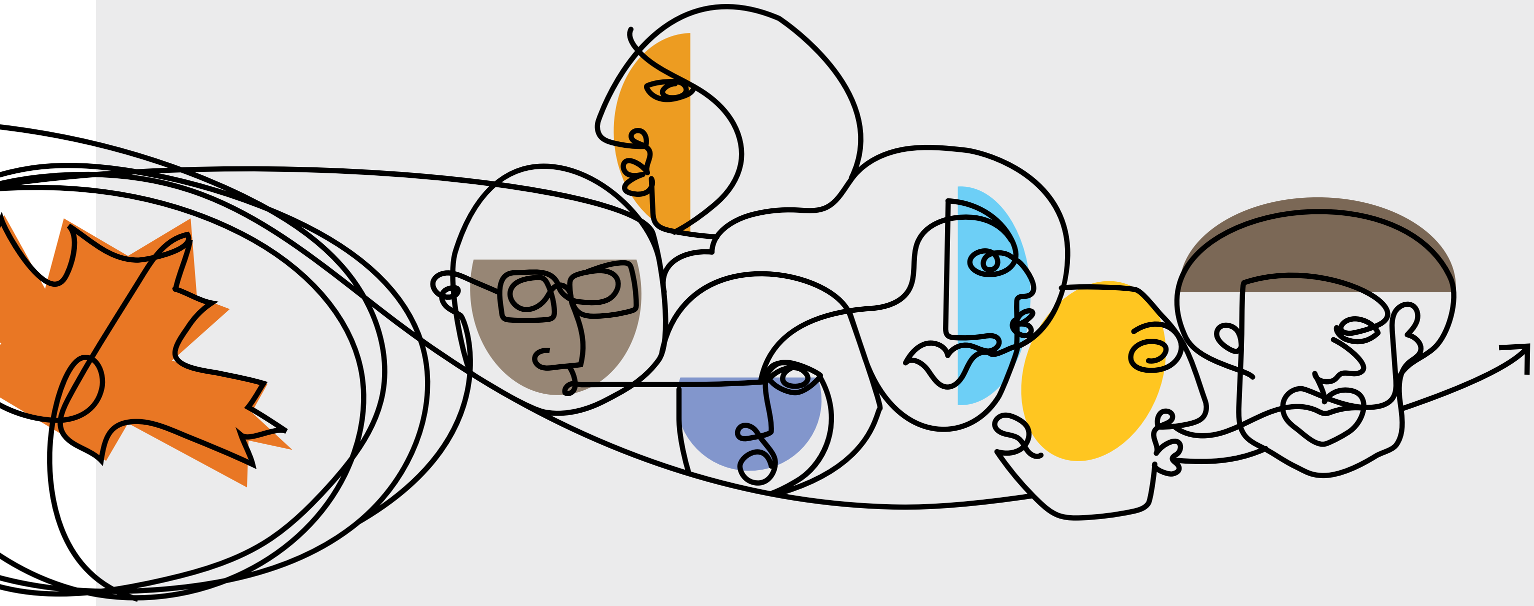
CHAPTER 3

ETHNIC AND RACIAL DIVERSITY OF PEOPLE AFFECTED BY DEMENTIA

Variation exists in dementia risk and dementia care across different ethnocultural and ethno-racial communities in Canada.



> Canada is considered one of the most multicultural countries in the world. In the 2016 Canadian census, over 250 different ethnic origins were recorded as part of the Canadian demographic landscape. This diversity is now widely considered a fundamental Canadian value and is largely the result of several waves of immigration over the past 50 years.

An aging multicultural population

Prior to 1970, newcomers to Canada arrived mainly from European countries or the United States. However, because of significant changes to Canadian immigration policies, the major places from which people migrated changed in the 1970s. These changing immigration patterns, shifting away from European countries toward countries from Asia, Africa, and the Middle East, have resulted in a Canadian population that is more ethnically, racially, linguistically and culturally diverse.

With an aging population in Canada, we are now witnessing a rapidly growing number of older adults from a wide range of ethnic and racial backgrounds. With age as the strongest risk factor for dementia, this diversity in older Canadians is also reflected within the population of people living with dementia in Canada.

Over the next 30 years, we can expect even further changes to the ethnic and racial makeup of people living with dementia in Canada. Consequently, care services for people living with dementia need to be designed to meet the diverse needs of these populations. Canada's national dementia strategy emphasizes the need for increased understanding and expanded data on health-related issues in ethnic and cultural minority communities in order to assist efforts in dementia risk reduction.

This chapter will highlight some of the experiences of individuals living with dementia across different ethnic and racial groups in Canada. This is a complex, deep area of work that deserves a dedicated, fulsome review. Our report will only cover the initial framework relevant to the estimations and projections from the Landmark Study model with a deeper review planned for the future.

Key definitions for this chapter

Prior to discussing the impact of dementia across different ethnic and racialized communities, it is important to first consider some helpful definitions for this chapter.

Box 4. Key definitions: ethnic origin, race, culture, and racialization

Ethnic origin: Ethnic origin refers to the ethnic or cultural origins of a person's ancestors. An ancestor is usually more distant than a grandparent (Statistics Canada, 2017). This includes shared language, religion or traditions. Ethnic origin does not have to have a genetic component but can, especially if this includes common ancestry.

Race: Race is a social construct. This means that society forms ideas of race based on geographic, historical, political, economic, social and cultural factors, as well as physical traits, even though none of these can legitimately be used to classify groups of people (Bhopal, 2004).

Culture: Culture refers to the shared knowledge, values and beliefs of a group of people that is built and shared over generations (Samovar & Porter, 2003).

