

Official Language Minority Communities and Dementia

Public Health Agency of Canada

Executive Summary

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Cette publication est aussi disponible en français sous le titre : Communautés de langue officielle en situation minoritaire et la démence

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Signed:

A handwritten signature in black ink, appearing to read "Rick Nadeau", is written over a light gray, textured rectangular background.

July 11, 2022
Rick Nadeau, President
Quorus Consulting Group Inc.

Executive summary

Background

Canada's first national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire* was released in June 2019. It supports the vision of a Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, understood, and effectively treated. The strategy identifies three national objectives: prevent dementia; advance therapies and find a cure; and improve the quality of life of people living with dementia and caregivers.

Official Language Minority Communities (OLMCs) consist of Francophones who reside outside of Quebec and English-speaking residents of Quebec. These communities are highlighted in the national dementia strategy as a population likely to face barriers to equitable care due to challenges related to accessing services and information in their first language, including being able to communicate with health professionals to correctly describe symptoms, understand health-related guidance, and receive appropriate care.

This research will assist in supporting the implementation of Canada's national dementia strategy. Furthermore, this research supports government and department priorities on dementia by contributing to the Public Health Agency of Canada's (PHAC) core responsibilities of health promotion and chronic disease prevention. Ultimately, the research findings will be used to inform PHAC programs and initiatives to ensure they reflect the distinct experiences and needs of OLMCs. It is also expected to be available to other organizations providing dementia-related services for OLMCs. Finally, this information will support annual reporting on the national dementia strategy to Parliament, as required by the *National Strategy for Alzheimer's Disease and Other Dementias Act*.

Research objectives

This project focused exclusively on OLMCs to obtain a deeper understanding of their knowledge, experiences, and attitudes related to dementia prevention and dementia-inclusiveness. Specifically, research objectives included, but were not limited to:

1. Capture dementia prevention knowledge and attitudes:

- General beliefs and knowledge related to dementia, including the signs and symptoms of dementia
- Knowledge of dementia risk and protective factors, including individual actions and environmental factors

- Reported steps taken or anticipated to prevent dementia or delay onset, intentionally or not
- Barriers and enablers to reducing dementia risk
- Availability and suitability of dementia prevention information, resources, supports, and guidance, including whether OLMC individuals feel they have adequate access in their language of choice

2. Assess dementia-inclusiveness experiences:

- Availability and suitability of dementia information/guidance/supports, including whether OLMC individuals feel they have adequate access to these resources in their language of choice
- Familiarity with and experience with aspects of built and social environments that are dementia-inclusive
- Potential for their community to be dementia-inclusive in a way that meets the needs of OLMC individuals, including:
 - Barriers and enablers of social engagement/connection
 - The overall level of community support

Methodology

The research methodology consisted of seven online focus groups with members of OLMCs 18 years of age and older, and seven in-depth interviews with unpaid caregivers and persons living with dementia who are also members of OLMCs. Data collection was held between March 28th and June 16th, 2022 and included individuals from across the country. Each focus group lasted approximately 90 minutes and each interview lasted approximately 40 minutes. Participants were informed upfront that the research was being conducted on behalf of Health Canada and PHAC and they each received an honorarium of \$120 for their participation. In total, 50 individuals participated in the research.

Research findings among OLMC general population

This section summarizes the findings from seven online focus groups with members of OLMCs across Canada.

Familiarity with and attitudes regarding dementia

Familiarity with dementia was quite mixed across all participants, where familiarity and personal experience with the condition increased as the age of participants increased. How well participants

were able to describe dementia was largely tied to what they had observed through their personal experiences. As such, the bulk of the information participants were able to convey pertained to symptomology such as gradual loss of memory, being disoriented, changes in mood, etc. Many participants referred to Alzheimer's disease in this context.

The general sense, especially among younger participants, was that dementia was something that much older people can experience and that it involved the gradual decline in certain cognitive abilities, especially memory.

Prevention

The extent to which participants were worried about their own risk of developing dementia was largely linked to whether one of their relatives had experienced it. A few felt that they might be at a higher risk given a previous head-related injury, such as a concussion. There was also a generally accepted perception among participants that the risk of developing dementia was related to age. As such, older participants tended to be more concerned compared to younger ones, irrespective of whether any of their relatives had developed the condition.

Although there was a broadly accepted view that dementia was related to age, participants also believed that it is possible to reduce the risk of developing dementia and that this condition is not an inevitable part of aging. Many seemed to be under the impression that by remaining active and by making sure that their mind or brain was well "exercised," dementia could be delayed if not entirely held at bay.

Very few participants had had any sort of conversation with anyone, including a healthcare provider, or had done any research on their own to better understand the risk of developing dementia or what steps they could take to reduce their risk. Information pertaining to risk factors or what steps could be taken to reduce their risk tended to be online and it tended to be in English, whether among Quebec OLMC participants or among Francophones living outside of Quebec.

Many participants suspected that genetics played an important role and many also assumed that poor health in general, including a lack of intellectual stimulation, would be a likely risk factor. Additionally, a few suspected that trauma to the head, such as a concussion, could be a contributing factor.

