

**EMBARGOED FOR RELEASE UNTIL SUNDAY, JULY 22, 2018, 8 AM CT/9 AM ET**

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**FROM THE ALZHEIMER'S ASSOCIATION INTERNATIONAL CONFERENCE 2018**

## **FIRST DEMENTIA PREVALENCE DATA IN LESBIAN, GAY AND BISEXUAL OLDER ADULTS**

***Plus:*** – *Survival Time for People with Dementia is Six Years, Regardless of Age.*  
– *Prevalence of Dementia Increases with Age, Even in “Oldest Old.”*

**Chicago, July 22, 2018** – 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, PhD, 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, PhD, 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, PhD, of VU University Medical Center in Amsterdam, and colleagues investigated survival time of 4,495 early-onset dementia patients in a memory clinic (aged  $66 \pm 10$  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  $\geq 105$  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.”

### **About the Alzheimer’s Association International Conference (AAIC)**

The Alzheimer’s Association International Conference® 2018 (AAIC®) is the largest and most influential international forum to advance dementia science. AAIC convenes world-renowned basic and clinical researchers, early career investigators, clinicians and the care research community. AAIC 2018 features more than 100 sessions, 550 podium presentations and 2,000 posters on basic science, clinical trials, emerging research, risk/prevention, innovative practice techniques, imaging, technology and more. Visit [alz.org/aaic/](http://alz.org/aaic/) (public) or [alz.org/aaic/press](http://alz.org/aaic/press) (news media).

### **About the Alzheimer’s Association**

The Alzheimer’s Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer’s disease through the advancement of research; provide and enhance care and support for all affected; and reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer’s®. Visit [alz.org](http://alz.org) or call 800.272.3900.

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- Jason Flatt, PhD, MPH, et al. Dementia Prevalence Among Sexual Minority Older Adults. Funder: U.S. National Institute on Aging.
- Hanneke Rhodius-Meester, MD, et al. Median Survival in Memory Clinic Cohort Is Short, Even in Young Onset Dementia. Funders: Alzheimer Nederland; Stichting Dioraphte.
- Yvonne Leung, PhD, et al. 100 Years and Beyond: Investigating the Prevalence of Dementia in Centenarians and Near-Centenarians from 17 Population-Based Studies. Funder: The Dementia Momentum Initiative.

Proposal ID: P1-619

## **Dementia Prevalence Among Sexual Minority Older Adults**

**Background:** By 2030, there will be nearly five million sexual minority older adults aged 60 and older in the U.S. who identify as lesbian, gay, or bisexual. Current estimates suggest that over 200,000 sexual minorities in the U.S. are living with dementia, but almost nothing is known about the prevalence of dementia in sexual minorities who do not have HIV/AIDS. We examined the prevalence of dementia over 9.5 years among sexual minority older adults who participated in the Kaiser Permanente Research Program on Genes, Environment, and Health (RPGEH).

**Methods:** There were 3718 sexual minorities who were aged 60+ in RPGEH at baseline (January 1, 2007). Dementia diagnoses were collected from medical records from January 1, 2007 to July 31, 2016. We computed the crude prevalence of all cause dementia and self-reported chronic conditions at baseline.

**Results:** The mean age at baseline was 69.7 years (SD=7.8), with 43.6% female, 81.2% White, 10.2% Asian, 4.4% Latino, 3.5% Black, and 14.1% with an education of high school or less. For sexual identity, 38.0% identified as bisexual, 36.8% gay, and 25.2% lesbian. Over 9.5 years of follow-up, the overall crude prevalence of dementia was 7.4% for sexual minority older adults. For self-reported chronic disease conditions at baseline, 40.2% reported a previous diagnosis of hypertension, 20.8% depression, 16.1% diabetes, 12.7% cardiovascular disease, and 6.0% stroke. In addition, 7.5% reported being a current smoker and 45.3% a former smoker.

**Conclusions:** These preliminary results are the first to describe the prevalence of dementia in sexual minority older adults. Differences in age, race/ethnicity, sex, sexual identity, and educational attainment will be explored. Depression, hypertension, stroke and cardiovascular disease may be contributing factors. Future studies aimed at better understanding risk and risk factors for dementia in sexual minority older adults are also needed.