Racialization: This is the process in which groups are designated by society as being part of a particular "race" and on that basis they are treated differently. Some people and institutions use the terms "racialized person" or "racialized group" rather than "racial minority," "visible minority" or "person of colour" in order to explicitly recognize that race is a social construct (Ontario Human Rights Commission, 2023).

While some of these terms are at times used interchangeably, they can have distinctive meanings and consequences when speaking to health status and access to health services for different populations in a society. The concepts of ethnicity, race and culture in public health and health care are central to addressing health inequities, yet they are often overlooked and not measured well by health systems and researchers.

For the Landmark Study projections, we used ethnic origin groupings based on 2016 Canadian census data. We recognize that these groups are extremely broad and do not fully capture the complexity of ethnic origin and dementia risk in Canada. However, the analyses can provide some initial broad insights into what dementia differences we can expect across ethnicity and race in Canada over the next 30 years.

Significant gaps in dementia risk exist across ethnic and racial groups

There have been many international studies on how frequently dementia occurs in racialized populations. Studies from the United States and the United Kingdom have consistently reported on racial and ethnic differences in dementia within these populations. However, in Canada, data on these differences is currently lacking.

A 2016 American study by Mayeda and colleagues looked at new dementia cases that developed in a large, diverse cohort of older adults in northern California. They found that rates of dementia onset varied widely (over 60%) between six racial and ethnic groups. Of the six groups, they found the highest rates of dementia were among African Americans and Native Americans. The lowest rates were among Asian American populations, with intermediate rates for Latin American, White, and Pacific Islander populations.

In a similar UK-based study, researchers found significant differences in dementia risk across three groups (Pham et al., 2018). This study looked at primary care electronic health records over an eight-year period and examined diagnosis rates by Black, White and Asian groups. They found similar findings, with risk being lowest among Asian people and highest among Black people in their study population.

Relying on internationally published reports like the two outlined above, a recent systematic review pulled together further evidence examining differences based on ethnicity and race in the risk of developing dementia (Shiekh et al., 2020). After compiling data from 19 studies taken from various locations around the world, the research team found that subjects in the Black group had the highest incidence rates (new cases) of dementia, those in the Asian group had the lowest incidence rates, and subjects in the Latin group was found to have similar incidence rates as the White group. While this study confirmed that there are clearly differences in risk of developing dementia, the authors suggested that a better understanding of the causes for these differences is urgently needed.

In Canada, we need to both develop our understanding of the extent of these differences and aim to identify the factors that drive these differences. While there have not been a lot of Canadian studies on this topic, there is emerging evidence that strongly suggests that Black populations in Canada have a higher occurrence of dementia compared to other populations, while at the same time experiencing gaps in culturally responsive care and adequate supports (Iroanyah et al., 2021).

Why do differences in dementia rates exist across ethnic and racial groups?

The reasons for these differences are complex. We highlight some of the key drivers, including differences in dementia risk factors, social determinants of health, and the stress resulting from social conditions experienced by distinct groups within the Canadian population. However, this is a critical area of research that needs to be further explored for a diverse aging population.

Potential disparities in rates of dementia risk factors

One explanation for variations in dementia risk may come from differences in modifiable risk factors across race and ethnicity. Modifiable risk factors for dementia are factors related to dementia risk that can be changed (e.g., hypertension, obesity, smoking, depression, physical inactivity, diabetes). One study by Lee and colleagues (2022) took a closer look at racial and ethnic differences across 12 well-established modifiable risk factors for dementia. They found that risk factors such as diabetes, physical inactivity, obesity, and exposure to air pollution were higher in Latin American and Black individuals. These researchers' analyses concluded that the proportion of potentially preventable dementia cases was highest among both Black and Latin American groups.

Unfortunately, many people may not be able to address these modifiable factors due to their personal situation and resources. These risk factors are only truly modifiable if the proper supports are provided by our communities, public health agencies and other governmental organizations.

Social determinants of health negatively affecting brain health

Racial and ethnic differences in dementia may also be linked to how different populations experience social determinants of health (refer to Box 3).

Experiencing racism is a social determinant of health associated with poorer physical and mental health, as well as faster cognitive decline with aging. As a form of psychosocial stress, the experience of racism over time has been found to cause structural changes in brain physiology and accelerate brain aging and memory declines. For instance, a study from Boston University found that African American women who were exposed to or experienced racism had increased risk for lower cognitive function (Coogan et al., 2020).

The Forrester Framework of Minority Stress, created by African American scholar Dr. Sarah Forrester and colleagues in 2019 (discussed in Chapter 2, page 29, or refer to Forrester et al., 2019) also helps explain how people in Canada from different racial and ethnic groups might be at higher risk for developing dementia. The theory is that increased risk for dementia occurs due to social conditions that chronically activate a physiological stress response. Social factors such as racism, lower levels of education, and lower socio-economic status directly impact stress levels and contribute to physiological dysfunction—which can negatively impact the brain and heighten the risk of dementia.

Unlike acute health issues (e.g., infection, physical trauma), the factors that produce most dementias are multiple and complex. To effectively address dementia risk across all people in Canada, we will need to think about dementia not just as an individual biologically-driven condition but as a social one, by also thinking more closely about the underlying causes and core determinants of brain health.

Differences in biomarkers connected to dementia risk

In addition to differences in people's lives and environments, there are also differences that have been found in the biomarkers linked to dementia and dementia risk across ethnic and racial groups. Biomarkers (short for "biological markers") are any aspects of biology that can be measured accurately and help indicate the medical state of the body.

