

# Increasing Awareness and Understanding Perspectives of Dementia Caregivers:

National Survey Technical Report  
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## 1.0 Introduction:

Today there are over 1 billion older adults globally, and by 2030 it is estimated that 1 in 6 persons will be over the age of 60 years.<sup>1</sup> While the development of Alzheimer's disease or other dementias is not a normal part of ageing, the prevalence of this collection of diseases does increase with age.

People with dementia can live dignified lives but as their disease progresses, they increasingly rely on others in order to exercise their autonomy.<sup>2</sup> Echoing the mandate of the UN Decade of Healthy Ageing ('the Decade'), the IFA is dedicated to helping maintain and increase the functional ability of older adults through policy and practice change, which in the context of dementia must include robust and meaningful engagement and incorporation of the voices and perspectives of those supporting and providing care.<sup>1</sup>

Carers can be defined by their relationship to the person with dementia and their care input. Many dementia carers are relatives or extended family members, but close friends, neighbours or volunteers (in addition to paid supports) can also take on responsibilities for caring. The degree of care provided by caregivers can vary greatly, from assisting with hands on day-to-day support through to helping organize the care delivered by others.<sup>3</sup>

Caregivers can spend approximately 26 hours per week caring for a person living with dementia which represents a significant amount of the caregiver's time, often encroaching and impeding their ability to ensure their own needs are met and health prioritized.<sup>4,5</sup>

### 1.1 Impact on the Mental and Physical Health of Caregivers

Beyond simply time investment caregivers also experience higher levels of stress and are at higher risk of injury and depression than the general population. As dementia progresses, the needs of the person living with dementia increase, behavioural and psychological symptoms of people living with dementia can become more challenging to manage and have a significant impact on a caregiver's health.<sup>4,6</sup> Compared to non-caregivers, dementia caregivers report higher levels of stress, more depression and anxiety symptoms, and lower levels of subjective well-being, self-efficacy. Caregivers also experience worse physical health outcomes when compared to the general population, including higher levels of stress hormones, compromised immune responses, greater medication use, and greater cognitive decline.<sup>7</sup>

Furthermore, in cases where the person living with dementia needs to transition to a long-term care home or another facility, feelings of guilt can arise for caregivers as well as additional financial strain.<sup>4</sup>

### 1.2 Financial and Employment Considerations for Caregivers

Caregivers are also more susceptible to financial and employment difficulties, particularly when caring for a person diagnosed with early onset dementia. Caregivers are often responsible for considerable out-of-pocket costs, including costs for home modifications, help with activities of daily living, support for recreation, transportation, travel or accommodation, specialized aids or devices and medications, and rehabilitation services. On average, caregivers spend \$4,600 out-of-pocket annually for each person under their care who is living with dementia.<sup>8</sup>

For more than half of Canadian caregivers who are employed may face serious negative financial consequences, including lost income due to reduced hours of work which in turn can negatively impact pension and retirement income.<sup>9</sup> Caregivers often need to adjust work schedules to accommodate for medical appointments or emerging care issues. This creates a considerable barrier particularly for those that may not be able to find employment that will allow for an appropriate balance between work and caregiving. In some instances, these barriers have led to caregivers needing to leave the workforce entirely. Caregivers of persons with young onset dementia tend to be younger, provide more hours of care, and may experience greater financial impacts as a result of caregiving, as do those caregivers who already have a low income.

While there are federal tax measures in place to recognize the impact of caregiving expenses and many provinces and territories provide similar credits, the policy landscape is inconsistent and inadequate given the significant impacts associated.<sup>4,10</sup>

## 1.3 The Problem

The significant physical, mental, and financial impacts of caring for an individual living with dementia must be addressed and yet despite the importance of caregivers and the significant burdens on this population efforts to understand the perspectives, needs and insights of this community in Canada have been limited.

Caregivers are crucial members of a care team and improving support for caregivers is integral to improving the quality of life of the person they are caring for as well as ensuring their own health and well-being. Increasing collective understanding and creating opportunities for caregiver voices to be heard is aligned with goals of the WHO's Global Action Plan on the Public Health Response to Dementia and is essential towards increasing awareness of the involvement of, and barriers that caregivers face daily.

With this in mind, and in responding to action area 5: Support of dementia carers of the WHO's Global Action Plan on the Public Health Response to Dementia— Proposed Actions for International, Regional, and National Partners—the International Federation on Ageing developed a national survey, to help address existing gaps in knowledge and identify opportunities to mitigate tangible barriers.<sup>3</sup>

This report will also assess the degree to which survey findings align with Canada's current National Dementia Strategy to better understand and inform recommendations to improve and respond to caregiver needs.

