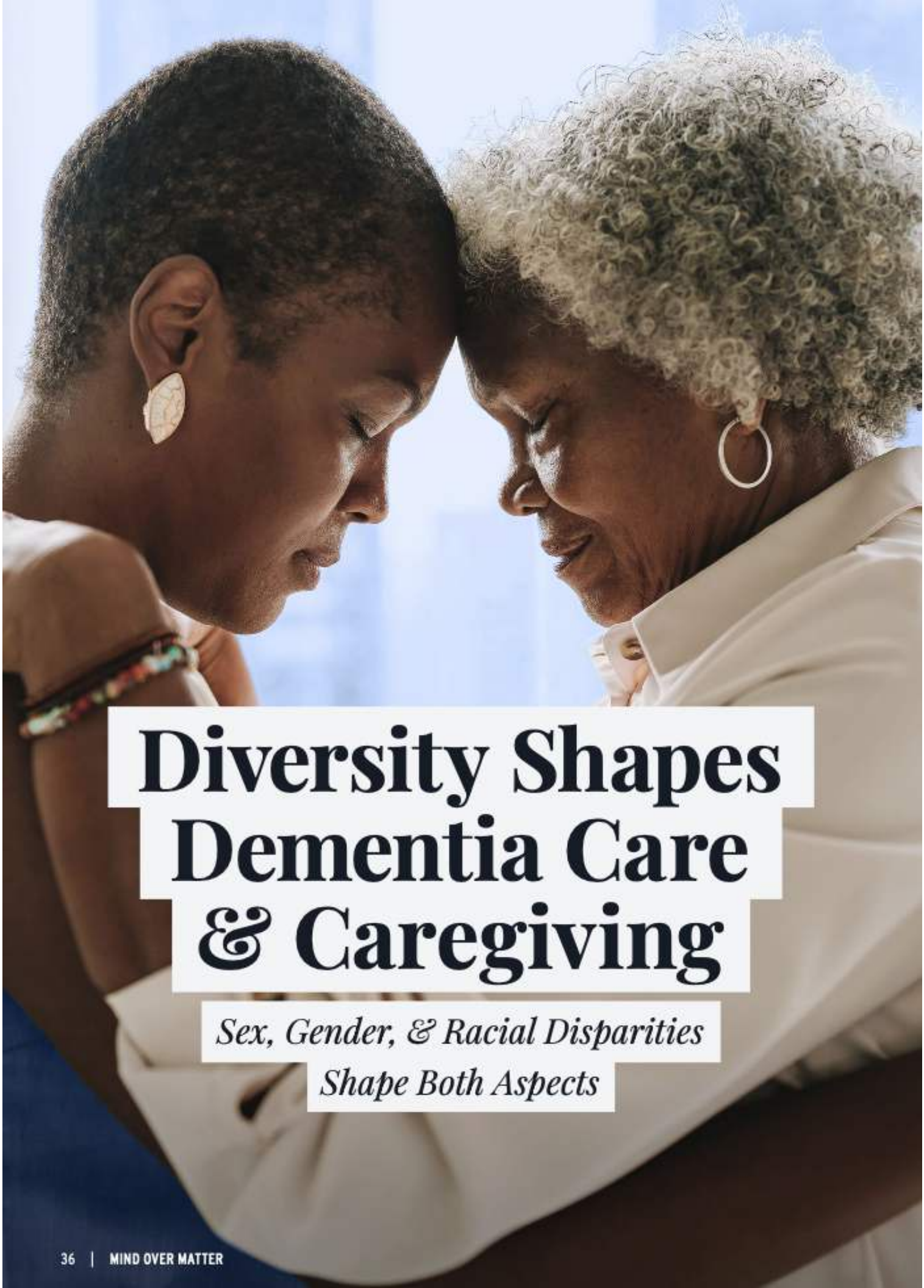


Diversity Shapes Dementia Care & Caregiving

Sex, Gender, & Racial Disparities Shape Both Aspects

In March 2026, the Sex and Gender Hub of the Canadian Consortium on Neurodegeneration in Aging (CCNA) hosted a Sex, Gender, and Dementia Consensus Meeting in Toronto. The session on how sex, gender, and racial diversity shape dementia care and caregiving was particularly insightful.

CCNA is the premier collaboration for Alzheimer's and dementia research in Canada and a global leader of investigations into all aspects of neurodegenerative diseases, from prevention to treatment to improving the quality of life of those living with these diseases.

The CCNA Sex and Gender Hub brings together clinicians and scientists in the aging and dementia research community who are interested in learning more about incorporating sex and gender considerations into their work. Women's Brain Health Initiative is a key funding partner of CCNA's Sex and Gender Hub.

In the session, two panellists shared perspectives on how sex, gender, and racial disparities affect care for people living with dementia and their care partners.