One of the key biomarkers for dementia risk is the Apolipoprotein epsilon 4 gene (APOE- ε4). APOE- ε4 has been linked with the risk of late onset Alzheimer's dementia (Farrer et al., 1997). There are three alleles (types) of the APOE gene (ε2, ε3, or ε4) and each individual has two of these genes (one from each parent). This leads to six possible combinations of the gene (ε2/ε2, ε2/ε3, ε2/ε4, ε3/ε3, ε3/ε4 and ε4/ε4). People carrying the ε4 type have a higher risk of developing Alzheimer's dementia, whereas people carrying the ε2 type have a lower risk. Black populations have a higher rate of ε4 compared to White populations, who in turn have higher rates of ε4 compared to Asian and Latin American populations (Alzheimer's Association, 2021).

Most of what we understand about APOE and developing dementia has been mainly studied in European ancestry populations (Weiss et al., 2021). Studies that have looked at Alzheimer's dementia risk related to APOE in Black populations have varying results. More research is needed to better understand how APOE status influences Alzheimer's risk across different ethnic and racial groups.

Research has also found differences across ethnic and racial groups across other blood biomarkers, neuropathological changes in Alzheimer's disease (changes in the brain that include amyloid plaques and neurofibrillary tangles), brain volume changes, and functional connectivity (Roselli et al., 2022). As more research is conducted in this area, it will help develop better disease modifying drugs and therapies for all people living with dementia.

People from racialized communities may receive poorer quality of dementia care

Despite how diverse older adults in Canada are, we still understand little about dementia care experiences across different ethnic and racialized communities. Sang A. Lee's and colleagues (2022) have shown that there are ethnic and racial disparities in dementia diagnosis and screening. There are many potential reasons. While language can be a barrier, as may be lack of awareness and education on dementia in communities, a similar lack of education among health-care professionals as well as dementia diagnostic assessments that do not account for cultural and language differences can all lead to diagnostic errors.

Racialized health-care users can also experience racism when receiving health-care resulting in experiences that may include professional misconduct, negligent communication, parallel structure, discrimination, and unequal access to services (Mahabir et al., 2021).

Different cultural views and stigma about dementia can also prevent individuals and families from seeking a diagnosis, as well as make it difficult to accept a diagnosis or ask for help with dementia care. Dr. Naaheed Mukadam and colleagues (2010) conducted a systematic review to better understand why people from minority ethnic groups present to specialist care once their dementia has progressed more toward the moderate or severe stages of dementia. They found that barriers for accessing specialist help for dementia included:

- "not conceptualising dementia as an illness;
- believing dementia was a normal consequence of aging;
- thinking dementia had spiritual, psychological, physical health or social causes;
- feeling that caring for the person with dementia was a personal or family responsibility;
- experiences of shame and stigma within the community;
- believing there was nothing that could be done to help; and
- negative experiences of healthcare services" (Mukadam et al., 2010).

These are just some of the barriers that members of racialized communities may face in accessing dementia care. A focus on higher risk and equitable care is outlined as a focus of activities in Canada's national dementia strategy (Public Health Agency of Canada, 2019). This has led to growing federal efforts on higher-risk population groups and equitable care, including support for a range of projects related to dementia guidance across underserved ethnic and cultural communities.

Not enough research to understand differences in the experiences of care partners across ethnic and racial groups

Not much research has been done about the experiences and outcomes of care partners across ethnic and racial groups. The limited research has found differences between Black, White, Latin American and Asian care partners in levels of stressors, resources, psychological outcomes, and caregiver self-care (Pinquart & Sörensen, 2005; Waligora et al., 2019). Expanding work in this area would help inform and expand the range of services that are provided for these essential providers of care.

Diversity is missing in dementia research overall

There is generally limited research and data focused on the dementia experiences and care needs of racialized communities. This lack of knowledge has significant implications for the development of policies, programs, supports and services that can meet those needs.

It is essential that the field of Canadian research expands to better understand the unique experiences of all people living with dementia in this country.

Federal research granting agencies have recently sought ways to address systemic racism in their funding models and to increase representation of racialized applicants who have been found to be excluded in previous funding cycles. There is evidence to show that research in ethnic and racialized communities conducted by researchers from those same communities ensures broader representations of thought and results in better uptake among information because of co-design and early engagement.

There has also been a lack of inclusion of participants from racialized groups in research studies on dementia. Barriers to participation include a lack of trust, geographical barriers, and research recruitment protocols that don’t consider the needs, experiences and best practices for recruitment of racial and ethnic minority populations (Shaw et al., 2022). Research has shown that community-led research and community representation of research leads can increase engagement, quality of research, data collection and implementation.

Although there has been some research in Canada on dementia experiences of some minority ethnic groups, there has been a relative absence of research around prevalence and incidence rates for these groups. Furthermore, the data and research that is available is limited in scope and sample sizes. Canada has yet to establish systematic infrastructure for collecting race-based data on groups living with dementia, though several jurisdictions have taken it upon themselves to fill in those gaps (e.g., the Anti-Racism Data Act by the BC provincial government, the Fair Care Project by the Nova Scotia Department of Health and Wellness, and more recently, Shared Health in Manitoba).

The growing need for intersectionality in dementia care and research

Person-centred approaches to dementia care and research cannot be considered in isolation from broader social systems and environments in which people live with dementia. An intersectional approach to dementia and dementia care can help us to consider how multiple social identities (e.g., race, gender, class) overlap to shape health outcomes, including dementia.

To fully support people living with dementia and their care partners, it is important to consider the totality of their experiences. By taking a holistic approach, policies, programs, supports and services may account for the many influential aspects of dementia experience (Dilworth-Anderson et al., 2020). These considerations are vital to ensure that people's unique experiences are captured and reflected when developing truly inclusive dementia care.