## 2.0 Methodology and Materials

### 2.1 The Emergence of Canada's National Dementia Strategy

Highlighting the need to rapidly address the growing impact of dementia, the Canadian National Strategy for Alzheimer's Disease and Other Dementias Act (the Act) was passed in June 2017. The Act requires the federal Ministry of Health to develop a national dementia strategy, informed by a national conference and a Ministerial Advisory Board. Following the 2018 National Dementia Conference: Inspiring and Informing a National Dementia Strategy for Canada, Canada's first national dementia strategy A Dementia Strategy for Canada: Together We Aspire was established.<sup>11</sup>

The strategy highlights three main objectives:

1. the prevention of dementia
2. the advancement of therapies and finding a cure, and
3. the improvement of the quality of life of people living with dementia and caregivers.

To achieve these goals, the strategy makes clear the necessity of supporting evidence-informed care to improve the quality of life of people living with dementia as well as their caregivers. Furthermore, the strategy identifies groups at higher risk of dementia, as well as those who face additional barriers to receiving equitable treatment and care. Groups who have experienced historical and on-going discrimination and exclusion, as well as those who require additional and uniquely tailored supports, include but are not limited to: Indigenous peoples, individuals with intellectual disabilities, older adults, women, ethnic, racial, and cultural minority populations, LGBTQ+ individuals, official language minority communities, rural and remote communities, and those with young onset dementia.<sup>11</sup>

### 2.12 Highlighting the Caregiver Experience in Canada's National Dementia Strategy

The first national objective, Prevent Dementia has a focus on advancing research to identify and assess modifiable risk and protective factors; building the evidence base to inform and promote the adoption of effective interventions; supporting measures that increase social contributions and encouraging the development and refinement of built environments that help to foster healthy living and the adoption of healthy living behaviours. Canada's national dementia strategy further highlights that interventions that promote healthy living can reduce the risk of developing dementia. Behaviours associated with healthy living can include physical activity, adequate and consistent sleeping patterns, healthy eating, and avoiding behaviours that may harm health such as smoking.<sup>11</sup>

Jeopardizing healthy living, caregivers experience higher levels of stress, and face higher risks of injury, depression, and financial and employment difficulties than the general population. Dynamic and unpredictable working conditions, paired with a lack of training for friends/family caregivers can lead to burnout and high turnover rates for care providers. Under the national objective Prevent Dementia, risk factors for dementia include: lower levels of early life education, midlife hypertension, obesity, hearing loss, smoking in later life, depression, physical inactivity, diabetes, and social isolation. Efforts made to prevent dementia must also make consideration of the allocation of supportive resources for caregivers, given that they are already at an increased risk, and/or experience a higher rate of the risk factors for dementia themselves. Thus, for those at an increased risk of developing dementia, delaying its onset may also improve quality of life and reduce the personal, family and societal costs of care.<sup>11</sup>

Included in the mandate of supporting all people living with dementia is the importance of ensuring that the lives of caregivers are valued and supported, the quality of their lives is optimized, and their experiences are well understood. Under the third national objective to “Improve the quality of life of people living with dementia and caregivers” are five areas of focus:

1. Eliminate stigma and promote measures that create supportive and safe dementia-inclusive communities.
2. Promote and enable early diagnosis to support planning and action that maximizes quality of life.
3. Address the importance of access to quality care, from diagnosis through end of life.
4. Build the capacity of care providers, including through improved access to and adoption of evidence-based and culturally appropriate guidelines for standards of care.
5. Improve support for family/friend caregivers, including through access to resources and supports.

This national objective further exemplifies the inaccessibility of many dementia services and supports, stating that people living with dementia and caregivers would benefit from easier access to care and supports available in their communities.

### 2.13 A Dementia Strategy for Canada: Together We Achieve- 2023 Annual Report

As stated by the Act in 2019, the Government of Canada is required to share an annual report on the effectiveness of the national dementia strategy. The 2023 annual report highlights the progress that has been made towards achieving the objectives outlined in the strategy, including the improvement of the quality of life of people living with dementia and their caregivers.<sup>12</sup>

Compared to 2018-2019, the percentage of caregivers of people living with dementia experiencing distress remains higher than the rates amongst other caregivers. In 2022, 38.1% of caregivers (providing home care to people living with dementia) experienced distress, compared to 19.7% of caregivers for someone without dementia. While the distress rates remained constant between 2018 to 2022 for caregivers of persons living with dementia, they continue to be significantly higher than caregivers for someone without dementia.<sup>12</sup>

While Canada’s national dementia strategy, and annual report include the objective, “Enhanced Dementia Surveillance Initiative: Strengthening Canada’s data”, monitoring of annual changes to the experiences and perspectives of caregivers of persons living with dementia remains rather limited. The primary findings from the annual report show:

1. those who moved to long-term care were more likely to have moderate or more severe cognitive impairment relative to those who stayed in their homes (32% vs 21%); and
2. those who moved to long-term care were more likely to be cared for by a family caregiver experiencing distress (41%), relative to those who stayed in homecare (32%).<sup>12</sup>

Ultimately, Canada’s national dementia strategy, and subsequently, the 2023 annual report, reveals a lack of monitoring of the perspectives and lived experiences of dementia caregivers, and further shows a need for policy makers to be well informed on the activities, challenges, and desires of caregivers. A greater effort is needed to ensure programming is offered and available not only to persons living with dementia, but specific to the caregivers.

