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Quality of Life and Dementia Qualitative and Quantitative Research

Executive Summary

Prepared for The Public Health Agency of Canada

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This public opinion research executive summary presents the results of focus groups conducted by Earncliffe Strategy Group on behalf of the Public Health Agency of Canada. The research was conducted from January 12 to June 3, 2021.

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EXECUTIVE SUMMARY

Earnscliffe Strategy Group (Earnscliffe) is pleased to present this report to the Public Health Agency of Canada (PHAC) summarizing the results of a two-phased qualitative and quantitative research project exploring quality of life and dementia.

Previous public opinion research conducted in 2019-20 indicated that two out of three Canadians agree that people have negative assumptions about the abilities of people living with dementia. To support implementation of the national dementia strategy, PHAC sought to build on this research to further inform work towards the strategy's priorities of eliminating stigma associated with dementia; promoting measures that create safe and supportive dementia-inclusive communities; and addressing the importance of access to quality care for those living with dementia. The findings from the research will be used to help inform program development and other initiatives undertaken by PHAC and others working on dementia related initiatives. Further, the research findings will be used to validate key components of quality of life for people living with dementia in a Canadian context to inform efforts intended to improve the quality of life. These findings will support annual reporting on the national dementia strategy and inform other efforts to track progress on improving the quality of life of people living with dementia, which is one of the strategy's national objectives.

The purpose of the research is to gain a first-hand Canadian perspective on the key components that constitute quality of life for people living with dementia, drawing on lived experience. The contract value for this project was \$188,810.90 including HST.

To meet the objectives of the research, Earnscliffe conducted a two-phased qualitative and quantitative research approach. To complete both phases of this research and with the intent of reaching as diverse a group of people living with dementia as possible, a creative sampling approach that involved leveraging our quantitative research partner, Leger's, proprietary online panel to canvass for people living with and/or caregivers of people living with dementia was used. The majority of those living with dementia (interview participants and survey respondents) were referred by their caregiver.

As the sample was drawn from an online panel, and the sample universe is not known, it was not possible to set quotas to ensure representativeness. Although efforts were made to balance for gender and region, Leger's panel does not include any panelists in Canada's territories and therefore there were no completions (either qualitative or quantitative) with northern Canadians. Because most interview participants and survey respondents were identified through their caregiver, this may have introduced bias in the research.

The first qualitative phase involved a series of 40 in-depth interviews with people living with dementia and/or their caregiver. The interviews were conducted between January 12 and February 12, 2021. The interviews were approximately 45 minutes in length. Interviewees were offered the option to complete the interview by telephone or video conference. Please refer to the Qualitative Methodology Report in Appendix B for distribution of interviews across target group, region, and completion mode (i.e., telephone or video conference).

The second phase involved a quantitative survey, conducted online or by telephone according to the respondent's preference, of 556 people living with dementia and/or their caregiver. Of those, 51 were

people living with dementia who completed the survey on their own; 190 were people living with dementia who completed the survey with the help of their caregiver; and, 315 were caregivers who completed the survey on behalf of the people living with dementia for whom they cared. In the tables throughout the report, 8 caregivers from the total of 556 were not included as they did not identify whether or not they were current or former caregivers.

The original survey was conducted from March 4-23, 2021 in English and in French, and took an average of 10 minutes to complete. Following the completion of the data collection, demographic results were found to be not necessarily consistent with what is known about people living with dementia (e.g., participants were younger in age). A hypothesis was made that in some cases the caregiver aiding the person living with dementia had answered the demographic questions about themselves instead of the person living with dementia. To confirm the integrity of the results and to gather the proper demographic information, PHAC in consultation with Earncliffe, made the decision to return to the sample with a follow up survey. The return to sample (RTS) survey was conducted from May 13-June 3, 2021 in English and French, and was completed by 481 people living with dementia and/or their caregiver from the first survey. A full description of the data cleaning process and reconciliation of original and RTS data has been provided in Quantitative Methodology Report in Appendix E.

It is important to note, when reading the qualitative findings, that qualitative research is a form of scientific, social, policy, and public opinion research. In-depth interview research is designed to elicit the full range of ideas, attitudes, experiences, and opinions of a selected sample of participants on a defined topic. Because of the small numbers involved, the participants cannot be expected to be thoroughly representative in a statistical sense of the larger population from which they are drawn, and findings cannot reliably be generalized beyond their number.

The key findings from the research are presented below. Please note a glossary of terms can be found in the Qualitative Methodology Report in Appendix B that explains the generalizations and interpretations of qualitative terms used throughout the report.

