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Stigma related to dementia in Canada

Executive Summary

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Stigma related to dementia in Canada Survey

Executive Summary

Prepared for the Health Promotion and Chronic Disease Prevention Branch, Public Health Agency of Canada (PHAC) by Nanos Research

July 2023

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Executive summary

Background and objectives

With a mandate to improve the health care, protect the health and prevent disease among Canadians, the Public Health Agency of Canada (PHAC) retained Nanos Research to conduct public opinion research among Canadians related to stigma associated with dementia. Specifically, to conduct a national survey which examines Canadians' knowledge of and attitudes towards dementia and stigma related to dementia.

Dementia is an umbrella term that describes symptoms affecting brain function caused by neurodegenerative and vascular diseases and injuries and is characterised by a decline in cognitive abilities, including memory, language, judgment, and planning, as well as mood and behaviour.

Dementia has a significant impact on Canadians and the impact continues to grow, with about 6.5% of Canadians 65 years of age and older living with diagnosed dementia as of 2019-20, disproportionately impacting women.¹ This figure excludes those under 65 who may have an early onset diagnosis or those not diagnosed but living with the symptoms – meaning its impact is likely even more significant. As Canada's aging population continues to increase, the proportion of Canadians living with dementia is expected to increase as well.

PHAC plans to utilize the research findings to support the continued implementation of Canada's first national dementia strategy, *A Dementia Strategy for Canada: Together we Aspire*, as required under the *National Strategy for Alzheimer's Disease and Other Dementias Act* which came into effect in 2017.

The research findings will also inform efforts to help develop a better understanding of dementia among Canadians, including how to be supportive when interacting with individuals living with dementia to make communities more welcoming and inclusive. It also builds on the baseline study conducted in 2020 and will measure any changes in attitudes, knowledge and perceptions related to dementia and dementia-related stigma.

The specific research objectives included, but were not limited to:

- Assess general knowledge and gather attitudes regarding dementia.
- Gather information on perceptions and experiences of stigma related to dementia.
- Gather perceptions of the causes of stigma.
- Explore what stigma means to different people.
- Measure Canadians' attitudes and reasons towards the possibility of living well with dementia.
- Measure attitudes/knowledge on how to best interact with someone who may be living with dementia in the community.
- Understand how stigma may vary across demographic groups including cultural groups.
- Explore the influence of stigma on uptake of dementia prevention advice and/or recommendations.
- Explore the influence of stigma on seeking health care advice related to dementia or a potential diagnosis and reasons.
- Measure Canadians' attitudes/feelings related to talking about a diagnosis of dementia with health care providers.
- Measure Canadians' attitudes/feelings related to disclosing a diagnosis of dementia to family, friends, employer, colleagues, etc.

¹ Public Health Agency of Canada. Canadian Chronic Disease Surveillance System (CCDSS), Data Tool 2000–2017, 2019 Edition. Ottawa (ON): Public Health Agency of Canada; 2021.; <https://health-infobase.canada.ca/ccdss/data-tool/Age>

Methodology

The survey is comprised of 5,056 Canadians, 18 years of age and older, including 1,604 self-identified unpaid caregivers (defined as someone who provides or has provided unpaid care and support to someone living with dementia in the last five years)*, 756 Canadians who identify as members of Black (n=181), Hispanic (n=68), Southeast Asian (n=254), or South Asian (n=253) ethnic groups and 188 individuals who identify as Indigenous. The survey was conducted across Canada in each province and territory between March 11th and 29th, 2023 and additional supplementary fieldwork was conducted between June 7th and 25th, 2023 in an effort to target more individuals in these key ethnic communities who are disproportionately impacted by dementia. There were 4,689 interviews conducted during the original fieldwork period, and an additional 367 interviews were completed during the supplementary June fieldwork.

The sample was drawn from two sources:

- 1) The Nanos Probability Panel, which contains about 50,000 Canadians who were randomly recruited to join the panel by land- and cell-lines with live agents.
- 2) Random recruitment by land-and cell-lines and administered the survey online.