## 2.2 Study Design

Responding to the objectives outlined in Canada's National Dementia Strategy, the International Federation on Ageing initiated the Increasing Awareness and Understanding Perspectives of Dementia Caregivers project. Recognizing the importance of adequately addressing the significant physical, mental and financial impacts of caring for an individual living with dementia, a survey was developed to help increase our understanding of the perspectives of Canadian caregivers including; impacts on daily life, and importantly what resources and supports are most needed to help ameliorate some of the negative impacts this population faces.

## 2.3 Survey Design and Recruitment

Following an in-depth review of Canada's National Dementia Strategy and existing literature on the Canadian caregiving context, a 15-minute, ~40 question survey was created by the International Federation on Ageing (IFA). The survey was programmed and disseminated via QuestionPro, which allowed for a variety of question formats to be asked, including multiple choice, Likert scale and rankings, and written responses.

To ensure fair and consensual participation in the survey, a consent statement outlining the topics covered, length of time, and confidentiality of responses was shared with participants. The survey was disseminated using non-probability sampling, with the support of the market research and analytics company, Leger, who shared the survey to their pre-existing network of Canadian caregivers of people living with dementia. The survey was completed by 397 respondents, over a two-week period. Of note, the survey did not include responses from those who provide care for anything other than dementia, limiting the ability to compare the experiences of dementia care providers with other types of caregivers.

## 2.4 Survey Analysis Process

The data collected through the national survey was compiled through QuestionPro, highlighting the percentage and number of responses to each question, and providing access to long answer written responses before undergoing additional analysis. Significant quantitative figures were reported in the results section and interpreted in the statement of findings. Written responses were reviewed and underwent thematic analysis, in which, general initial codes were given to each response. Emergent patterns were then sorted into over-arching emergent themes and categories for each open-ended question.

## 2.5 Ethical considerations

Ethical issues were taken into consideration to ensure minimal to no harm was done to survey participants. Participation was voluntary, and respondents were given the opportunity to withdraw at any time without penalty. All data was de-identified to ensure confidentiality. Before commencing the survey, participants were required to agree to the terms of participation. Outlined in the terms of participation was an explanation of the purpose of the study, including the creation of this report; what involvement in the survey will require, including responding to multiple choice and written questions, and requiring roughly 15 minutes to complete; risks with participation, including the personal and, at times, upsetting nature of the questions; benefits to participation, including the possibility of having an outlet to voice their experiences as a caregiver; and the use of responses in the publicly shared technical report. Further ethical considerations were made through the design of the survey, as the authors ensured that questions were worded in lay terms and organized in a manner that dispersed potentially difficult questions, as to ensure respondents did not feel an unnecessary emotional burden to participation.

## 3.0 Survey Results

### 3.1 Demographic Composition of Caregivers

Canadian caregivers for people with dementia responded to the International Federation on Ageing's (IFA) survey on the experiences and perspectives of being a caregiver for a person with dementia. The survey was completed by 397 people. Of the 397 respondents, 108 identified as men (27%), 286 as women (72%), and two as non-binary or gender diverse (0.5%).

The reported sexual orientations of respondents varied across the spectrum, with 84.4% of respondents identifying as heterosexual or straight, and nearly 16% identifying as a member of the LGBTQ+ community (including those who are asexual, bisexual, gay, lesbian, pansexual, queer, and demisexual).

The age of respondents varied, with 27% reporting to be between the ages of 56-65 years of age, 20% between 66-75, 18.4% between 46-55, 12.6% between 26-35, 12% between 36-45, 5% between 76-85, and 4% between 18-25, and 0.5% over 86 years of age.

Most respondents reported being of White or European descent at 82.4% of respondents, followed by 5.3% of East Asian descent, and 2.8% of Southeast Asian descent. Those of Middle Eastern, Indigenous, Latin American, Black, or African American, and South Asian descent were all significantly underrepresented composing 0.76%, 1%, 1%, 2.5% and 2.3% respectively.

Following the survey requirements, 96% of respondents reported to be Canadian citizens, with approximately half of all respondents currently residing in Ontario (46%). Following Ontario, the most frequently reported province of residence was British Columbia at 14%, followed by 12% in Alberta, and 10% in Quebec.