Overall Quality of Life

Self-Assessment of Quality of Life

- The survey revealed that while the majority (55%) of people living with dementia rate their quality of life as at least good, there is clearly a bell curve distribution with most responses dividing between fair (31%) and good (34%) and smaller proportions describing it as better than good (very good or excellent) (21%) or poor (13%).
- During the qualitative in-depth interviews, while most interviewees struggled to define quality of life from a conceptual perspective, they were able to provide an assessment of their own quality of life. Beyond the necessities of life (i.e., food, water, shelter), the most important aspect of quality of life for people living with dementia was being with or spending time with (depending on their own personal circumstances) family or loved ones. Those living alone (because they were capable of caring for themselves) also tended to think they had a generally good quality of life, especially because they had the freedom to do what they wanted, when they wanted.

Current Life Satisfaction Overall

- The survey revealed that many (39%) people living with dementia offer a neutral assessment of their current life satisfaction, saying they are neither satisfied nor dissatisfied with their life as a whole right now; but more describe themselves as satisfied (35%) than dissatisfied (24%).
- The majority of interviewees indicated that they currently live at home with a spouse/partner or close family member (their primary caregiver). A few currently live at home alone while three indicated that they live in a group home, long-term care facility or hospital setting.
- Most interviewees were generally very happy and comfortable where they live. When asked to describe the source of that comfort and joy, most tended to speak of the proximity of family and loved ones and the comfort of familiar surroundings and the security (peace of mind) that it provides. In addition to these factors, those currently living alone often pointed to the freedom of being able to do what they wanted, when they wanted, and having the ability to continue doing that.
- The few interviewees who were dissatisfied with their current living situation were either isolated from family and friends, did not have the financial means to live in a more desirable neighbourhood, or were not able to enjoy the outdoors as much as they would like.

Factors Impacting Quality of Life

- Survey respondents were asked to select which aspects most impact their quality of life from a list of fourteen different values and to offer any that they value that did not appear on the list. Approximately half of respondents in the survey say that good physical health (51%), having frequent support and visits with family and friends (51%), feeling comfortable in their surroundings (51%), good mental health (48%), being able to stay in their home as long as possible (48%), and being independent in daily living needs (47%) have the most impact on quality of life.
- Slightly fewer respondents in the survey believe that having a sense of purpose (45%), living with loved ones (43%), not having to worry about money (42%), being able to move around their community (41%), and making decisions about one's own healthcare (41%) have the most impact on quality of life.
- Among the factors reviewed in the survey, being able to be close to nature or enjoy the outdoors (35%), feeling a sense of belonging in one's community (27%), and being able to participate in religious or spiritual activities (21%) are the least likely to impact quality of life.
- Qualitative interviewees were asked to define quality of life (unprompted). While not common to all, especially given individual circumstances and/or stage of dementia, the more common factors that emerged that seemed to most positively impact their quality of life, included: family, health, safety and security, financial stability, freedom, having goals, having tasks to complete, being outdoors or in nature, food/enjoying a good meal, faith/religion, pets, hobbies or activities to participate in, sleep/naps, running errands, and travel.

Rating Specific Aspects of Life

- Survey respondents were then asked to rate their own quality of life on eleven different measures. When survey respondents were asked to rate aspects of their own quality of life (or that of the person living with dementia that they were responding on behalf of), the most positively rated aspects (percent excellent or very good) are relationship with family and friends (42%), access to health services (35%) and finances (29%). Roughly one in five respondents give excellent or very good ratings for their ability to live independently (22%), sleep (20%), and ability to spend time outdoors or in nature (20%). Of the quality of life factors examined in the survey, along with physical health (17%) and mental health (16%), those related to autonomy tend to be the lowest rated, including the ability

to: move around freely in their community (16%), socialize with others (15%) and engage in hobbies and leisure (14%).

- The factors that seemed to most negatively impact the quality of life of interviewees tended to revolve around dementia symptoms, including: the loss of memory/vocabulary, hallucinations/altered sense of reality, lack of mobility/dexterity, lack of energy, and lack of focus. These symptoms were often described as hindering their ability to do the things that most positively impact their quality of life. However, it is important to reinforce that this perspective was often provided by the caregiver; the person living with dementia was often unaware of these symptoms or the impact it has on their abilities.