Furthermore, intersectionality can tell us how intersecting identities shape and influence access to care and health service utilization, as well as the extent to which these services are equipped to respond to the complex care needs of individuals. For example, this type of approach will give us specific insight into how dementia impacts Black women of lower socio-economic status versus Black men, White women and White men of lower socio-economic status, and the extent to which services are equipped to address the needs of each group.

The population of people living with dementia in Canada is becoming more diverse. Now is the time to enhance our understanding of diversity to ensure that future dementia care will be both culturally safe and appropriate in meeting the needs of all individuals living with dementia in Canada.

Intersectionality

Intersectionality describes how multiple and simultaneous characteristics (e.g. ethnicity, race, gender and class) "intersect" to form an individual's identity in broader systems of power that can result in forms of oppression or privilege (Crenshaw, 1989).

When these intersecting identities engage with health care, education, housing, and other systems, they have been shown to exacerbate inequalities. The results can lead to increased health differences and increased dementia risk.

The Landmark Study is based on findings from a simulation model that combined data from the 2016 Statistics Canada census and findings from the literature to estimate the impact of dementia in Canada over the next 30 years.

The results portrayed in this section use estimates on self-reported broad ethnic origin categories used by Statistics Canada. Ethnic origin refers to the ethnic or cultural origins of the person's ancestors. The Landmark Study model is simplified to assume only one ethnic origin of individuals, when in reality many Canadians often report more than one ethnic origin of their ancestors.

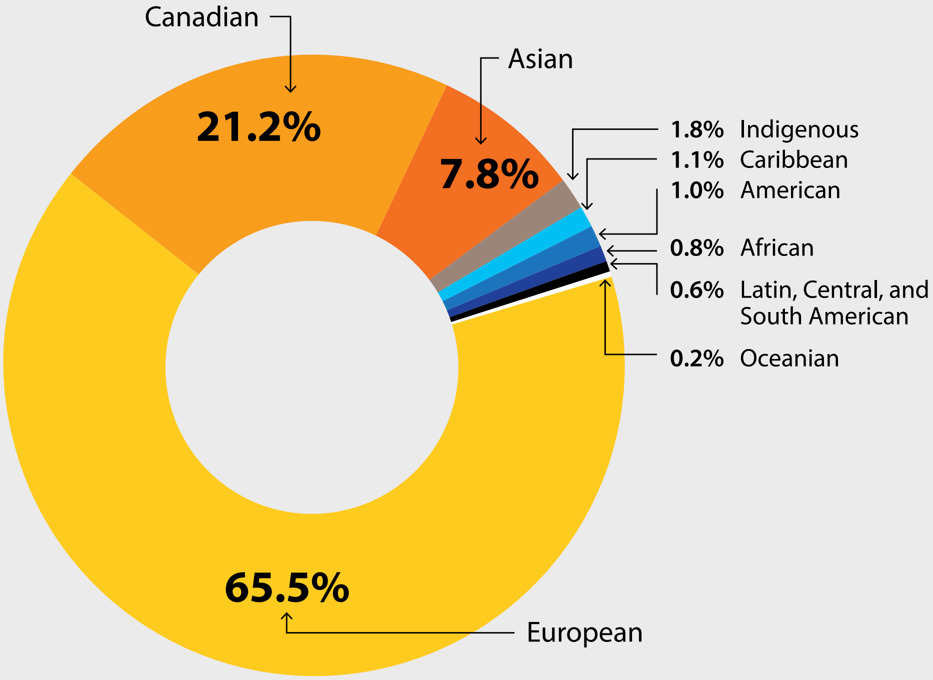
It is also important to clarify that "Canadian" is one category that was commonly self-reported in the 2016 Canadian census and reflects an individual's thoughts on their ancestral background and ethnic origin.

By 2050, one in every four persons who develops dementia will be of Asian origin

Using the data from the Landmark Study model, we were able to begin to understand the self-reported ethnic origins of people living with dementia in Canada.

The estimated proportions of ethnic origins for people living with dementia in Canada in 2020 are illustrated in Figure 7. Almost two thirds of the individuals living with dementia are of European ancestry, with the remaining one third made up of individuals reporting Canadian; Asian; Indigenous; African; Caribbean; Latin, Central, and South American; and American origins. By 2050, this population profile is projected to drastically change.

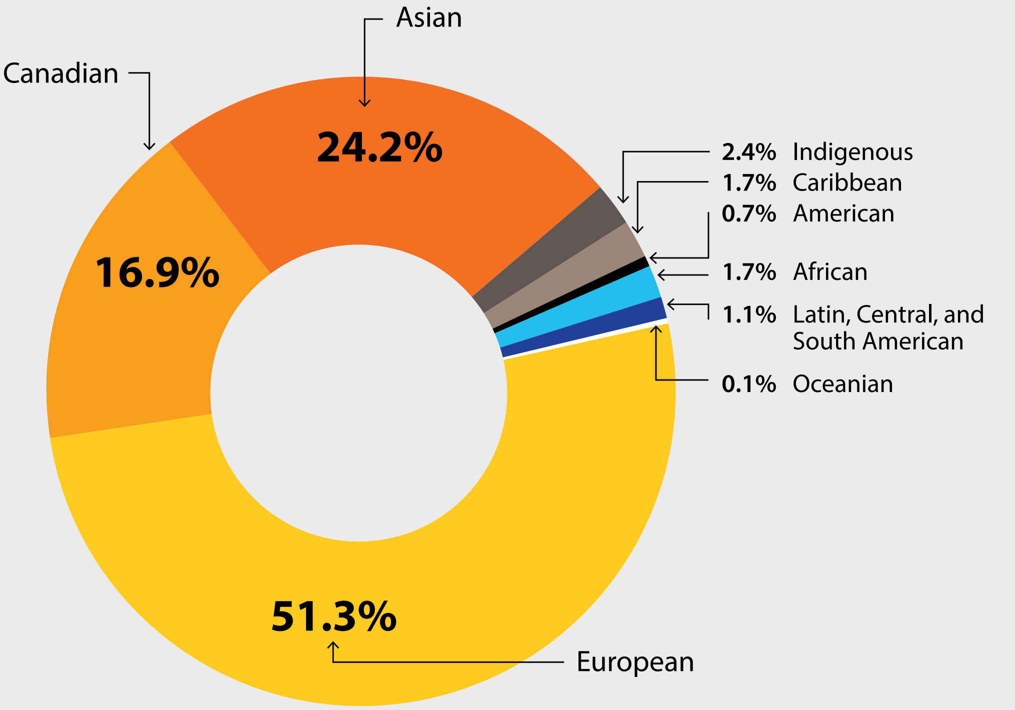
Figure 7. Ethnic origins of people living with dementia in 2020 according to the Landmark Study model, using 2016 Canadian census categories