The total income of respondents was dispersed across the range of responses, with the highest frequency of respondents (18.9%) making between \$80,000- \$99,999 before taxes annually, followed by 15.4% making \$100,000 - \$149,999, 15% making \$40,000- \$59,999, 10% making \$20,000 - \$39,999, 9% making \$60,000 - \$79,999, 8% making \$150,000 - \$199,999, 4% making \$19,999 or less, 4% making \$200,000 - \$249,999, and 3% making \$250,000 or higher annually.

### 3.2 Understanding the Care Context

Most respondents (77.53%) reported providing care for a member of their family, with half of all respondents indicating that they provide care for one of their parents (50.5%). Notably, the largest proportion of respondents (29.5%) stated that the person they provide care for lives in a long-term care facility (LTCF), followed by 21.2% of respondents indicating that the person they are providing care for resides at their place of residence. Only 10.3% of respondents state that the person with dementia that they provide care for lives alone or independently.

More than 3 out of 4 caregivers (77%) have reported to provide care for a person with an official dementia diagnosis in the previous 12 months. Of the persons with dementia being cared for, 46.7% were reported to be diagnosed with Alzheimer's Disease, 15.7% with Mixed Dementia types, and 8% with Vascular Dementia. Of note, approximately 1 in 4 (21%) of respondents were unsure of the type of dementia the person they care for has.

With respect to severity, the majority of respondents indicated that they are providing care for someone with moderate to severe dementia, with 33% of respondents indicating that they provide care for a person with moderate dementia (Characterised as people who need more help with daily activities and self-care; people may experience poor judgment and deepening confusion, great memory loss, significant changes in personality and behaviour, and require help with some daily activities), and 31% for a person with severe dementia (Characterised as people who experience a continuous decline in mental function, and growing impact on movement and physical capabilities; people may experience the loss of ability to communicate, a decline in physical abilities like walking, and require daily assistance with personal care).

### 3.3 Caregivers' Employment and Financial Status

Only 12.6% of caregivers receive some form of income, whether partial or full, from caregiving, while 83.7% of respondents receive no income at all from their role as a caregiver. Furthermore, over a quarter of all caregivers (30%) agree, or strongly agree that their role as a caregiver has conflicted or impeded their success at work. Similarly, 28% of caregivers agree, or strongly agree that their role as a caregiver impacts their ability to gain or hold employment. Caregiver responses highlighted the lack of work-place flexibilities afforded, with more than half of caregivers (53%) being afforded 10 or less sick or mental health days from their employer annually. For those who are employed as caregivers, 59% of respondents take time off monthly to fulfill their role as a dementia caregiver and more than half of respondents (52%) indicated that time taken away from paid employment has increased in frequency since they began caregiving.

When asked about the financial impact that caregiving for a person with dementia has had on their savings or retirement funds, nearly half of caregivers indicated that they have felt impacted (49%).

13% of caregivers stated that their savings have been moderately or significantly impacted by their role as a dementia caregiver. Furthermore, 68% of respondents indicated that their out-of-pocket expenses have increased since they started caregiving.

### 3.4 Caregivers' Use of Supportive Resources

Caregivers highlighted a lack of resources available for both people living with dementia, as well as for themselves as caregivers. When asked, "Based on the stage of dementia of the person you provide care for, do you believe there are adequate resources and treatment options accessibly available for them?", nearly half of respondents (42%) disagreed.

Almost all caregivers (95%) indicated that their knowledge of dementia has increased since they began caregiving, with 41% of respondents stating this increase of knowledge was significant. Nearly half (45%) of all respondents learn the most about dementia from talking with medical professionals, including doctors or nurse practitioners. Reading, listening to podcasts or watching videos from evidence-based sources; and learning through local or community-based organizations were tied for the second most informative sources of learning about dementia (20% of respondents respectively). Respondents found friends, neighbors, or family members as the least informative source, with 37% of respondents ranking them as the least informative resource.

When survey respondents were asked, "In the last 12 months, have any sources not [previously] mentioned taught you about dementia?" written responses were varied but could be sorted into three key emergent themes: 1) Self-driven research, 2) Media representation, and 3) Lived experience. Answers representing self-driven research, include caregivers seeking and attending academic discussions on dementia, reading news articles and publications about dementia, and attending college courses and workshops about dementia and caregiving. Many respondents also highlighted how helpful and comforting seeing social media and traditional media representations of dementia and caregiving are. Multiple respondents discussed how social media and online communities provide support and information, including platforms like TikTok that provide a forum to highlight caregivers' experiences. Finally, responses highlighted how informative experiencing a loved one with dementia can be, and how they learn through experience and proximity to those who also care for persons with dementia.