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Proposal ID: P1-357

## **Median Survival in Memory Clinic Cohort Is Short, Even in Young Onset Dementia.**

**Background:** Dementia is per definition progressive, and eventually leads to death. However, dementia patients show considerable variability in survival time, with often an average 7 à 10 years mentioned. Most earlier studies have been conducted in population based cohorts of elderly, mostly with dementia due to Alzheimer's disease (AD). There is less information on survival in younger dementia patients, and in patients with non-AD types of dementia. We investigated survival after a dementia diagnosis in a memory clinic based cohort with a relatively young age and representation of different types of dementia.

**Methods:** We included 4495 subjects who enrolled between 2000-2014 in the Amsterdam Dementia Cohort (mean age  $66 \pm 10$ , female 45%, MMSE  $24 \pm 5$ ), with subjective cognitive decline (SCD), mild cognitive impairment (MCI) or any type of dementia. Information on mortality was obtained from the Dutch Municipal Register (accessed: 14th September 2017). We determined and compared across SCD, MCI and types of dementia, median survival times using Kaplan-Meier analyses. Next, we compared risk of dying for dementia types and studied whether baseline factors (APOE, MMSE, sex and age) modified survival time, using Cox proportional hazard models. Finally, we studied whether median survival in our cohort has changed over the past decade.

**Results:** Median (95% confidence interval) survival time in any type of dementia was short with 6.0(5.8-6.2) years. Median survival time depends on the type of dementia, ranging from 6.4(5.8-7.0) years in frontotemporal lobar degeneration, 6.2(6.0-6.5) years in AD, 5.7(4.1-7.3) years in vascular dementia, 5.1(4.5-5.7) years in dementia with Lewy bodies to 3.6(3.2-4.0) for more rare causes of dementia (including e.g. CJD). When comparing younger ( $\leq 65$  years) and older ( $> 65$  years) patients, median survival time hardly differed. Over the years, survival time in younger patients remained unchanged ( $p .718$ ), whereas older patients showed a marginal increase in survival time ( $p .000$ ).

**Conclusions:** Median survival time in patients with dementia is short with a median of 6 years. Despite all efforts for better care and cure, survival in young onset patients has not improved since 2000, emphasizing the need for disease targeted treatment.

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Proposal ID: O1-05-05

## **100 Years and Beyond: Investigating the Prevalence of Dementia in Centenarians and Near-Centenarians from 17 Population-Based Studies**

**Background:** Longevity has risen rapidly over the past few decades, with the world-wide population of centenarians projected to reach over 2 million by mid-century. The physical and cognitive health of centenarians are therefore of much interest. We present findings from a collaboration of 17 centenarian studies (Table 1) through the International Centenarian Consortium for Dementia (ICC-Dementia), examining the cognitive profile, prevalence of dementia and its risk factors.

**Methods:** Data harmonisation was conducted by applying uniform diagnostic criteria of dementia, and cognitive and functional impairment to the collected data using standardised protocols. Cognitive and functional status was based on common measures across studies, Mini-mental State Examination (MMSE) and Activities of Daily Activities (ADLs) respectively. Eight criteria sets were used to examine dementia prevalence. Variability of data and missingness were examined, with missing values being imputed. Individual participant level item-wise data were used for the analyses, and sensitivity analyses were performed.

**Results:** Data from 4121 centenarians and near-centenarians (95-110 years old) were analysed, using four cut points for MMSE, and two for ADL. Based on the most conservative criteria, prevalence increased with age (from 95-99 to  $\geq 105$  years) for dementia (from 35.96% to 75.61%), cognitive impairment (from 45.24% to 78.72%), and functional impairment (from 67.64% to 91.55%) (see Fig. 1 to 3). Logistic regressions showed significantly increased odds of having dementia, and cognitive and functional impairment with age, institutionalization and lower education level with conservative and liberal criteria for impairment classification. Interestingly, sex did not differ significantly when more liberal criteria were used. Detailed cognitive profiles and the variability of data between participating studies will be presented.

**Conclusions:** Harmonising data from participants with diverse ethnoracial and socio-economical background is challenging, yet offers invaluable opportunities to examine the contributing factors to longevity, around the world. The current findings have implications for policy development for successful ageing and service development at the extreme end of life.

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