Experiences Impacting Quality of Life

- Investigating the experiences of people living with dementia over the past year during the COVID-19 pandemic (March 2020 to May/June 2021 at the time of the survey) in the survey finds that the majority (87%) identify having had negative feelings or experiences. In the past year, over half of people living with dementia felt isolated (59%), sad (55%), or anxious (54%) for an extended period of time. Half of people living with dementia have felt helpless related to a loss of independence (49%) and approximately one-third have felt ashamed or embarrassed about their symptoms (35%).
- The survey revealed that the majority (85%) of people living with dementia have also experienced challenges or difficulties in the past year. Over half (53%) have had difficulty communicating their needs to others, and four in ten (39%) had people talk to their caregiver rather than to them even though they were present. There are a variety of other negative experiences identified by significant proportions of people living with dementia, including:
 - Approximately one-third of people living with dementia have:
 - been excluded from decisions about health care or finances that affect them (35%);
 - encountered people who focused on things they can no longer do instead of the things they can (33%); and,
 - had difficulty navigating a public space (31%).
 - Approximately one-quarter of people living with dementia have:
 - heard people make negative comments about their ability to do things (26%);
 - experienced a transition in care such as moving between health care settings (26%);
 - had support group meetings or activities cancelled (26%); and,
 - been unable to go where they needed to or wanted due to accessibility issues (24%).

Ease of Discussing Dementia Diagnosis

- The survey revealed that one-quarter (25%) of people living with dementia are comfortable talking about their dementia diagnosis and symptoms with those outside of their close circle, and only 6% say they are very comfortable doing so. The same amount of people living with dementia are neutral (26%), while 43% are uncomfortable talking about it.
- In the qualitative interviews, a few had refrained from sharing the news of their diagnosis with members of their family and/or friends. When probed, more often than not, this decision was generally made by those with early onset dementia, whose symptoms were not yet discernable, and a desire not to burden anyone unnecessarily. A few of these same people had refrained from sharing the news with their employers for fear of being penalized.
- With regards to any perceptible changes in family and/or friends' behaviour upon learning of their dementia diagnosis, interviewee experiences varied, although most felt that their interactions had not changed at all or had in fact improved.

The COVID-19 Pandemic

Awareness of the COVID-19 Pandemic

- The survey revealed that the vast majority (91%) of people living with dementia report that they have heard, read, or seen something about the COVID-19 pandemic.
- The qualitative interviews revealed that despite having some general awareness of COVID-19, some people living with dementia may not have a true understanding of the nature and/or severity of the pandemic, as some caregivers reminded the person living with dementia during the interview about public health restrictions to prompt awareness of the pandemic.

Impact of COVID-19

- The vast majority of people living with dementia feel COVID-19 has had a negative impact on their quality of life (84%), including one-third (32%) who describe the effect as very negative. Few say that COVID-19 has had no noticeable impact (14%), and almost none (2%) describe the impact as positive.
- In addition to the disruption of certain services, many (about half of) interviewees described having a hard time with the public health restrictions with respect to the inability to get together with family and friends or do the things they used to do; while for a smaller number (some interviewees), this pandemic period has not proven to be much different than their previous day to day (i.e., staying at home).
- For some interviewees, the disruption of services was particularly problematic. Some mentioned missing the support group meetings/activities and religious services they attended regularly. Mostly, they missed the opportunity these activities provided to socialize in a comfortable setting. A few also mentioned needing to adapt to video or telephone appointments and feeling uncomfortable with digital technology.

Change in Frequency of Contact Since COVID-19

- Among the vast majority of participants in the survey who were aware of COVID-19 and have an unpaid caregiver, seven in ten (69%) say they do not see their caregiver any less as a result of the pandemic, while 23% that say they see their unpaid caregiver more. Almost one-third (31%) say the pandemic has caused them to see their unpaid caregiver less often.
- Participants in the in-depth interviews spoke about the impact of having less physical contact with people in their lives. In fact, the most important change during the pandemic seemed to be the lack of physical contact and in-person visits. The impact of this was different depending on the situation. For some, the lack of physical contact was depressing and isolating. However, for most, it was not all that noticeable because they were living with family and still seeing family members regularly at a distance and/or talking regularly on the telephone or on video calls.

Caregiving and Support

Types of Care Providers

- The majority (62%) of people living with dementia have an unpaid caregiver, while half as many (31%) have a care provider who is paid by the healthcare system, and less than one-quarter (22%) have a care provider who they pay themselves or is paid by someone in their household.
- The majority of participants in the qualitative interviews do not pay out of pocket for additional support. Those who do not personally pay for a care provider either did not have the means to do so

or did not feel their dementia was at a stage that required that level of care yet. Of the few who have a paid care provider, a few were on the receiving end of provincial government support in the form of a personal care worker. Often the support provided by these personal care workers included administering medications, personal care, meal preparation, and/or general supervision/companionship.