Notably, over three quarters of respondents (76%) indicated that their access to community resources and supports has not changed since they began caregiving with no additional supports or resources being made available. Furthermore, approximately half of all caregivers (49%) stated that time spent with friends and family had not increased at all since they began caregiving for a person with dementia.

### 3.5 Responsibilities as a Caregiver

Approximately three quarters of caregivers (74%) spend more than 5 hours a week providing in-person care, with an additional 31% of caregivers indicating that they spend between 5-15 hours a week providing in-person care for a person with dementia. More than half of caregivers' state that they are sometimes, often, or always the only person who is available to provide care (63%).

The most reported task that caregivers provide support with is transportation; transporting the person they care for to medical appointments, leisure activities and social events (77.3% of respondents indicated they perform this task). Following transportation assistance, the second most performed task (68%) for caregivers is assisting with domestic duties, including meal preparation, dish washing, grocery shopping, cleaning the home, doing laundry, and cleaning shared spaces. The third most frequently reported task (61%) was assisting with medical treatments such as taking medications, engaging in mind-stimulating activities, and engaging in therapeutic practices. Almost half of all caregivers (43%) also indicated that they provide support with personal care, including bathing and showering, nail care, foot care, genital care, dental care, grooming, and dressing. Through their written responses caregivers also indicated that companionship, and simply spending quality time together was also a common and important task.

Most respondents (89%) indicated that their responsibilities and tasks as a caregiver have increased in intensity since they began caregiving, with nearly half of all respondents marking this increase as moderate or significant (44%).

Less than half of all respondents (40%) indicated that if there was another available option, they would want to spend less time caregiving.



### 3.6 The Impact of Caregiving on Lifestyle

Dementia caregiving had a range of impacts on the lifestyle choices of Canadian caregivers. Half of caregivers (50%) affirmed that their role as a caregiver for a person with dementia has impacted their ability to eat regularly and well. Following similar trends 64% of respondents indicated that being a caregiver had impacted their ability to be physically active and over three quarters of respondents (76%) indicated that being a caregiver had impacted their duration and quality of sleep. Two thirds of respondents (66%) indicated that being a caregiver had impacted their ability to have meaningful social connections and nearly half of respondents (46%), indicated that being a caregiver had impacted their sexual relationship.

Most respondents (79%) indicated that being a caregiver had impacted their ability to take vacations, with 26.5% of respondents stating that their ability to take a vacation had been significantly impacted.

Furthermore, nearly half of all respondents (49.5%) positively indicated that being a caregiver had impacted their ability to attend their own medical appointments, including doctor, dental, massage therapy, physiotherapy, or a psychologist.

### 3.7 Caregivers' Coping Strategies and Support Systems

The most frequently reported coping methods used by caregivers in the past 12 months was reading, watching television, or listening to music at 64.5%, followed by socializing or talking to friends or other caregivers at 64.3%, and exercising, walking or yoga at 58.4% of respondents.

The least reported coping methods used by caregivers in the past 12 months were prescription drugs (12.5%) and religious, spiritual or meditation practices (16.6%). Notably, 1 in 5 respondents indicated accessing professional counselling or therapy services to cope with their caregiving responsibilities.

The most frequently reported source of support to caregivers was a spouse or partner (39%) which often involved modifying their life or work arrangements to help provide support with an additional 38% of caregivers reported their extended family members providing them with support. Notably, only 9% of caregivers indicated that they had received support from their communities.

When asked whether as caregivers they feel that the supports, they have access to consider their race, gender, sexual orientation, religion, or culture-based needs (including providing translation or information available in other languages), most respondents indicated that they do not receive cultural supports.

It is noteworthy that only 41% of caregivers feel adequately supported in their role.

When asked what kinds of support they would like to have more of, over half of all caregivers (61.2%) stated they need more financial support, government assistance or tax credits; 46% stated they need more home care support; 39% wanted more information and advice; and 38% needed more emotional support or counselling.

When caregivers were asked "What does the public not understand about dementia caregiving?", respondents highlighted a number of key areas for further consideration including;

1. How difficult and all-consuming caregiving is,
2. Having dementia is more than just having memory loss,
3. The isolation and lack of support that caregivers experience,
4. How resource intensive caregiving is, and the lack of resources accessible to caregivers
5. The heterogenous nature of a caregiver's day to day experiences
6. The experience of "loosing" a loved one while they are still alive, and
7. The joy that caregiving brings and the inherent value of persons living with dementia.



Image 1: Caregiver responses to the question “What does the public not understand about dementia caregiving?”

