How do we ensure Canadians with or at risk of dementia have access to the best care, living environment and programs regardless of where they live or who they are?

Summary of the Canadian Academy of Health Sciences
Major Forum on Dementia (September 17, 2015)

Context

More Canadians are living longer, the average age of the population continues to rise, and people expect their old age to be healthy and vital. One of the biggest threats to quality of life and health in aging is the loss of cognitive abilities and functional autonomy that are associated with dementia caused by neurodegenerative brain diseases.

Every year, the Canadian Academy of Health Sciences (CAHS) convenes a Major Forum on a health topic that needs the attention of a breadth of expertise, experience and scholarship. In September 2015, the CAHS focused on this topic of dementia in Canada, bringing together social scientists, biomedical researchers, healthcare practitioners and technology experts to discuss the critical challenge of dementia in Canada and to establish the broadest possible view of this compelling global health priority and its societal impact.

The purpose of the symposium was to review the extensive epidemiological estimates of the Canadian and global scale of the problem of dementia, cover the state of science and potential for treatment breakthroughs in the next decade, address the systems of care including medical, psychosocial, as well as, environmental considerations to help understand the implications for public policy. The researchers who presented and participated in panel discussions focussed on the implications for the growth in the number of Canadians living with dementia over the next 15 years, emphasizing that this growth will reshape our social, economic, medical and political landscape.

The overarching message was that while there is an abundance of longitudinal observational research underway in Canada with multiple pilot interventional projects, there is no coherent effort to ensure the translation of research and best practices to all of the communities in Canada. In the area of prevention, the promising research has no obvious pathway for implementation or scale up. There is a clear imperative to advance systems of care delivery, re-shape our living and built environment, mobilize technology, and develop an end-to-end national program so that all Canadians with Alzheimer's disease or other forms of dementia be supported in their communities as long as possible, receive quality care in all settings, and when residential care is required, experience a satisfying quality of life, and as the disease progresses to more advanced stages – have a high quality late life and end-of-life – regardless of where they live or who they are. The important focus of the day was on identifying solutions and unique Canadian programs and capabilities. Forum participants recommended that the CAHS undertake a Major Assessment to provide detailed recommendations for health and social policy.

This short paper summarizes the highlights of the discussion.

Magnitude of the dementia challenge

Today approximately 750,000 Canadians are living with dementia, 72% of them women[1]. While there has been a decline in dementia *prevalence* among people greater than 70 years of age over the past few decades,[2] attributable to a combination of medical, lifestyle, demographic and social factors, because of the increase in the average age of the population, the total number of people with dementia is expected to continue to rise significantly. By 2031, there will be an estimated 1.4 million Canadians with dementia[3]. Global numbers mirror Canada's; worldwide, there are nearly 47 million people living with dementia today, a number expected to almost double by 2030 and more than triple by 2050[4].

The economic cost of dementia in Canada in 2011 has been estimated at $33 billion; by 2040, that is expected to rise exponentially to $293 billion[5].

Alzheimer's disease accounts for 60-80% of the neurodegenerative diseases commonly included under the umbrella term dementia[6]. Approximately 28 percent of the risk for Alzheimer's disease lies in preventable and treatable risks such as diabetes mellitus, midlife hypertension and obesity, physical inactivity, depression, smoking and low education[7, 8].

State of the Science

With Alzheimer's disease and other forms of dementia, there are, at present, no definitive pharmacological solutions, and failures are mounting with more than 200 drug development failures in the last 30 years[9]. Recent experimental therapeutic efforts targeting the amyloidopathy of Alzheimer's disease have had disappointing results[10,11].

In the area of prevention, there has been a growing interest and evidence base focussed on the modification of treatable risk factors to delay the onset of dementia. The recently reported FINGER study, which investigated intensive multi-domain interventions including dietary counselling, exercise training, cognitive training, and vascular risk factor control, achieved significant benefits in cognition and well-being[12]. These studies set the stage for larger multi-national studies, pragmatic prevention programs, and integrative efforts with other chronic disease management platforms in Canada.

The Canadian Consortium on Neurodegeneration in Aging (CCNA), in partnership with the Canadian Institutes of Health Research, has received funding to set up a national research program in three broad themes including prevention, treatment and quality of life. It brings together more than 350 investigators working in interdisciplinary teams and across state of the art scientific platforms to advance its broad research agenda.