- Those at the receiving end of external support (i.e., care provider to help with medication, personal hygiene, physical exercise) felt that it was extremely helpful; especially the caregivers for whom this support provided them with a regular respite during the week. For the person living with dementia, it was a pleasant distraction and an opportunity to socialize.
- In terms of community support, most generally felt that they had what they needed. In fact, when asked what is making it difficult for them to stay engaged/involved, most were unable to list any resources they thought were lacking.
- Community support needs differed significantly based on individual circumstance and/or severity of dementia. For example, some people living with dementia who live alone explained that they live in an urban community setting deliberately to ensure they have ready access to the community supports they need. Others, who live with their caregivers, explained that they had chosen to move to a more rural setting so that they could live away from the hustle and bustle of urban life and be closer to nature.

Types of Professional Care Providers

- Among those who have a paid caregiver, more than two-thirds (69%) say they have a personal support worker, while almost half say they have a nurse (47%) and/or a doctor (43%) as part of their ongoing care. Less than one in five (17%) have a developmental service worker.
- Over half (55%) of people living with dementia who have paid care providers have at least one that provides care for them in their own home.
- When interviewees were asked if they were aware of any services or benefits available to assist people living with dementia, responses were split. Those aware of services recalled receiving help or introductory information from the Alzheimer Society although many had not followed through and reached out. Other supports that were mentioned included the availability of doctors, nurses and personal care workers, although some had difficulty navigating the provincial health care systems to access these services. Few, if any, spoke of federal and/or provincial benefits available to them. One or two mentioned insurance and/or tax relief but details were vague.

Knowledge of Paid Care Providers

- The majority (72%) of survey respondents feel that their paid caregivers are very knowledgeable or somewhat knowledgeable about supporting people living with dementia. However, one in five (22%) say their paid caregiver is not knowledgeable.

Tasks Performed by Paid Care Providers and Unpaid Caregivers

- The survey revealed that for those who have them, over the past year, paid caregivers have most commonly been helping with activities of daily living (76%) and general health care and health monitoring (72%); less so with house maintenance (40%), transportation (29%), or financial affairs (16%).
- The variety of support being provided by unpaid caregivers is much broader than is typically being provided by paid caregivers. Caregivers are about as likely as paid caregivers to be providing assistance with activities of daily living (69%) and general health care (78%), but are far more likely to be assisting with transportation (74%), financial affairs (72%), and house maintenance (69%).

Relationship to Unpaid Caregivers

- The survey revealed that of the people living with dementia who have unpaid caregivers, the most common relationship type is a child (66%). Less common relationships include spouse (26%), grandchild (10%), child-in-law (10%), or a friend (10%).
- When asked to describe their relationship with their caregivers in the survey, the majority of qualitative participants conveyed an overwhelming sense of appreciation and gratitude to have these people in their lives to support and care for them. Quite often, this question elicited a lot of laughter especially when the person living with dementia described the occurrence of “trying” moments in addition to all of the “good” moments.
- When asked whether they had a support system of family or friends (beyond their unpaid caregivers), responses seemed to vary widely based on individual circumstances and severity of dementia. Those with early onset dementia and those living with their caregiver(s) spoke of having fairly strong networks of family and friends with whom they were in regular contact. Some at more advanced stages of dementia spoke of having some contact with close family but limited friend networks.

Frequency of Contact with Unpaid Caregivers

- Prior to COVID-19, the majority of people living with dementia in the survey (67%) say they interacted daily with their unpaid caregivers. Most of the remaining respondents (29%) say they interacted with these caregivers at least once per week.
- People living with dementia who are not aware of COVID-19 have a similar experience with their unpaid caregivers as those who are aware of COVID-19 in terms of frequency. Two-thirds (67%) interact with their unpaid caregiver daily.

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I hereby certify as a Representative of Earnscliffe Strategy Group that the final deliverables fully comply with the Government of Canada political neutrality requirements outlined in the Communications Policy of the Government of Canada and Procedures for Planning and Contracting Public Opinion Research. Specifically, the deliverables do not include information on electoral voting intentions, political party preferences, standings with the electorate or ratings of the performance of a political party or its leaders.

Signed:



Date: August 5, 2021

Stephanie Constable
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