"We were pleased to initiate and advance this important discussion on diversity for the biomedical research community. Considerations of sex, gender, and racial disparities must be incorporated into neurodegeneration research so that we can address them and improve outcomes and quality of life for people living with dementia and their care partners," said Dr. Gillian Einstein, lead of the CCNA Sex and Gender Hub, the Wilfred and Joyce Posluns Chair in Women's Brain Health and Aging and professor of psychology at the University of Toronto, and a member of Women's Brain Health Initiative's expert panel.

SEX DIFFERENCES IN HEALTHCARE UTILIZATION

Dr. Geneviève Arsenault-Lapierre, a researcher at the Centre for Research and Expertise in Social Gerontology (CREGÉS) and an adjunct professor at McGill University in Montreal, shared compelling insights into sex and gender disparities experienced by people living with dementia and their care partners.

She and her colleagues found striking differences in how women and men with dementia access the healthcare system. For their study, published in *Journal of Aging and Health* in March 2024, they examined data in Quebec's health database from all people aged 65 and older who received a new dementia diagnosis between 2000 and 2017. In total, the analysis included data from almost 224,000 people with dementia, and women accounted for 62% of the total.

Dr. Arsenault-Lapierre and colleagues examined 23 indicators of healthcare use across five areas: primary care, prescriptions, hospitalizations, long-term care, and mortality.

Their results showed that compared to men, women with dementia saw primary care physicians more often and had fewer emergency department visits, hospitalizations, and nursing home admissions. Women also had a lower mortality rate than men.

"In Quebec and across Canada, it's advantageous for people with dementia to be cared for as early as possible in their disease trajectory, by primary care physicians, and not wait so long that they need acute care in hospital settings," Dr. Arsenault-Lapierre told Mind Over Matter®.

As further evidence for this point, she presented the results of another study by colleagues at McGill University that looked at the effect of continuity of primary care on hospitalizations.

They found that community-dwelling individuals over 65 with dementia who had all primary care visits with the same primary care physician over the preceding year had a 13% to 19% lower risk of potentially avoidable hospitalizations compared to those who saw two or more primary care physicians. The paper was published in *Journal of the American Geriatrics Society* in May 2021.

In Dr. Arsenault-Lapierre's study, she found that a higher percentage of women than men used dementia medications, antidepressants, and sleep aids. Interestingly, there was no difference in antipsychotic prescriptions between women and men.

"The higher use of many types of medications by women may indicate potentially inappropriate prescribing, but we can't know for sure because we did not have access to health charts to review physicians' notes on why the medications were prescribed," said Dr. Arsenault-Lapierre.

"The sex differences may also reflect that women tend to access care earlier in the dementia journey, at the primary care level, and therefore, have more access to medications compared to men over time."

SEX DIFFERENCES IN PERCEIVED HELPFULNESS OF DEMENTIA CARE

A separate international study led by Dr. Arsenault-Lapierre and colleagues found that sex and gender did not affect whether people with dementia or their care partners felt helped by the healthcare system. The study was published in *Dementia* (London) in August 2025.

"We prefer to use the term care partners rather than caregivers. 'Care partners' includes family members and neighbours, whereas 'caregivers' includes professional, paid workers in addition to informal, unpaid carers,' Dr. Arsenault-Lapierre explained.

The investigators analyzed responses from 56 people with dementia and 229 care partners living in Canada, the Netherlands, the United Kingdom, and Poland. Participants responded to two main questions: did the diagnostic process feel helpful, and did the support received after diagnosis feel helpful?

For respondents living with dementia, more women than men found the diagnostic process and post-diagnosis support helpful. However, given that there were only 39 women and 17 men with dementia who provided answers, the differences weren't large enough to draw a conclusion about the impact of sex.

"To see big differences between women and men on this point, we would need to conduct a much larger study and take other factors, such as dementia type, comorbidities, and healthcare literacy levels into account," Dr. Arsenault-Lapierre explained.

Sex and gender did not appear to affect whether care partners found dementia diagnosis and post-diagnostic services helpful. What boosted helpfulness perceptions, though, was awareness of and satisfaction with services available after diagnosis.

DEMENTIA STATISTICS AMONG BLACK PEOPLE

According to the Alzheimer Society of Canada:

There is a lack of dementia research that focuses on the experiences of racialized communities.

The prevalence of dementia among Black families of African descent in Canada is projected to rise by 507% between 2020 and 2050, according to *The Many Faces of Dementia in Canada: The Landmark Study*, published by the Alzheimer Society of Canada in 2024. This is a much higher rate than the projection of 187% for the overall Canadian population.

Research from the U.S. and the U.K. shows that **dementia disproportionately affects Black people compared with white people and those from other racial groups.**

Black people experience higher dementia incidence and prevalence, earlier onset, later diagnosis, more negative experiences with the healthcare systems providing dementia care, less knowledge of dementia signs and symptoms, and earlier development of white matter hyperintensities, a sign of earlier brain aging.

RACIAL INEQUITIES

Providing care to people with dementia is profoundly demanding, both physically and emotionally. People caring for people with dementia from racial minority groups face additional obstacles.

