

Submission to the House of Commons Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities

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Implications of the COVID-19 Pandemic on Dementia Incidence and Dementia Care for Seniors Living in Canada

Dementia refers to a group of symptoms resulting from neurodegeneration—including Alzheimer’s Disease, vascular dementia, Lewy body and frontotemporal dementia—that affects memory and brain function and interferes with everyday functioning.ⁱ The global prevalence of dementia is increasing as the population agesⁱⁱ and is expected to triple by 2050.ⁱⁱⁱ In this submission to the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities (the Committee), we outline key considerations pertaining to the study of care provided to people living with dementia during the COVID-19 pandemic and recommend a formal investigation into the impact of the pandemic on future incidences of dementia in Canada. These recommendations build on an existing foundation created by our *National Dementia Strategy and Framework on Palliative Care*, and leverage known evidence-based initiatives to provide better care for the most vulnerable seniors in our society.

I. Summary of Recommendations

Recommendation 1: Governments should increase funding towards the development and promotion of training programs in behavioural supports and person-centred dementia care for healthcare workers servicing seniors living with Alzheimer’s Disease and dementia across continuum care settings.

Recommendation 2: To ensure seniors living with Alzheimer’s Disease and dementia as well as their family members and care partners are adequately supported, there is a need for improved access to behavioural support services in long-term care and in the community—such as the creation of more behavioural support units within long-term care homes and behavioural support community teams.

Recommendation 3: To ensure all seniors, especially those living with Alzheimer’s Disease and dementia, receive high-quality and goal-concordant care as they approach the end of life, advance care planning must be part of the Canadian health and social care systems. While individuals can engage in advance care planning independently or with their loved ones, most prefer to be guided through this process. This can be achieved through increased financial provision to not-for-profit and community-based organizations focused on capacity-building in hospice palliative care services across the care continuum.

Recommendation 4: Presently, there is inequitable access to palliative and end-of-life care in Canada for seniors dying from non-cancer diseases, such as Alzheimer’s Disease and dementia. Many people with advanced dementia, including those living in long-term care homes, are not routinely assessed for their palliative care needs. Routine assessment of palliative care need should be embedded as part of the assessment process for home and community care as well as for placement in long-term care.

Recommendation 5: Dementia is an irreversible but preventable condition. Approximately 40% of dementia cases are attributed to modifiable risk factors, such as smoking, physical inactivity, hearing loss, depression and social isolation.^{iv} Successful screening of individuals with these risk factors at an earlier stage followed by effective interventions has the potential to prevent or delay dementia onset. While there has been some early and anecdotal evidence suggesting significant cognitive deterioration among seniors over the course of the pandemic, the long-term impact of social isolation and declines in mental and physical health resulting from the pandemic on the future incidence of dementia among seniors in Canada is yet to be determined and must be studied.

II. Context

Since March 2020, over 25,000 Canadians have died from COVID-19; the vast majority of them (approximately 70%) are people over the age of 80 with underlying comorbidities and living in long-term care homes.^v The impact that COVID-19 has had on the population in long-term care is tragic. However, outside of the lives lost during the pandemic, roughly 20,000 Canadians have continued to die from non-COVID-related causes each month. In Ontario alone, we estimate nearly 9,000 non-COVID-related deaths per month. Among those, are the countless adults who have lost their lives due to dementia.

Dementia is associated with a limited life expectancy^{vi} and is one of the leading causes of death in Canada.^{vii} The median life expectancy in people living with dementia is approximately 4.1 years; this decreases to just 2.4 years in seniors over the age of 85 years. Sadly, people dying of frailty or gradual physiological decline, including dementia, are the least likely to receive palliative care,^{viii} despite often being significantly more disabled in the years prior to death.^{ix}