By 2050, the projected proportion of people of Asian ancestry who are living with dementia is projected to increase substantially from 8% in 2020 to 24% in 2050 (refer to Figure 8 below). In other words, by 2050 one out of every four persons who develops dementia in Canada will be of Asian ancestry. Asian Canadians are a diverse population whose ethnic origins include Chinese, Indian, Filipino, Vietnamese, Lebanese, Pakistani, Iranian, Korean, Sri Lankan, Japanese, and more. Similarly, all groups within these analyses are made up of diverse groups of people.

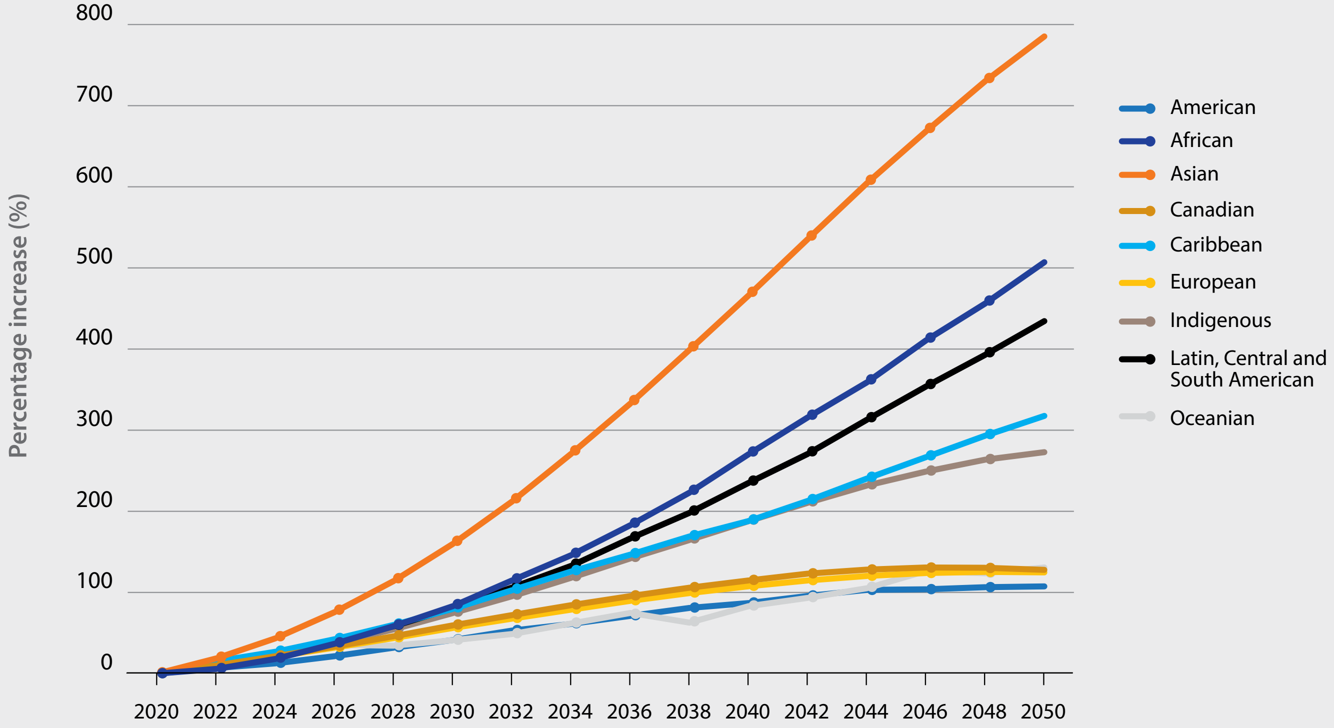
Also, projections by 2050 include a reduction of the proportion of people living with dementia who have self-reported European origins and people who have Canadian ethnic origins, along with increases in individuals with Indigenous, Caribbean, and African ethnic origins. These shifts reflect the diversity of older adults in Canada. With changing immigration patterns over the past number of decades, we are seeing a shift in the landscape of who develops dementia in Canada in terms of ethnicity and race.

Figure 8. Ethnic origins of people living with dementia in 2050 according to the Landmark Study model, using 2016 Canadian census categories



These shifts in proportions are a direct result of the differential rates of growth in population across ethnic-origin groups. Figure 9 illustrates the percentage increase from 2020. While there is growth across the board, the fastest growth occurs in individuals of Asian ethnic origins.