The resulting sample contains Canadians who were all randomly recruited by telephone, thus allowing a margin of error to be associated with the research. Of note, 2,406 interviews of the 5,056 total interviews were recruited from the Nanos Online Probability Panel and the other 2,650 interviews were recruited directly by a dual frame Random Digit Dialed sample of land- and cell-line numbers and administered the survey online.

The randomly recruited probability sample has a margin of error of +/-1.4% at a 95% confidence interval. The margin of error for each of the key target groups is between 2.4 (unpaid caregivers) and 12.1 (self-identified Hispanics) percentage points due to their varying and comparatively smaller sample sizes.

Results are weighted to population proportions for region, age, and gender from the 2021 Census. A Chi-square test and pairwise Z-tests were used to compare subgroups to each other (e.g. women versus men, Ontario vs Quebec). Comparison between subgroups and to the total sample (e.g. Ontario versus Canada overall; 65 to 74 years old versus Canadians overall) were made by observing significance based on the margin of error.

All respondents self-administered the survey online.

*Of note, the [benchmark survey](#) which was completed in 2020 included 938 unpaid caregivers (22% of the total sample). Where relevant, the analysis provides any differences of note between the results of this survey and the 2020 survey. The significance of the differences between the surveys can be observed based on the margin of error of plus or minus 1.4 percentage points (95% confidence interval) for the 2023 survey and plus or minus 1.5 percentage points (95% confidence interval) for the 2020 survey.

Key findings

Dementia knowledge

Most Canadians believe dementia is having a moderate (38%) to large (51%) in Canada today, with a notable increase in those who say the impact is large compared to the [2020 benchmark survey](#) (35% said large impact in 2020).

Around one in four Canadians consider themselves knowledgeable about dementia (28%), which is an increase of 4 percentage points compared to the 2020 benchmark survey (24%). Despite Canadians not considering themselves to be very knowledgeable, most are able to correctly identify whether a series of statements about dementia are true or false. A majority correctly note that it is true that there are things we can do to reduce the risk of dementia (81%, an increase in 7 percentage points from 74% in 2020) and that the rate of dementia in the population increases notably after age 80 (75%). A majority correctly identify it is false that people living with dementia all have similar symptoms (77%) and that dementia is an inevitable (i.e., normal) part of aging.

Only one in four (25%) correctly identified that it is false that genetics is the most important factor determining the level of individual risk for dementia, while 28% correctly identified that higher levels of education may reduce the risk of developing dementia as true.

Proximity to dementia

Readers should note that this survey contained 1,604 unpaid caregivers (32% of the total sample) compared to 938 included in the 2020 benchmark (22% of the total sample). This should be kept in mind when comparing results from the two surveys, especially as it relates to proximity to dementia.

Just under four in five Canadians report knowing someone that is living or has lived with dementia (77%, consistent with findings from 2020), most commonly an extended family member (44%), a parent (25%) or a friend (24%). One in five (20%) report they do not know anyone who is living or has lived with dementia.

Close to one in three Canadians surveyed (32%) say they have provided some form of unpaid care to someone living with dementia in the last five years, reporting they have assisted with errands such as grocery shopping (21%)*, general health care and health monitoring (16%), activities of daily living (16%; 24% in 2020), with financial affairs (15%) and 5% reported having provided other types of unpaid care. *Note: This response option was not provided in 2020.

For Canadians who reported having provided unpaid care and support to a person living with dementia, around three in four (72%) say they have experienced some issues or difficulties while they were with the person they were providing care for. Over one in two say they have had people talk to them rather than the person living with dementia (51%), while over two in five say they have encountered people who focused on the things the person living with dementia can no longer do instead of the things they can (45%). Around one in five each say they have had trouble accessing appropriate housing for the person living with dementia (20%), have been unable to go where they needed or wanted due to accessibility issues (17%) or have had difficulty navigating a public space such as a grocery store, bus or train (17%). About one in four (26%) reported they did not experience any of these issues or difficulties.