Systems of Care and Innovations

While researchers continue to develop novel solutions for prevention and treatment, the immediacy of the unmet needs of the 750,000 Canadians currently living with dementia loom starkly.

For people with milder and early stages of dementia, the highest need is for better systems of home and community care. There is no national system or strategy to provide medical and psychosocial care for people with dementia, and there are significant gaps and inconsistencies in care, particularly in rural and smaller communities.

The type of home support available across Canada varies widely, and almost everywhere provides limited scope of care. The family and friends of dementia patients provide much of the care, and the healthcare system tends to be reactive rather than to guide or integrate care. There are noteworthy programs that have been developed within provincial boundaries but which have not yet been taken up in other jurisdictions. In Saskatchewan, researchers and clinicians created a "one stop shop" intervention clinic using telehealth to allow more care to be provided in their home community, addressing rural urban disparity. In Quebec, a collaborative care model has been developed with primary care at the center of the interdisciplinary team coordinating care and supporting affected individuals through their disease course.

Quality of life, mobilization and sustaining a safe environment are critical for people living with dementia in their homes and community settings. There are several promising solutions, ranging from community design to technology. The concept of dementia-friendly communities and built environments are being explored, to enhance accessibility, way-finding and ease of engagement in community life. Technology can also support people with dementia to stay in their homes, including "smart" homes that prompt tasks and collect data that is provided to healthcare providers. Robotics may also provide supports ranging from sustaining cognitive strength to self-driving cars.

The key needs for people with early and mild dementia are more integrated systems and levels of supportive home and community care, educational interventions, particularly in rural settings, and support for navigation of the healthcare system. Simultaneously, it is critical to examine the work-force currently caring for people living with dementia in their communities, to enhance continuity and sophistication of care for paid caregivers, enhance culturally competent care, and provide greater support for unpaid caregivers.

In advanced dementia care, service challenges are focussed in institutional settings. There is a high dependence on residential care in the later stages of living with dementia, but there is currently no national strategy or comprehensive approach at the provincial level for residential long-term care. Additionally, there are decades long challenges in providing consistent quality of care in these settings and a rapidly increasing need to deliver quality *late life* experience and high *end-of-life* care quality. Many dementia patients also spend time, sometimes unnecessary time, in acute care, a setting ill prepared to care optimally for people with dementia. Efforts to prevent unnecessary hospitalization at the end of life and to manage necessary hospitalization more optimally are both urgent imperatives on a

dementia management agenda. Finally, in late and advanced dementia, unpaid family and friend caregivers shoulder a sometimes even higher proportion of the care burden resulting in deleterious health, social and economic outcomes for them and for society.

What should be done?

Overwhelmingly, the portrait for dementia prevention and care in Canada is one of high need with little or no integrated, evidence-based approach or strategy. At the same time, there are stellar contributions and innovations that have been provided by researchers in Canada setting up the need to consider how best to spread, scale and sustain such new programs and particularly how funding can be found to support them. The need is real, immediate and will continue to grow. The participants in the CAHS Forum recommended that the Academy sponsor an initiative to provide a clear, evidence-based case for a coherent national approach to the care and management of this growing number of vulnerable older adults and their families – one that informs system level policy change. This initiative should quickly consolidate the current need, evidence and promising innovations for prevention and systems of care, including highlighting the unique access issues for Canadians in remote and rural communities. The assessment should focus on how to create an integrated, high quality system of care across the country, moving beyond a series of pilots to a comprehensive and tangible action plan that is immediately actionable.

Recommended question for a major assessment

The recommended question and related sub-topics for this assessment should be:

How do we ensure Canadians with or at risk of dementia have access to the best care, living environment and programs regardless of where they live or who they are?

- *What are the most critical medical and psychosocial elements for prevention, treatment and care that could be immediately implemented?*
- *What would a national action plan focused on systems of care and prevention look like?*
- *How can we quickly implement a financially feasible, yet highly effective action plan in the Canadian context, including delivering it to scale and measuring its effectiveness? What should the change, engagement and implementation plan include?*

Respectfully submitted,

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