## 4.0 Discussion

As the Canadian population continues to age rapidly, the responsibility to provide care will only continue to increase, impacting the lives of the family, friends, and communities of those in need of additional care supports. Understanding the experiences and hearing the perspectives of those who provide care for persons living with dementia is crucially important in identifying mechanisms through which the support of caregivers, and those living with dementia, can be improved. The significant physical, mental, and financial impacts of caring for an individual living with dementia must be addressed and yet despite the importance of caregivers and the significant burdens on this population, efforts to understand the perspectives, needs and insights of this community in Canada have been limited.

Improving the supports, resources, and experiences of caregivers not only has the ability to profoundly impact the health, financial status, and quality of life of caregivers, but it also presents an opportunity to improve the care structures for persons living with dementia, ultimately enhancing Canadian communities. Furthermore, understanding the culture, race, gender, class, age, and sexual orientation-based diversity in the caregiving experience is crucial to creating and improving the lives of caregivers and those they care for.

## 4.1 Statement of Principal Findings

Building upon and further strengthening evidence from existing literature, data from the Increasing Awareness and Understanding Perspectives of Dementia Caregivers survey tells a strong narrative: Canadian caregivers continue to feel isolated and alone in the responsibility of caregiving, impacting their healthy lifestyle behaviours, saving plans, interpersonal relationships, and connections to their communities.

### 4.1.1- Family and Community Care

Findings reaffirm that the responsibility for caring for a person with dementia largely lies with the friends, family members, and close network ties of persons with dementia, with most caregivers (77.53%) providing support to a family member, and with half (50.5%) providing support to a parent with dementia. As previously noted, as the Canadian population ages and government facilities continue to be over-burdened, informal caregivers, such as family members, will continue to bear the brunt of responsibility for the provision of care.<sup>2</sup> This is further supported by the data indicating that only 29.5% of respondents

state that the person they provide care for lives in a long-term care facility (LTCF) and only 10.3% of respondents state that the person with dementia that they provide care for lives alone or independently. Thus, not only do informal caregivers for people living with dementia require the tools to provide care, but their communities must also respond to the environmental and social needs of people living with dementia and their care providers.

Improving and enhancing environments to accommodate healthy ageing and the active engagement of older adults is of paramount importance. Launched by the World Health Organization (WHO), the WHO Toolkit for Dementia-Friendly Initiatives: Towards a Dementia-Inclusive Society, is a document created with the purpose of raising public understanding of dementia to support people living with dementia to remain in their communities.<sup>14</sup> The toolkit takes a person-centered, rights-based approach that is founded in international commitments, such as the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), the 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs) and Universal Health Coverage (UHC). As such, dementia-friendly communities ought to be inclusive, and facilitate engagement in community for all people, not just those living with dementia.<sup>15</sup> However, research into the integration of dementia inclusive practices and guidelines into Canadian cities and communities, as well as the interconnection between age-friendly and dementia-friendly initiatives internationally, remain largely absent. Paradoxical survey findings show that local or community-based organizations are ranked as one of the most informative sources of learning about dementia, yet less than 1 in 10 caregivers indicated that they had received support from their communities. Thus, findings support the conclusion that while community resources can be largely beneficial to caregivers, access to these resources is limited. Efforts must be made to improve the availability and accessibility of community resources and increase public knowledge and care for persons living with dementia and their care providers.

#### 4.12- Resources and Supports Available to Caregivers

The responsibility of being an informal care provider has serious and meaningful implications to the well-being and lifestyle of Canadians. Findings suggest two key points regarding the status of supports and resources for caregivers: 1) Caregivers need increased supports to aid in their roles as caregivers, and reduce the burden of care providing, and 2) Independent to, but impacted by their role as a provider of care, Canadian caregivers need additional resources and supports to address the negative impact that caregiving has on their lifestyle choices and healthy behaviours.

First, as currently expressed, caregivers do not receive adequate resources to support them in their duties providing care for a person living with dementia. Responses highlight how isolating of an experience providing care can be, with 59% feeling inadequately supported in their role.

“As dementia becomes more common, I would have expected an “emergency network” would exist to provide support to the caregivers. I remember a situation where I spent 90 minutes to get someone to come home to calm down my partner - no emergency help was available except “911”. Although reluctant to call, I did because that was the only recourse. I feel that was a misuse of an important resource. What is required, in my humble opinion, is a “24/7 emergency dementia crisis resolution network” to help out caregivers. Sometimes, caregivers get overwhelmed and family members are not always available!”

“Most of the time I feel like it’s all on me.”

“Have to fight for provincial healthcare support, and then, in rare circumstance when support is available, I am generally disappointed with the quality of service provided.”

“Some days are really hard and I don’t know where to turn. People listen but they don’t actually help. I need help and not words.”