Figure 9. Percentage increase in number of people living with dementia from 2020 by ethnic origin, using 2016 Canadian census categories



With these differences in dementia growth and the appreciation that there are cultural differences in dementia care needs, health systems and health professionals will need to develop resources to better match the diversity of the population. This may include addressing language barriers, but should also include:

1. Efforts to reach underserved communities to address possible issues such as stigma, lack of knowledge of dementia, and different understandings of dementia.
2. Research to better understand how to meet both the care needs of individuals living with dementia and the needs of care partners who support them.
3. Developing culturally safe, accessible, and relevant resources and training for health-care professionals.

The Landmark Study model can also provide projections for the number of new dementia diagnoses across each ethnic origin category. According to the findings, the ethnic origin with the largest numbers of dementia people of European ancestry, followed by people of Asian ancestry and people of self-reported Canadian ancestry (refer to Table 2).

Table 2. Projected annual number of people with newly developed dementia in Canada (annual incidence) by ethnic origin and year (start of each decade), using 2016 Canadian census categories

ETHNIC ORIGIN	2020	2030		2040		2049	
	PEOPLE	PEOPLE	INCREASE	PEOPLE	INCREASE	PEOPLE	INCREASE
African	**2,200**	3,600	**64%**	5,200	**136%**	7,000	**218%**
Asian	**12,600**	29,500	**134%**	52,700	**318%**	71,200	**465%**
Canadian	**25,100**	36,100	**44%**	44,800	**79%**	44,100	**76%**
Caribbean	**2,800**	4,200	**50%**	5,400	**93%**	6,800	**143%**
European	**72,700**	101,700	**40%**	127,200	**75%**	129,300	**78%**
Latin, Central, and South American	**1,700**	2,800	**65%**	3,800	**124%**	5,100	**200%**
Indigenous	**3,900**	5,400	**39%**	7,400	**90%**	8,200	**110%**
Oceanian	**200**	500	**150%**	600	**200%**	800	**300%**
American	**2,500**	3,100	**24%**	3,700	**48%**	3,800	**52%**

Overall, these findings highlight the need to address, capture, and study diversity in all domains of dementia. From research studies to care systems, we need to work toward more inclusivity to optimize health and health care for all. More research exploring the lived experience of racialized groups with dementia is also needed to help understand qualitative factors impacting diagnosis, treatment choices, and access to health-care systems as well as to community resources.

With these findings, we have only begun to scratch the surface of the dementia differences that exist across ethnic and racial groups in Canada. Further work is needed to develop our understanding of the many differences that exist regarding the experience of dementia across population groups. Through intentional design, Canadian policies, programs, services and supports need to be tailored to meet the different needs across groups.

FACES OF DEMENTIA
ARLENE'S STORY

Here, Arlene speaks about being a caregiver during her parents' experiences with dementia, and she provides perspective on the need for culturally appropriate care and other dementia-care urgencies through a health-care worker lens.

"MY father was a lawyer in the Philippines, and my mother was an accountant. Both immigrated to Canada in 1974. My dad sacrificed a lot, because he had to leave his legal profession, which was his passion, to pursue a better future for his children in Canada. An aunt sponsored us, then we lived in a one-bedroom apartment, and a couple of months later we were able to get our own place.

For several years, Dad worked as a mortgage officer, then for the government for a bit, and on the side he pursued paralegal work. He assisted numerous Filipino Canadians to establish businesses, as well as incorporate associations and key organizations like the Philippine Chamber of Commerce and the Filipino-Canadian Nurses Association. He sat on the board of Scarborough Community Legal Services to help newly immigrated Filipino professionals secure employment and pursue accreditation of their degrees in Canada. He believed in unifying the Filipino community and provided a platform for them to be recognized and taken seriously in Canada. At the age of 59, under Bob Rae's provincial leadership (which sought in part to increase employment equity in the justice system), my dad became the second Filipino Canadian justice of the peace of Ontario.

In 2017—he would have been 83 at the time—we started noticing some changes. He was making some poor decisions when driving. Once, he got lost, and he was driving around Scarborough (where we live) for five hours. He didn't take his insulin for a month. And he had a stage of delirium.

My mom, at the same time, was starting to have some memory issues as well. Her onset seemed to come after she had shingles, and other complications from her arthritis and newly diagnosed diabetes. She was

Story continues on next page

Photo: Courtesy of Arlene and family.

> **"I think I'd personally like to see more culturally specific approaches to informing people with dementia about dementia. As my dad's dementia progressed, he kept defaulting to Tagalog. Having a language barrier may influence diagnosis or in explaining the condition to the person and the family, to help prepare them for what to expect."**

registered in a falls and balance clinic, and later participated in a memory clinic, as she was starting to forget things. For much of her life with dementia, she has actually had a very crisp memory—remembering birthdates, addresses, and activities when we were young. But her dementia challenges affected her short-term memory, and she would forget when to take medication, how to sequence activities, and what happened at recent events.

During the first few months of COVID, they stayed with me until it was safe for them to return to their condominium. We noticed then, as their memory declined, that they would require full-time care, which became a family affair complemented by caregiving support. Then we found out in December 2021 that my dad's lung cancer had returned from 20 years prior.

While his dementia progressed, and he began to speak less and less, we still had special moments when Dad would surprise us with his wit and charm, making jokes and then more seriously asking us about our work and family. For the most part, while little was said, Dad just seemed happy, content, and enjoyed spending time with my mom. A short time before he died, he had the wherewithal to know and say in Tagalog, "Thank you, I want you to know that I'm really grateful for the care that you've provided me and Mom." After I recorded that, I was joking with him. He said, "Did you record it?" I said, "Yes." He said, "Okay, good. That's what I want."

Faith is important to my family; we would do the rosary, and Dad would say it with us. But towards the end, he was very weak. I remember us being with a priest; we did last rites the week before he died. My dad was so weak at that time. But he was present. He knew. He wasn't eating. He was in a lot of pain. We were giving him lots of medication. Soon after, he passed.

