COMMENTARY

The Canadian dementia challenge: Ensuring optimal care and services for those at risk or with dementia throughout the country

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ABSTRACT

In the next 15 years, Canada is predicted to face a doubling in its population affected by dementia. By 2038, an estimated 1.1 million Canadians will be experiencing dementia, with unprecedented impact on social, economic and health landscapes. In September 2015, the Canadian Academy of Health Sciences convened a Forum, with the specific thematic goals of reviewing progress towards effective dementia treatment and prevention, improved systems of care, advanced living and built environments, and impactful technology developments. The orientation of the Forum was to focus on potential solutions and advances in these areas. These areas are integral to the goal of a national end-to-end program, where all affected Canadians can be optimally supported in their communities and receive quality of care – regardless of where they live or who they are.

KEY WORDS: Dementia; prevention; national strategy; services

La traduction du résumé se trouve à la fin de l'article.

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Canada is currently in the midst of an unprecedented demographic shift in its aging population, with more Canadians than ever living longer, and with an aging average age that continues to rise. Our societal and personal hope for old age is that it is healthy and vital. One of the biggest threats to quality of life in aging is the loss of cognitive ability and functional autonomy associated with dementia caused by neurodegenerative brain diseases.

Today's estimates are that there are 750 000 Canadians living with dementia, 72% of them women.[1] While there has been a recently recognized decline in dementia prevalence among people over 65 years of age over the past few decades, because of the increase in the average age of the population, and demographic shift to those over age 65, the total number of people with dementia is expected to continue to rise significantly.[2] Canadian population estimates are that by 2038, across all ages, there will be an increase of 2.3 times, to a total of 1.1 million persons affected by dementia.[3] An additional 17% of the population can be expected to have cognitive impairment, not dementia (CIND) with their cognition falling outside of the normal range, but not sufficiently impaired to meet diagnostic criteria for dementia.[4] 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.[5] A major driver of this growth will come from low- and middle-income countries as their citizens' longevity increases.[6] The economic cost of dementia in Canada in 2011 was estimated at $33 billion; by 2040, that is expected to rise exponentially to $293 billion.[1] The effects of dementia and cognitive impairment will be far reaching within our communities, affecting systems of care, the built environment, transportation, and the workplace.

Alzheimer's disease (AD) accounts for 60%–80% of the neurodegenerative diseases commonly included under the

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umbrella term "dementia".[1] For AD and other forms of neurodegenerative dementia, there are currently no definitive pharmacological solutions, and failures are mounting with more than 200 drug development failures in the last 30 years.[7] Recent experimental therapeutic efforts targeting the amyloidopathy of AD have had disappointing results,[8,9] with many pharmaceutical companies leaving this field of research, given the costs of development failure. At the same time, approximately 28% of the risk for AD lies in preventable and treatable risks such as diabetes mellitus, midlife hypertension and obesity, physical inactivity, depression, smoking, and low educational attainment.[10,11] Some of the downward trend in prevalence of dementia may be attributable to a combination of medical, lifestyle, demographic and social factors, as well as treatment of vascular risk factors.

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 and to lessen cognitive decline. The recently reported FINGER study investigated intensive multi-domain interventions, including dietary counselling, exercise training, cognitive training, and vascular risk factor control over 24 months, in individuals aged 60–77 years at higher risk of dementia, with significant benefits achieved in cognition and well-being.[12] This study and others have set the stage for larger multinational studies, pragmatic prevention programs, and integrative efforts with other chronic disease management platforms in Canada.

In September 2015, the Canadian Academy of Health Sciences (CAHS) convened a Forum on the topic of dementia in Canada, bringing together social scientists, biomedical researchers, health care practitioners and technology experts to discuss the breadth of critical challenges of dementia in Canada, with a focus on potential solutions. 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 landscapes.