The vast majority of seniors living with Alzheimer's Disease and dementia remain in the community until death and are cared for by informal caregivers. The level of support that is needed by a senior living with Alzheimer's Disease or dementia, however, often far exceeds what most caregivers are able to provide at home. Informal caregivers are those with no formal clinical training and are likely a partner/spouse, family member or close friend. A prior report by the Canadian Institute for Health Information (CIHI) suggest that 4 in 10 caregivers of older adults with dementia experience caregiver distress. This distress may lead to anger or depression and, for some, will result in feelings of inability to continue their caring activities.^x Factors leading to higher caregiving distress include cognitive impairment, conflict, delusions, responsive behaviours such as verbal or physical abuse, and wandering.^{xi}

Responsive behaviours in persons with dementia, mental health, substance use and/or other neurological disorders refers to how their actions, words and gestures are a response to something important in their personal, social or physical environment.^{xii} Of the more than 261,000 older adults experiencing a dementia while living at home, 1 in 5 have severe cognitive impairment and 1 in 4 exhibit responsive behaviours.^{xiii} In long-term care, an estimated 50% of residents in this setting exhibit responsive behaviours.^{xiv}

Even before the pandemic, there were concerns about the impact of the rising prevalence of dementia on our population and health care system. According to estimated produced by CIHI, there are roughly 431,000 adults living with dementia in Canada.^{xv} Between 2011 and 2019, it is estimated that the proportion of long-term care residents living with moderate to severe cognitive impairment passed 60% in most Canadian provinces and reached nearly 70% in Ontario, with roughly two thirds of these having a stated diagnosis of dementia.^{xvi} While there is a clear preference for many seniors to age in place, it is critical that our government recognize the challenges to caring for seniors living with Alzheimer's Disease or dementia that exists in both the formal and inform care systems.

III. Considerations and Recommendations for the Committee's Study on the Impact of COVID-19 on Seniors

In Canada, we have a *National Dementia Strategy* as well as a *Framework on Palliative Care*. Both have outlined several recommendations for research and promising practices to improve the health and quality of life for seniors living with dementia in Canada and those at the end of life. While COVID-19 has

presented novel challenges for our governments, healthcare system and population, prior to this pandemic, there have been significant investments made by the Canadian Government to advance the quality of life and care for our aging population. As such, we believe that by aligning new and additional funding from the federal government to “Finish the Fight Against COVID-19” with these existing frameworks and support previously-identified promising strategies, we can more rapidly minimize the impact of the pandemic on vulnerable seniors living with cognitive impairment and dementia in our society.

First, given the high proportion of seniors living with cognitive impairment and responsive behaviour across continuing care settings, there must be increased funding to initiate high-quality research on non-pharmacological interventions to support dementia care. Although behavioural and psychological symptoms of a dementia (BPSD) are sometimes treated with anti-psychotic medication, research generally indicates that these treatments are clinically ineffective and present significant risks to the patient, such as increased risk of cerebrovascular events.^{xvii} Therefore, training personal support and healthcare staff to understand these symptoms through non-pharmacological interventions is vital to discussions about necessary improvements in our long-term care system. As such, the federal government should consider funding to develop and promote training programs for healthcare workers in home care and long-term care that is based on evidence of best practice to ensure we are appropriately providing care to adults experiencing BPSD and supporting their quality of life both in long-term care and for those at home. Furthermore, given the well-established impact of dementia caregiving, interventions should better support familial/informal caregivers and alleviate them from care responsibilities, where appropriate, to mitigate caregiver distress and give them more time to focus on emotional and social connectedness.

To ensure all seniors, especially those living with Alzheimer’s Disease and dementia, receive high-quality and goal-concordant care as they approach the end of life, advance care planning must be part of the Canadian health and social care systems. While individuals can engage in advance care planning independently or with their loved ones, most prefer to be guided through this process. This can be achieved through increased financial provision to not-for-profit and community-based organizations focused on capacity-building in hospice palliative care services across the care continuum. Palliative care is commonly misunderstood as only being relevant for people who are actively dying and in the final weeks or days of life. However, the relief of suffering through the provision of holistic and compassionate care is an essential component of care for all patients with a life-threatening illness. Among newly admitted residents to long-term care homes, where median life expectancy is just 18 months, most receiving care in this setting have limited life expectancy and can benefit from palliative care. For care of residents with and without COVID-19, palliative care approaches are vital to quality care in long-term care. However, the capacity of LTC homes to introduce and embed palliative care approaches can be hindered by poor communication about prognosis. Survival prognosis is rarely discussed with people diagnosed with dementia.^{xviii} This lack of discussion is partly because of a paucity of easily accessible data and accurate tools that clinicians, families and caregivers can use to provide easily understandable personalized risk.^{xix,xx,xxi} Clinicians, even palliative care specialists, often have difficulty estimating survival beyond a few weeks.