Both my sister and I work in health care, and we have been fortunate to have access to physicians for those initial memory assessments for our parents and for other things, like social workers, palliative care information, neurology and more. But the actual process of caring for my parents has been fairly complex. My parents have been very fortunate to have three daughters to care for them—from health to finance to property and any administration required to manage my mom's affairs. I think this is commonplace within the Filipino community, and an unsaid expectation and cultural value—to care for your elderly.

The care of my parents has truly been a family affair. Now, my mom lives part-time with each of us—taking turns living with each daughter. We take turns to be able to provide respite support to each other, and importantly to share some quality time with our mom. To help us, we have caregivers for 10 hours a day while we are working. When I say "family," I also mean that we have been able to hire caregivers who are family—one is my best friend, another is my cousin, and the third is the nanny who took care of my boys when they were young. In our eyes, they are our family. It has always been important for us, and especially my mom, to be cared for by people who provided a sense of familiarity.

I think I'd personally like to see more culturally specific approaches to informing people with dementia about dementia. As my dad's dementia progressed, he kept defaulting to Tagalog. Having a language barrier may influence diagnosis or in explaining the condition to the person and the family, to help prepare them for what to expect. We need more physicians pursuing geriatric psychiatry, and we need to support training for those from diverse communities. In the interim, if that is not available, maybe have an advanced practice leader, social worker, or something like that—someone who comes in after the doctor speaks to the family, who has a conversation from a cultural perspective.

For example, in my culture and in my family, I have no problem having my 16-year-old and my 15-year-old take care of my mom and dad. Other cultures might say, "Oh they're too young, they can't do that." Another example: there are a lot of educational materials for dementia that talk about "the caregiver" as a single person, rather than as a network of family and friends. We need more experts and resources that are culturally appropriate.

I'd also say that, in the health-care system, we really need to take a hard look at patient support and dementia—and what that means for home care, where resources are very limited right now. We need more changes, more caregivers trained up and ready. What I think would be nice is if we could have some government subsidies to support home care for people with dementia. In a lot of ways, home care is about dignity—especially from a cultural perspective. Most long-term care homes don't offer our food or other ethnic foods. If you're at home, you can eat your cultural foods. You're still a person. You exist.

We also need to improve dementia care navigation. I've had a cousin reach out to me because he knows I work in health care, and he was having issues getting his dad diagnosed. I told him what he needed to do. But what about for people who don't have someone like me in their family? How are they supposed to know where to go get a memory test?

Also, we still have a shortage of family care practitioners, many physicians are retiring, and that influences dementia care and diagnosis right now. We're losing continuity of care. People are going to have to figure out how to do it on their own. But no one, really, should be alone with this."

> **"A short time before he died, he had the wherewithal to know and say in Tagalog, 'Thank you, I want you to know that I'm really grateful for the care that you've provided me and Mom.' After I recorded that, I was joking with him. He said, 'Did you record it?' I said, 'Yes.' He said, 'Okay, good. That's what I want.'"**

FACES OF DEMENTIA
AMA'S STORY

Ama is a caregiver for her father, who is living with dementia following a few strokes. Here, she talks about the importance of family and health-system support, the need for advocacy, and other aspects of her family's experience so far. She lives in Alberta.


Ama's father

"MY dad was a hard worker his entire life. He was an investment banker for many years, and he retired from that and took up a whole new career, where he started doing carpentry, and then scaffolding. He also used to work for a group home and take care of kids with special needs. And he also used to work in agriculture. He's got a few degrees. He'd always worked, and he'd always been a productive person.

Over the years, we noticed a decline in his health in general, and not being as productive. My mom started noticing that he wasn't paying bills on time, or he was putting additional money on bills because he didn't want anything to be past due.

He started burning things on the stove. I remember there was one time he pulled a bag from the fridge and put it in the microwave, thinking it was food, but it was actually his insulin.

I think it was when his main caregiver, my mom, went out of town two years ago to take care of her own mom for a few months that we—me and my sisters—saw more of a big difference and that he really wasn't okay on his own. I went to the house and I couldn't believe how run down it was. It was a real mess, and he just couldn't see anything wrong. He'd lost sight of what you need to do to take care of yourself.

Photo: Courtesy of Ama and family.

> **"He can remember, "Oh, it's end of March, time to do my taxes!" And he will get his taxes all organized and ready. So he can function very well in certain areas, but in other areas he's just not on top of it."**

So that's when we arranged all these services to help, especially when my mom is away taking care of her mom. Now, we have home care come three times a day, because if nobody's there, he won't remember to take his medication, he may not eat, and he may overeat (which is harmful since he is diabetic). Home care also checks his blood pressure and his blood sugar. And we've hired someone to come in and clean once a week and prepare meals for him.

It's still weird for me—it's hard for him to grasp an understanding of what he's sick with, and what he needs to do to take care of his health, but then he can remember, "Oh, it's end of March, time to do my taxes!" And he will get his taxes all organized and ready. So he can function very well in certain areas, but in other areas he's just not on top of it.

He got his licence taken away last year after they did a CT scan or MRI. He was becoming more forgetful and slow to react, so it wasn't safe for him [to drive]. This was a big blow because driving was kind of the last part of his independence. He really loved to drive. It was a way for him to get out of the house. Now he's home all the time and doesn't have much motivation to get out and do things. It's more us, his kids, and my mom, taking the reins and making sure he goes to appointments, and making sure he's active.

Support is a big thing. I don't know how people do this without help! My dad is very blessed—he has kids who all live in the same city. I'm glad I have my sisters to help. I couldn't even imagine trying to do this by myself.