Many caregivers feel alone in their caregiving. In large, responses highlight the need for increased resources to support the tasks associated with caregiving, like home care supports, financial support, government assistance or tax credits, and additional information and advice on how to provide care. Thus, findings suggest that the approaches to supporting caregivers must recognize the diversity of their needs, and provide solutions that not only offer monetary, but in-person supports.

Further, Canadians expressed a lack of support in their roles as caregivers that consider their culture, race, gender, class, age, and sexual orientation-based needs, further reflecting feelings of being misunderstood and forgotten. The following quote exemplifies the impact of receiving inadequate supports as a caregiver:

“The level of support was inadequate and became even less adequate as my need for support increased. I applied for respite and had to put my husband through rigorous testing, which was confusing for him and in the end, no support materialized.”

“We have no family support. It makes everything challenging because we are a Muslim household as well so there’s a lot of discrimination. My mother that has dementia wears a hijab. The lack of resources and support is overwhelming and disappointing.”

Second, caregiving greatly impacts individuals’ ability to provide self-care and engage in healthy lifestyle choices. Thus, caregivers require tailored supports for themselves that not only support their role and responsibilities in providing care, but also center their needs as individuals outside of their caregiving responsibilities. These caregiver-centric resources must address the lifestyle impacts that caregiving has and include the promotion and support of: healthy eating; physical activity; quality sleep practices; meaningful social connections; healthy sexual and romantic relationships; and routine medical check-ups, including doctor, dental, massage therapy, physiotherapy, and psychotherapy. Caregivers indicate, through quantitative and qualitative responses, that they need more emotional supports and counselling.

“Our support is very much each other...[caregiving] is a very stressful endeavor I think that there are not enough resources to help people navigate the system and the system is overwhelmed.”

“[the public does not understand that caregiving is] mentally draining and emotionally exhausting”

“They do not understand how mentally tiring it is or how frustrating it gets. Your life becomes not yours anymore because you always have to worry about the person with dementia and you have to rearrange your life to be available to them. Your entire life changes.”

As highlighted under the national objective Prevent Dementia in Canada’s National Dementia Strategy, caregivers for persons living with dementia experience environmental conditions and impacts that place them at greater risk for cognitive decline.<sup>11</sup> Findings continue to support the notion that caregivers require more resources, and those recourse must find a balance between creating supports that help reduce the burden associated with the tasks caregivers are performing and promoting self-care that is independent of caregivers’ responsibilities.

#### 4.13- Beyond Burden: The Complexity of Providing Care

Finally, despite the hardship that accompany providing care for a loved one with dementia, many caregivers highlight the joys, positive experiences, and complex emotions associated with providing care.

“That people with dementia can lead active, fulfilling lives for much of their disease if the proper attention and resources are available. They are still human beings with feelings, desires, and interests. You just have to be able to connect on their cognitive level now through music, art, and other means. If you invest the time and compassion and put the money in the right places people with dementia could be healthier, happier, and better cared for. That caregiving is exhausting emotionally, physically, and financially but it is also rewarding and fulfilling and can be the greatest yet most difficult gift you ever give your loved one and yourself.”

“They think it’s just a normal job that it’s easy to deal with them but it’s not, its tiring but at the same time its fulfilling.”

“...Alzheimer’s is such a tragic and painful thing to see happen to someone you love, but at the same time it’s like they almost revert back to being children, there is a sort of sense of like freeing where they say the truths that on their mind even if its just awful and I don’t know I’m not trying to glorify it, quite the opposite, but I also just see the beauty in it too, but at the same time I wish it never existed, I wonder though what’s going on in her head sometimes, I wish I could know what the confusion is like so that I could help her, I often feel helpless, but I won’t ever give up on her.”

“... It is heart wrenching to watch your loved one progress and get worse. I think people also don’t realize the amount of care these people need and that we do not have enough nursing homes, home care, and support for these types of patients... This whole process has been very difficult. If you don’t have a great deal of time and money you will fall through the cracks.”

It is noteworthy that despite the higher impacts on caregivers' lifestyle, behaviour, finances and savings, less than half of all respondents (40%) indicated that if there was another available option, they would want to spend less time caregiving.

It is not the case that caregivers for people living with dementia wish to pass the responsibility and subsequent impacts of providing care onto someone else, but rather, caregivers wish to be active in providing care, but must receive greater financial, emotional, cultural, and community supports.