The overarching message was that while there is important national funding for longitudinal observational research underway in Canada – including the Canadian Longitudinal Study on Aging, and the Canadian Consortium of Neurodegeneration and Aging – much of the intervention research is left at the pilot stage, without the scale-up mechanisms or funding to ensure the translation of research and best practices to all of the communities in Canada. Moving from the lab to the community does not generally have the necessary traction to attract sustainable funding and priority in the health delivery systems provincially. In the area of prevention, the promising research on risk factor modification has no obvious national pathway for implementation, scale-up or connection to other chronic health disease prevention programs. With this foreseeable demographic shift in the coming 2–3 decades, there is a clear imperative to advance systems of care, reshape our living and built environments and mobilize technological solutions to assist families and caregivers. An end-to-end national plan, following the lead of other countries, would be directed to allow all Canadians with AD or other forms of dementia to be supported in their communities as long as possible, to receive quality care in all settings including residential care where required in the more advanced stages of disease. This type of national program would enable the best quality of *late life* experience and *end-of-life* care for Canadians regardless of who they are or where they live.

For people with milder and early stages of dementia, the highest need identified in the Forum was for better systems of home and community care. There is no national system or strategy to address inconsistencies in care, particularly in rural and smaller communities.[13]

The type of home support available across Canada varies widely, and almost everywhere there are only provisions for a limited scope of care. The family and friends of dementia patients provide much of the care and the burden of such care goes largely unaddressed. The health care system tends to be reactive rather than proactive without integrated care planning. Noteworthy programs have been developed within provincial boundaries, but many to most have not yet been taken up as best practice in other jurisdictions. In Saskatchewan, researchers and clinicians have created a "one stop shop" intervention clinic using telehealth to allow more care to be provided in their home community, addressing rural urban disparity.[14] In Quebec, a collaborative care model has been developed with primary care at the centre of the interdisciplinary team coordinating care and supporting affected individuals through their disease course.

Quality of life, mobility 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 a wide array of technologies. Increasing numbers of public awareness and educational programs across Canada, such as "Dementia Friends",[15] "Dementia-Friendly Communities",[16] and "Dementia Friendly Cities",[17] are being actively implemented to create enhanced awareness and adaptation from the individual to community to city level. Advanced designs for built environments are being developed, 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 can provide non-obtrusive monitoring, pass along information to clinicians and family, and generate feedback loops for care. Robotics may also provide supports ranging from aids for sustaining cognitive performance to transportation in the form of self-driving cars. Simultaneously, it is critical to examine the workforce currently caring for people living with dementia in their communities, in order 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 optimizing 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 the best possible quality of *late life* experience and *end-of-life* care. 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 sometimes shoulder an even higher proportion of the care burden, resulting in deleterious health, social and economic outcomes for them and for society.

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. The stellar contributions and innovations that have been provided by researchers in Canada are setting the stage for an unprecedented effort to spread, scale up and sustain new programs with sustainable funding based on models that move away from silos to broader perspectives. 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 and the 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.

Our goal should be clearly stated – to ensure that Canadians with or at risk of dementia have access to the best preventive programs, systems of care, and living environments in Canada regardless of where they live or who they are. Canada could and should be an international exemplar of how to achieve this goal. Our ability to do so, or not to do so, will reflect core Canadian values with respect to aging.

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RÉSUMÉ

D'ici 15 ans, la population du Canada atteinte de démence devrait doubler. D'ici 2038, environ 1,1 million de Canadiens seront atteints de démence, ce qui aura un impact sans précédent sur le paysage social, économique et sanitaire. En septembre 2015, l'Académie canadienne des sciences de la santé a convoqué un forum dont les objectifs étaient d'examiner les progrès réalisés en vue d'améliorer l'efficacité du traitement et de la prévention de la démence, les systèmes de soins, les milieux de vie et les cadres bâtis, ainsi que l'impact des développements technologiques. Le forum a abordé les possibilités de prévenir la démence, d'offrir des systèmes de soins améliorés, de refaçonner nos milieux de vie et nos cadres bâtis, et de miser sur des solutions technologiques. Ces thèmes s'inscrivent dans l'objectif d'avoir un programme coordonné à l'échelle nationale capable de soutenir de façon optimale, dans leurs communautés, tous les Canadiens touchés par la démence et de leur offrir des soins de qualité, peu importe où ils vivent ou qui ils sont.

MOTS CLÉS : démence; prévention; stratégie nationale; services