However, there are many existing tools that can be used to support palliative and end-of-life planning for seniors dying with non-cancer diseases. For example, one tool developed by Hsu et al.^{xxii}—called the Risk Evaluation for Support: Predictions for Elder-life in the Community Tool in LTC (RESPECT–LTC)—is currently being piloted in long-term care homes in Ontario to support their ongoing efforts to embed palliative approaches to care in their processes and culture. RESPECT–LTC is a mortality-risk

communication tool that accurately predicts an older person’s six-month mortality risk as well as life expectancy to inform clinicians’ decision-making regarding the initiation of palliative and/or end-of-life care. RESPECT–LTC was co-designed with patients and caregivers. It informs care providers, residents and their families when the resident may be approaching the end of life by estimating their survival in days, weeks and months—a metric that has been shown to be patient-oriented and meaningful for care planning. RESPECT–LTC can stratify patients into 61 distinct risk groups to support the operationalization of frailty; each risk group represents an actionable timeframe—ranging from 28 days to >8 years—to empower long-term care homes in determining if and when the resident will benefit from a palliative care approach, which can be initiated as early as 12 to 18 months prior to death, or end-of-life care. Routine assessment of palliative care needs, using tools such as RESPECT, should be embedded as part of the assessment for home and community care as well as placement for long-term care.

Although dementia is an irreversible condition, research suggests that at least 40% of new dementia cases are attributed to modifiable risk factors, such as smoking, physical inactivity, hearing loss, depression, and social isolation. Successful screening of individuals with these risk factors at an earlier stage followed by effective interventions has the potential to prevent or delay dementia onset. During the past year, there has been some anecdotal and early evidence suggesting significant cognitive deterioration among seniors as a result of the pandemic. For example, a recent review found that various neuropsychiatric symptoms worsened or emerged in both older adults with or without a dementia diagnosis, who experienced prolonged social isolation and, in some cases, COVID-19 infection.^{xxiii} The authors argued that given the emerging evidence is from smaller studies conducted at the onset of the pandemic, it is vital that larger and more rigorous studies evaluate and track the longer-term impacts of prolonged and enforced social isolation on seniors.^{xxiv} Accordingly, we believe that the federal government must make a commitment to monitoring the long-term impacts of social isolation and subsequent declines in mental and physical health amongst aging populations. In this way, we can more effectively study the future incidence of dementia among seniors in Canada and be more appropriately equipped to support our aging Canadians.

This submission was prepared by **Dr. Amy T. Hsu**, Ph.D. Dr. Hsu is the University of Ottawa Brain and Mind—Bruyère Research Institute Chair in Primary Health Care Dementia Research, an Investigator at the Bruyère Research Institute, and a faculty member in the Department of Family Medicine at the University of Ottawa. Her research utilizes large, health administrative databases to understand the healthcare needs and use by older Canadians across the continuum of long-term care, from home care to the end of life. Prior to her scientific appointment at Bruyère, she was a Policy Analyst/Economist at Health Canada and Statistics Canada and has extensive experience in working with national administrative and survey data sources. **Anna Cooper Reed**, M.S.W., is a Ph.D. candidate at the Institute of Health Policy, Management and Evaluation. She also works as a Research Associate at the Bruyère Research Institute and practices as a social worker in both long-term care and hospital, primarily working with older adults.

***Bruyère** is a multi-site academic health care organization that is maximizing quality of life and helping people stay and return home. We deliver a wide variety of services in aging and rehabilitation, medically complex, palliative, residential and primary care. Our research leads to constant innovation in the services we provide with a focus on providing care that promotes independence. This work is enhanced by our Foundation that shares our story and raises funds with the support of our generous community.*

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