When the moderator presented the risk factors associated with dementia, many participants felt this was both informative and eye opening. The list prompted some to revisit their own level of risk, leading some to conclude that they may in fact be at a higher level of risk than initially suspected, especially regarding the various factors related to a "healthy lifestyle."

With a better knowledge of the risk factors, some participants indicated they had taken certain steps on their own to reduce their risk, although reducing their risk of developing dementia was

purely coincidental. The steps that were most likely to be mentioned included: eating better, more exercise, cutting back on alcohol and smoking, and leading a healthier life in general. If anything, a lack of motivation and a lack of time were the most common barriers to pursuing these steps. Participation in online or in-person programs or activities in their community was fairly limited with many pointing to the pandemic as the main cause.

Given the choice to participate in community-based programs and activities in English or in French, Francophone OLMC participants were more likely to be indifferent given their level of bilingualism. Most Anglophone OLMC participants in Quebec, whether in Montreal or beyond, would prefer programs and activities in English since many do not speak French well enough or at all.

Dementia-inclusive communities

Awareness of dementia-inclusive communities was nearly non-existent. To contextualize the discussion regarding dementia-inclusive communities, the following explanation was provided to all participants:

In a dementia-inclusive community, measures are in place that make it more possible for people living with dementia to protect and improve their health and wellbeing, live independently, safely navigate and access local activities, and maintain social networks.

Given this information, all participants agreed that their community is not dementia-inclusive. With the benefit of a few examples, participants suggested that their community would become more inclusive if the following were done:

- Better public education about what dementia is and how to communicate, live with and/or work with someone living with dementia;
- More community programs and services dedicated to people living with dementia;
- Community action groups consisting of volunteers who could accompany people living with dementia in their community to get groceries, socialize, etc.

Access to information, programs and care in the preferred language

Few participants had actively sought information about symptoms or treatments. Similarly, very few were aware of or had sought information on programs or activities in their community that support people living with dementia, whether offered in English or in French.

Many explained that the healthcare system in their community would not likely meet the needs of a person living with dementia irrespective of their preferred official language. There was also

some recognition that it would be important for members of OLMCs to access healthcare in their preferred official language.

Research findings among unpaid caregivers and persons living with dementia

This section summarizes the findings from seven in-depth interviews with members of OLMC's, among whom five were persons living with dementia and two were unpaid caregivers of persons living with dementia. The following regions are represented: Quebec, Ontario and British Columbia.

General quality of life

Most of the persons living with dementia had been diagnosed with dementia within the past few years, including a few who were persons with young-onset dementia. All these participants explained that they are fairly independent and for the most part, do not require constant support or supervision at this time. Nearly all persons living with dementia were living in their own homes, either with a spouse or a relative, including younger participants who lived with or had moved back in with their parents and sibling(s).

Persons living with dementia would for the most part say that their quality of life these days is fairly good. They felt they were very well supported and, other than having a diagnosis of dementia, they described their overall health as quite good. They further explained that, with the benefit of time and with more insight into their condition, they felt they had gained some perspective on their life and saw things in a brighter light than before.

When specifically asked what was most important to their quality of life, participants mostly focused on the family and friends providing them the help and support needed. Some also referred to their favourite hobbies or passions in life such as playing an instrument, singing, etc.

When asked to identify their preferred official language, participants explained that they are fairly bilingual. Anglophones living in Quebec (in the areas of Montreal and Sherbrooke) felt they had many opportunities to speak English, whereas the opposite was the case for Francophones living in Ontario and British Columbia who explained that they do not get to speak French as often as they would like, and that it was always a pleasant surprise when they met someone in their area who spoke French. Despite their bilingualism, all participants expressed a clear preference for one language over another and this was almost always the minority official language in their province. They felt more confident speaking this language, they felt they can be more open in their conversations, and a few explained that speaking the minority official language in their province was a source of comfort.

Support systems

Most persons living with dementia explained that they needed very little in terms of support to live comfortably and safely, although for most of these participants, various measures or changes in their living situation had taken place to foster this general sense of comfort and safety. Some of these changes included taking a break from work and/or their studies, staying at home/not going out, moving in or living with family, and greater involvement in their hobbies. Another important contributing factor to participants' general sense of comfort and safety was access to and the availability of friends and especially family. In the end, participants felt that their needs were being met.

Nearly all persons living with dementia in this study relied exclusively on unpaid caregivers for their day-to-day support. For nearly all persons living with dementia, at least one unpaid caregiver lives with them and would be described as very involved, with contact occurring daily. Furthermore, persons living with dementia are able to speak with unpaid caregivers most central to their care in their preferred official language, which was seen as quite important for participants.

Only a few of the older participants relied on a paid care provider who tended to needs in their home. Otherwise, participants had access to a variety of healthcare professionals which included family doctors, psychologists, nurses, therapists, and specialists. Persons living with dementia in Quebec (in the areas of Montreal and Sherbrooke) did feel they could interact with their healthcare team in their preferred language (English), while Francophones living in Ontario and British Columbia could not speak their preferred language (French). That said though, some participants preferred using the language used by the majority in their province whereas others felt it was important to their care and wellbeing that they have access to a healthcare team who could speak the language spoken by the minority.

