: 6.4 years in frontotemporal lobe degeneration; 6.2 years in Alzheimer's disease; 5.7 years in vascular dementia; 5.1 years in dementia with Lewy bodies; and 3.6 years for rarer causes of dementia. Survival time hardly differed when comparing younger patients (age 65 or younger) to those older than 65. However,



over time and compared to the general Dutch population, survival time in older patients showed a marginal increase, while survival time in younger patients remained unchanged.

"These findings suggest that, despite all efforts, and despite being younger and perhaps physically healthier' than older people, survival time in people with young-onset dementia has not improved since 2000," said Rhodius-Meester. "While these results still need to be replicated and confirmed, they do highlight the urgency of the need for better treatments and effective prevention strategies."

Prevalence of Dementia Increases with Age, Even in "Oldest Old"

Evaluating data from 17 centenarian studies conducted across 11 countries through the International Centenarian Consortium for Dementia (ICC-Dementia), Yvonne Leung, Ph.D., a postdoctoral fellow from the Centre for Healthy Brain Ageing (CHeBA), University of New South Wales in Sydney, and colleagues examined dementia prevalence, risk factors and cognitive and functional impairment in 4,121 centenarians and near-centenarians (aged 95-110).

When statistical predictive models were applied to examine impairment as a function of age, sex and education, researchers found that:

- Prevalence increased with age (from 95-99 to 105 years) in all societies for dementia (from 35.75 to 75.61 percent), cognitive impairment (from 45.24 to 78.72 percent) and functional impairment (from 67.46 to 91.55 percent).
- The risk of dementia, cognitive and functional impairment varied significantly between countries, suggesting cultural and lifestyle factors play a role in remaining physically and cognitively



healthy as we age.

- Participants with higher levels of education expressed lower prevalence of dementia and cognitive impairment than those with fewer years of education.
- Women in this age group had a higher risk of dementia and cognitive impairment compared to men.

"This is the first study to define the global prevalence of dementia in this advanced age group using a set of common diagnostic criteria," said Dr. Leung. "These data, and this type of research, may help identify protective factors to reduce the risk of dementia, and provide insights into longevity and brain health."

Provided by Alzheimer's Association

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