## 4.2 Comparison of Findings to Canada's National Dementia Strategy

Ultimately, Canada's national dementia strategy, and annual reports offer a strong framework for ensuring that those who provide care for a person living with dementia are not left behind. Aligned with the goals of the IFA, Canada's national dementia strategy sets forward a path towards improving the quality of life of people living with dementia and their caregivers. Included in the national strategy's mandate of supporting all people living with dementia is the importance of ensuring that the lives of caregivers are valued and supported, the quality of their lives is optimized, and their experiences are well understood. Canada's national dementia strategy further aligns with survey findings through highlighting that "family members and friends who provide care to people living with dementia experience high levels of stress, are at higher risk of injury and depression and are particularly susceptible to financial and employment difficulties."<sup>11</sup>

What has been revealed, however, is the need for greater efforts to ensure national strategies are translated into actions, providing significant changes to caregivers' experiences. Survey findings reveal the significant, negative, impacts that taking on the role of caregiving can have on Canadians. Furthermore, findings highlight the need for urgent resource allocation to caregivers to improve their physical, mental, romantic, and financial wellbeing. In addition, while Canada's national dementia strategy, and subsequent annual reports, do highlight the need for additional and uniquely tailored supports for groups who have experienced historical and on-going discrimination and exclusion, national strategies reveal a lack of monitoring of the perspectives and lived experiences of dementia caregivers, and further shows a need for policy makers to be well informed on the diverse activities, challenges, and desires of caregivers.<sup>11</sup>

## 4.3 Study Limitations

Increasing Awareness and Understanding Perspectives of Dementia Caregivers presents a preliminary study addressing the limited knowledge in the experiences, impacts, and desires of Canadian caregivers for people living with dementia. While barriers to participation were taken into consideration and steps were made to mitigate these to the extent possible, there are still inherent limitations associated with the utilization of online surveys and using non-probability sampling techniques.

A lack of access to digital technologies can represent a barrier to participation in this study, as could different levels of digital literacy. Those with higher levels of digital literacy may have been more inclined to participate and access the survey, and further, those with lower socioeconomic status may not have access to digital technologies that would allow for participation in this survey.

Another challenge is that the sample of study participants is not representative of the general population across Canada. Approximately half of all respondents currently residing in Ontario (46%), which is higher than dispersion of the Canadian population, at 39%. Following Ontario, the most frequently reported province of residence was British Columbia at 14% of respondents, followed by 12% in Alberta, and 10% in Quebec. These figures also do not accurately express the geographic dispersion of the Canadian population, thus, underrepresenting the experiences of Canadian caregivers in provinces and territories outside of Ontario.<sup>16</sup>

Canada is known for its ethnocultural diversity, with one in four people being a part of a racialized group.<sup>16</sup> In this survey, the proportion of Black, Indigenous, People of Color (BIPOC) individuals was lower than would be observed in the general population, with 82.4% of respondents reporting to be White or of European descent. Furthermore, as the survey was only made available in English, French speaking Canadians and individuals who may lack proficiency in English or have difficulty with literacy are likely to be underrepresented in this study. While this does have implications regarding the generalizability of study findings at a national level, the effect of this underrepresentation would likely only serve to further strengthen and highlight the existing findings around the lack of culturally relevant supports available and need for further resources that are shaped by and for racial and ethnic groups.

Additional identified limitations include the scope and scale of questions asked, and the inherent limitation to understanding lived experience through survey methodologies. Best efforts were made to ensure a broad range of questions were asked, ensuring a robust understanding of the caregiving experience. Limitations persist in the range of questions asked, including the potential for the survey to overemphasize the burden, or negative experiences associated with caregiving. Unpacking the nuanced and complex emotions of caregivers is beyond the capacity of survey methodology, and this study. Alternative methodologies such as follow-up interviews to surveys can provide additional context and understanding to the range of emotions and experiences caregivers have.

## 5.0 Project Implications and Future Research

Evidence-based messages are at the core of public health campaigns developed and funded by government. This project contributes a gap in current research on understanding the experiences, perspectives, and needs of Canadian caregivers for people living with dementia. Findings from the Increasing Awareness and Understanding Perspectives of Dementia Caregivers study have highlighted the profound impact that providing care has on caregivers' lifestyle and behavior, employment and financial status, and overall well-being. The survey findings represent a crucial foundation from which innovative campaign materials, and targeted resources and supports focused on providing respite, care, support, and recognition for caregivers can be developed. Future research should prioritize specific subsets of caregivers, including those belonging to gender and sexual minority populations, ethnic and racial groups, Canadian immigrants, those of low socio-economic status, and older adults 65+ who are caregivers. Further, greater research is needed to seek to establish the successes, challenges, and best practices associated with implementing dementia-friendly initiatives and creating age-friendly Canadian communities.

## 6.0 Conclusion

As supported by the 2023 A Dementia Strategy for Canada: Together We Aspire, all Canadians have the power to contribute to supporting the quality of life of those living with dementia and their caregivers. Canadians have a social duty to increase their understanding of the lives of people living with dementia and those who benevolently provide care, by committing to eliminating stigmas and increasing available supports. Conclusive with existent studies, current resources, supports, and the policy landscape are inadequate given the significant impacts associated providing care for a person living with dementia.

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