It's also important to advocate for your family member. You have to have a voice and speak up! Home care is helpful but it's not perfect; you only qualify for so much, so if you want more of one kind of service, they have to take something away. In some cases, we've requested things done by his doctor and they haven't gotten back to us for days or weeks.

It's frustrating, it's time consuming, but that's the reality: If you're not happy with things and you need a change, you need to speak up. We are in touch with his case manager quite often, and his home care agency too, calling doctors and nurses, and following up if we don't hear back.

I'd also recommend keeping notes—logs of what's wrong, who the physicians are, where the person goes for care. Having all that stuff organized is helpful because it can get overwhelming. My sister is very organized in that aspect, she has a flowchart of my dad's entire care plan.

If asked what I'd want other people to know about our dementia experience? Well, it's not easy. I guess I would want people to cherish the time that they have now. Health is truly wealth. But also know that some things are out of your control. And if you don't have family to help you, a lot of work likely goes into figuring out where you can get help, and what services are available to you."

FACES OF DEMENTIA
NAVJOT’S STORY

Here, family care partner and researcher Navjot Gill talks about experiencing barriers to culturally sensitive, South Asian–inclusive dementia care with her grandmother, who is living with dementia, and her parents, who are care partners. She also discusses her work in dementia research, trying to make future services better and more inclusive.

“MY journey with dementia started when my grandmother was diagnosed back in 2016. At that time, I had an understanding of what dementia was through my college studies in physiotherapy. Initially, when my grandmother was diagnosed, it wasn’t that bad, in a way. You know, she still got by. But as it progressed, it just got to a point where one of us had to be at home all the time to ensure she was doing okay.

Early on, I tried explaining to my parents what dementia was. And that’s when I started to see that there were many programs and resources in our area for people living with dementia, but they were not culturally appropriate.

Photos: Courtesy of Navjot Gill and family.

> **"What we need are more resources—on paper and on video—that have South Asian representation."**

I saw, for instance, information about sleep issues and dementia, and I thought, "Oh, this might be useful. Let me see if I can show my parents." They were trying to manage some of that, but because it was in English and my parents aren't completely fluent in English, that didn't work.

And then I was like, "Okay, let me see if I can find something in Punjabi for them." And we really needed that in terms of my parents' understanding behaviour, such as losing one's way and restlessness in the late afternoon. For instance, my grandmother often talked about her "babies," not realizing they were grown-ups. In her mind, she is in her 40s, and my parents were like, "What are you talking about? Like, you know, your daughters are married, you have grandchildren, you have great-grandchildren." They would correct her every time. And I was like, "This is not what you're supposed to do." But there was no way I could explain it to them.

So I basically just searched, "Explain dementia in Punjabi." And the UK Alzheimer's Society has many resources. But their health-care system is different; their subculture is different; everything is different. I couldn't really bring that over to my parents here in Canada and be like, "Okay. This fits."

In the end, I did show them a dementia video that had been translated into Punjabi. It showed this European couple living in the suburbs, with a robotic voiceover in Punjabi—so the language was there, but my parents couldn't connect with that; they didn't see themselves being represented.

To me, that video, and others like it, have also reinforced this idea that exists in some South Asian communities—that dementia is a European disease and that it doesn't happen to people of colour. In fact, after watching that video, my dad was like, "See, I told you, it's a White couple." So that put them off.

Story continues on next page

What we need are more resources—on paper and on video—that have South Asian representation. Not just a robotic voiceover. We need something that normalizes that a brown person can have dementia too. And it needs to address specific behaviours and tips, not just describe the condition.

Luckily, there is now work being done. Sheridan College [and the Alzheimer Society of Peel] recently released a dementia toolkit in Hindi, which kind of explains different scenarios and what you should be doing.

But there's still a long way to go in terms of services being inclusive and culturally sensitive.

I worked as a program assistant with the Alzheimer Society, so I had first-hand experience of the amazing programs that they had, and I would always wonder, "What if my grandma could be a part of this?" But if I tell her to go play bingo, well, bingo is a Western concept. She didn't grow up playing bingo. She never understood bingo. I can't just push her into these things.

Then also issues with home care services. We had a PSW come in, but the PSW didn't speak our language. She would speak English and then my mom—who was working full-time, as was my dad—would still have to be there to translate and manage everything. Instead of PSW relief being a time when my mom could get a break from providing care, she absolutely had to be there—and grandma would get even more anxious, in fact, because the PSW was speaking in English and then my mom was translating. It wasn't very clear and was concerning to her.

So my parents don't have any respite. They don't have those care partner support groups they can go to because we don't talk about it in our community. It's a huge stigma.

And there's also a stereotype some health professionals have around filial piety: "If this person is brown, they're going to take care of their own." So health workers don't really give out as many resources to our families; they just assume that they don't need it when that's not the truth.

In truth, our families need to hear, "We're not questioning your ability to provide care. We're telling you the truth that you can't do this on your own. There's no way you can manage your own life and take care of someone living with dementia full-time. It would be best if you had care. You need to be able to ask for help, ask for resources, and advocate for yourself."

That's where my research comes in. It is focused on exploring the experiences of South Asian Canadians living with dementia and their care partners. I'm interviewing people living with dementia and their families, offering interviews in English, Punjabi, Hindi, and Urdu, starting with the languages I can speak—to make the research more inclusive. I'm also talking to health professionals to see their understanding regarding culturally competent care and how we can make that shift.

I'm not saying my research will bring a wave of change. But potentially, it will start the groundwork, which still needs to be added."

> “Women are disproportionately affected by dementia, both directly and indirectly. Women experience higher disability-adjusted life years and mortality due to dementia, but [globally] also provide 70% of care hours for people living with dementia.”

— World Health Organization