Dementia-inclusive communities

In terms of their daily and social activities, English was the common thread across all participants. Participants living in Quebec felt they were well supported in English while Francophones living outside Quebec felt they were only supported in English. Only a few in Quebec felt that their daily and social activities would suffer if they could not access them in their preferred official language. Although Francophones outside Quebec explained that access to English-only activities did not represent a barrier to participation, they suspected that they would probably be interested in exploring additional activities if they were in French.

Based on an explanation of the concept of dementia-inclusive communities (as defined earlier in this summary for focus group participants), only one participant, an unpaid caregiver, was aware of the concept. Many had difficulty imagining what such a community would look like or what

measures would be in place to make it dementia-inclusive. What they did seem to recognize was that their neighbourhood, community or city was not as inclusive as it could be. A few suggestions of activities or measures that could be considered to make their community more inclusive included the following: have more activities and clubs for persons living with dementia; make information more widely available for the general public about dementia; organize information sessions to find out about programs available for persons living with dementia; have a dedicated meeting place online and/or in-person for persons living with dementia; have a committee/organization to oversee the changes in the community; and, have more visual cues and signs to orient people when they are walking around the community.

The concept did get some pushback, however. A few participants felt that dementia is something personal, that as long as their family was around them, then they have what they need and that there is no need to get the entire community involved in supporting them.

Awareness of programs, clubs and activities for the general population in their community was high. Participants were confident that they would be able to easily find out about these programs and that the language in which these programs were available would not pose any sort of barrier or motivation to participation. Challenges to participation were more likely to be a lack of work-life balance, activities being too far from home, hours of operation, and pandemic-related closures.

None of the persons living with dementia were aware of activities specifically available to persons living with dementia in the community. As well, none had looked for these types of programs since their diagnosis and even if they were to be available in their community, a few would not be interested in participating. Among those who might be interested in activities tailored for persons living with dementia, possible activities of interest included:

- Activities that calm the spirit and help focus on emotions (e.g., anything to do with music);
- Physical activities to improve overall health that help control and focus emotions (e.g., weightlifting, yoga, swimming);
- Group cooking classes/discovering new recipes;
- Reading rooms/access to audiobooks;
- Knitting classes;
- Activities in a park (e.g., art in the park, music in the park, pet zoos/pet therapy);
- Adapted outdoor cafés; and,
- ‘Hybrid’ programs and spaces for the persons living with dementia and the unpaid caregiver so that the caregiver can have somewhere to go or something to do while the person living with dementia is participating in an activity.

Access to dementia-related information

Nearly all participants had done some research to find information related to dementia. Common topics included:

- Learning about dementia in general;
- Information on treatments;
- Information about the different stages of dementia and progression;
- Case studies, testimonials, and personal stories;
- Long term effects on the brain and the body;
- Types of activities that can slow or delay the progression of dementia; and,
- Nutrition and information about getting a good meal plan in place.

The vast majority of this research by participants was being done online through general Google searches. Other sources included word of mouth, healthcare teams, and social media. Most of the Quebec-based participants did their research in English, which was their preferred language for this type of information. Participants in Ontario and British Columbia relied mostly on English websites with only select use of French websites. These participants were not inconvenienced by any lack of French resources since in most cases they did not even try to find French content.

Nearly all participants felt they found the information they were looking for. If challenges were encountered, they were not language-related.

Moving forward, participants were interested in a few additional dementia-related topics, including: success stories of people who were able to delay progression of the condition; whether dementia is hereditary; whether having dementia puts a pregnancy or the mother at risk; dementia-care residences; and up-to-date treatments/treatment plans. A few expressed an interest in accessing information in their preferred official language moving forward, preferably through a bilingual website.

Impact of the pandemic

None of the participants felt they had lost access to any type of dementia-related information sources during the pandemic. The most notable impact on persons living with dementia was the more limited access to hospitals and their health care team and access to their social network.

A few participants explained how a greater shift to online had improved or maintained access to information and programs, including eliminating some transportation-related logistical challenges.

Moving forward, as public health restrictions continue to ease, there was some interest in returning to in-person activities and programs, although online options should not be entirely cancelled. A phased-in or gradual shift back to in-person was recommended.

Qualitative research disclaimer

Qualitative research seeks to develop insight and direction rather than quantitatively projectable measures. The purpose is not to generate “statistics” but to hear the full range of opinions on a topic, understand the language participants use, gauge degrees of passion and engagement and to leverage the power of the group to inspire ideas. Participants are encouraged to voice their opinions, irrespective of whether or not that view is shared by others.

Due to the sample size, the special recruitment methods used, and the study objectives themselves, it is clearly understood that the work under discussion is exploratory in nature. The findings are not, nor were they intended to be, projectable to a larger population.

Specifically, it is inappropriate to suggest or to infer that few (or many) real world users would behave in one way simply because few (or many) participants behaved in this way during the sessions. This kind of projection is strictly the prerogative of quantitative research.

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