Around two in five Canadians (37%) among those who report they are providing or provided unpaid care and support for someone living with dementia say they have experienced at least one challenge when accessing or using dementia recommendations or advice related to the care they are providing. Close to one in ten each say

the advice does not consider the cultural context for those to whom they provide care (12%), the advice is too expensive to obtain (11%), the advice is too complicated to understand or communicate (11%). Less than one in ten each say they do not trust the source of the advice (7%) or the advice is not in the right language (5%). Almost one in two say they have not encountered any challenges or barriers (46%).

Consistent with findings from 2020, close to one in four surveyed Canadians (24%) report they work in a sector where they may need or may have needed to interact with people living with dementia, most often reporting working in the following sectors of interest: health care (14%), retail (9%), financial services (8%), and community and religious/faith organizations (5%). Also consistent with the benchmark survey, one in five (20%) report they have volunteered in a sector that may need or may have needed to interact with people living with dementia.

Impact of perceptions of older people towards dementia stigma

Negative perceptions towards older people can be observed to impact views related to dementia stigma.

Canadians who strongly agree that people should generally retire at 65 because their ability to perform at a high-level declines were more likely to strongly agree that people living with dementia face a lower quality of life (31%) compared to those who strongly disagree that people should retire at 65 (18%). As well, those who strongly agree people should retire at 65 are more likely to strongly disagree/disagree that people living with dementia are sometimes able to work for years after the onset of symptoms (35% vs 18% of those who strongly disagree about the retirement age) and less likely to strongly agree/agree (52%) that people living with dementia can often continue activities they enjoy (78% of those who strongly disagree about people needing to retire at 65).

In addition, those who strongly agree that older people are less likely to be informed of the latest developments are more likely to strongly agree/agree that people living with dementia face lower quality of life (79%) than those who strongly disagree that older people are less informed (58%).

Taking steps to reduce the risk of developing dementia

An increasing proportion of Canadians report they have taken steps in the last 12 months to specifically reduce their own risk for developing dementia (34%, a significant increase from 22% in 2020), while 54% report they have not (70% in 2020).

Among those who report taking steps, they most often mention challenging their brain to keep it active (learning new skills, memory games, etc.) (60%), followed by being physically active on a regular basis (58%), eating healthy foods (35%) and being socially active (e.g., volunteering, social events, working) (13%).

Concern about developing dementia

Canadians are more likely to agree that they worry about the possibility of someone close to them developing dementia (70%) than the possibility of personally developing dementia (63%). A significant increase can be noted for concern related to personally developing dementia compared to 2020, with 63% who agree they are worried about this compared to 49% in 2020. Worry about the possibility of someone close to them developing dementia has also increased, from 64% in 2020 to 70% in 2023.

If they develop dementia, Canadians are most concerned about losing their sense of self, their independence or becoming a burden. More than nine in ten Canadians strongly agree/agree that if they were living with

dementia they would worry about becoming less independent (93%) and they would worry about becoming a burden to others (92%). Just under nine in ten (89%) agree that they would worry about losing their sense of self if they were living with dementia.

Comfort level interacting with people living with dementia

Eight in ten Canadians say they would feel at least moderately comfortable interacting with someone living with dementia (very comfortable (score of 4-5): 43%; moderately comfortable (score of 3): 37%), while 14% say they would not be comfortable (score of 1-2). The proportion of those who feel very comfortable has declined by 7 percentage points from one in two (50%) in 2020 to just over two in five (43%) in 2023.

Canadians who say they would feel very comfortable most often say this is because they currently know or have known people living with dementia (35%), followed by the reasons that people living with dementia are still people/everyone deserves to be cared for (31%), that they are generally confident in dealing with most situations/are patient (24%), and that they have information on supporting people living with dementia (9%). Among those who say they would feel uncomfortable, reasons cited most often are not being sure how to talk to or support/help the person (22%), followed by being worried about or unsure of how the person will behave/react (17%) and not having enough information about dementia (15%).

Individual perceptions of people living with dementia

Most Canadians agree that people living with dementia are sometimes able to continue to do a variety of things after diagnosis, specifically continuing to be active in their communities (72%), continuing to live in their own home (70%) and continuing to do activities they enjoy (69%). Despite these positive perceptions, nearly two in three Canadians agree (65%) that people living with dementia generally face a lower quality of life than people without dementia, although this has declined since the benchmark 2020 survey (70%).