Karen Myers Barnett is a first-generation Black Canadian who was born to parents from St. Lucia. She is also a sandwich generation care partner. Together with her father, she cares for her mother, Celestine, at home. Celestine was diagnosed with frontotemporal dementia (FTD) in 2008. Karen is also raising four children: two in graduate school, one in second year at university, and the youngest in the last year of high school.

Karen joined CCNA's Engagement of People with Lived Experience Advisory Group (EPLED) in June 2020. The group enables people living with dementia and care partners to be actively and meaningfully involved in dementia research, governance, goal setting, conducting studies, and knowledge mobilization. Said Karen:

> **"THE SINGLE MOST PROFOUND FORCE SHAPING MY LIFE HAS BEEN MY RACE. I JOINED EPLED BECAUSE THERE IS DEMENTIA AND DEMENTIA LOSS ON BOTH SIDES OF MY FAMILY, AND I'M PROUD TO CONTRIBUTE DIFFERENT PERSPECTIVES BASED ON MY EXPERIENCES.**

At the Sex and Gender consensus meeting, she shared what it feels like to encounter racism in dementia care. "Being a woman already changes your experience with the healthcare system.

"But what happens when you are a Black woman who is a caregiver? When clinical trials do not reflect your

community experience? When you are expected to be strong – even when you are exhausted? These headwinds can feel like a hurricane or a tornado."

She referred to sprinter Donovan Bailey's memoir *Undisputed*, in which he wrote about the difference between running with a tailwind or headwind: "The time on the clock doesn't tell you the whole story; the conditions that day at the track matter."

Karen told Mind Over Matter that she felt the need to address racial headwinds from the get-go by wearing business attire to her mother's medical appointments. "I wanted to ensure clinicians know I'm intelligent and that my role is to ensure my mother gets the care she deserves," she said.

She also told us that she couldn't find a culturally appropriate program for her mother when she was diagnosed with early-onset FTD. The programming in the city where they lived in southwestern Ontario did not reflect the community's racial makeup. "That ethnic spice, as I like to call it, helps people feel safe and welcome. It was not reflected on the inside of the building, giving the message that participants' cultures don't matter."

When it comes to incorporating racial diversity into dementia research and policies aimed at improving outcomes for people with dementia, Karen said, as a member of the panel, that efforts made must provide more than lip service.

> **SEX AND GENDER RESEARCH THAT DOES NOT ACCOUNT FOR ETHNO-RACIAL DIFFERENCES IN DEMENTIA EXPERIENCES IS LIKE TIMING RUNNERS WITHOUT ACKNOWLEDGING CONDITIONS. THE RACE ISN'T FAIR.**

"If Black Canadians experience worse dementia outcomes, then our representation in clinical trials, datasets, advisory boards, and leadership tables should at least reflect the census," Karen added.

"We need race-based dementia data, recruitment strategies that reflect communities, funding streams that prioritize health equity, and sex and gender analysis that includes structural racism and other intersecting identities as social determinants of health. If the wind matters in sport, it must matter in science. Institutions are the ones sustaining the winds," she said.

Karen also shared some examples of positive initiatives aimed at raising awareness about **how dementia affects the Black community,** as follows:

- Research led by the Alzheimer Society of Ontario and the School of Social Work at McGill University explored the intersection of race and dementia experienced in Black communities in the Greater Toronto and Hamilton areas during the COVID-19 pandemic. The study, published in *Dementia* (London) in November 2025, found that **pre-existing systemic inequities intensified the already heavy burden shouldered by Black care partners**.

- The short film ***Sugar Dumplin'***, produced in July 2025, **tells the story of a Jamaican Canadian woman who helped her father navigate a dementia diagnosis and move into a care home.** Traditional dishes from his past helped trigger memories and emotional connection. Visit **www.sugardumplinfilm.com** for more information.

- **"Dementia in the Afro-Caribbean Community"** is a three-part series of TV segments co-produced by Caribbean Vibrations TV and the Alzheimer Society of Ontario. **The segments aim to increase awareness, reduce stigma, and encourage open discussions about brain health in the Caribbean diaspora**. Find these episodes at **www.youtube.com/@Caribvibetv** and search for "dementia."

FUTURE WORK

"Considerations of sex, gender, racial, and other disparities, such as socioeconomics, deserve to be at the forefront of biomedical research and will make for better science in dementia research," Dr. Einstein said.

"The speakers in this panel raised critical themes that should shape how we view dementia research going forward. The Sex and Gender Hub is proud to have included this important conversation in our Sex and Gender Consensus Meeting, and it will be an important component of any manuscript that comes out of the meeting."

Women's Brain Health Initiative supports and advocates for the incorporation of sex, gender, and diversity into brain health and aging research. Following best practices means that if the research shows a difference between men and women, then the next step is to ask why. The "why" is the key to discovery. Learn more at wbhi.org/research.