Canadians are less likely to agree that people living with dementia are sometimes able to continue working for years after the onset of symptoms (41%), which is a decrease of 6 percentage points from the 2020 findings (47%).

Seeking and sharing a dementia diagnosis

Almost 7 in 10 Canadians say they would be very comfortable asking a health care provider for information about dementia symptoms leading to an assessment and diagnosis (68%).

Among Canadians who say they would not be comfortable doing this (7%), they most often say it is because they are afraid of facing what lies ahead (75%), a fear of others treating them differently (56%), a lack of trust that the health care system will provide proper care (47%; 3% in 2020*) and a fear of alarming those close to them (46%; 51% in 2020). Close to one in three say they are uncomfortable because of a fear of their employer finding out and having to stop working (31%; a decrease from 45% in 2020) or that there is no point in knowing if nothing can be done to change the progression (21%; decreased from 34% in 2020).

*Of note, having a lack of trust in the health care system was not prompted on in the 2020 benchmark survey, but was mentioned verbatim by respondents. It was included as a prompted response option in this survey.

When it comes to sharing a dementia diagnosis, Canadians are more likely to say they would be very comfortable telling a close family member (57%; 64% in 2020) or friends (40%; 49% in 2020) about the diagnosis

than neighbours or others in the community (24%; 31% in 2020) or an employer (20%; 31% in 2020). Comfort has declined across the board compared to the 2020 benchmark survey, with the biggest decrease being in comfort telling an employer about a diagnosis which declined by 11%.

Popular culture portrayal

Canadians are nearly twice as likely to disagree (33%) rather than agree (18%) that dementia is portrayed accurately in popular culture, such as in newspapers, film, television, and social media. More than one in four neither agree nor disagree with this (28%) and 21% are unsure.

Among those who disagree that dementia is portrayed accurately, close to six in ten say it is portrayed more negatively than it really is (60%), while 17% think it is portrayed more positively, 8% think it is portrayed in some other way, such as in a way that is not accurate or realistic (2%) or not portrayed at all or rarely shown (2%). Fifteen per cent say they are unsure.

Perceptions of stigma in society

Most Canadians agree that people have negative assumptions about the abilities of people living with dementia (83%; an increase of 15 percentage points compared to the 2020 benchmark survey), that people living with dementia are usually perceived as needing others to make most of their decisions (80%) and are usually viewed as needing supervision in case of dangerous behaviour (80%). Three in five agree (59%) that people living with dementia usually are viewed as needing around the clock assistance with daily living. Agreement is much lower regarding the statement that people in their community are knowledgeable, respectful, and supportive of people living with dementia (27%) and that people living with dementia are usually viewed as being able to communicate their ideas and wishes to others (24%).

Canadians are over 10 times more likely to describe the quality of life of people living with dementia as poor (43%) rather than excellent (4%), while 41% describe it as moderate and 12% are unsure.

Nearly three in five Canadians say their views towards dementia have not changed in the past five years (59%) while more than one in three say their views have changed and are either more negative now (10%) or more positive now (26%) while 6% are unsure. Those who say their views have changed most often say this is due to knowing or caring for someone living with dementia (46%), followed by general information from sources other than the media (25%), and now being worried about getting dementia/now experiencing aging (9%).

Contract value

The contract value was \$179,941.20 (HST included).

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For more information, contact the Public Health Agency of Canada at HC.cpab.por-rop.dgcap.SC@canada.ca

Political neutrality statement and contact information

This certification is to be submitted with the final report submitted to the Project Authority.

I hereby certify, as a Representative of Nanos Research, that the deliverables fully comply with the Government of Canada political neutrality requirements outlined in the Government of Canada's Policy on Communications and Federal Identity and Directive on the Management of Communications. Specifically, the deliverables do not include information on electoral voting intentions, political party preferences, party standings with the electorate, or ratings of the performance of a political party or its leaders.



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