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**CANADIAN RESEARCH ADVANCES IN DEMENTIA CARE PRESENTED AT  
ALZHEIMER'S ASSOCIATION INTERNATIONAL CONFERENCE 2016**

**NEARLY 20 PERCENT RISE IN ALZHEIMER'S AND DEMENTIA OVER 8 YEARS IN  
ONTARIO; BIGGER INCREASE SEEN IN MEN**

- Novel research into Parkinson's, Alzheimer's pathology could help identify new ways to treat the diseases -**
- New methodologies identified to safely deliver dementia care to Indigenous communities -**

**TORONTO, CANADA, July 25, 2016** – The prevalence of Alzheimer's disease and other dementias has increased more than 18 percent in Ontario, Canada, over the past eight years, according to new research reported today at the Alzheimer's Association International Conference 2016 (AAIC 2016) in Toronto. Although prevalence rates have remained higher among women (97.3 per 1,000 in 2012/13) than men (68.2 per 1,000), the increase over the study period was greater among men.

A wide range of Canadian research findings spanning clinical, epidemiological and care models were reported at AAIC 2016, demonstrating the breadth of the country's contributions to innovative research on Alzheimer's science and care. This is the first time Toronto has hosted this prestigious international conference, which is a catalyst for generating and dispensing new knowledge about dementia.

Additional findings from Canadian researchers presented at AAIC 2016 include:

- Discoveries identifying biomarkers of memory resilience in people with Alzheimer's disease and preserved motor function in people with Parkinson's disease, which may offer new targets for treatment.
- Creative and evidence-based methods of delivering culturally appropriate dementia care to several First Nation (Indigenous) communities in the province of Ontario.
- An Ontario-based physical and social recreation program provides significant improvements in physical function, activity and agility for people with dementia.

"The quality, diversity and breadth of research coming out of Canada is helping to build a broader understanding about Alzheimer's disease and dementia prevention, progression and management, and offers new insights, tools and approaches," said Larry Chambers, PhD, Scientific Advisor to the Alzheimer Society of Canada.

“The research findings coming out of AAIC 2016 underscore the need for, and value of, a holistic approach to Alzheimer’s research,” said Heather M. Snyder, PhD, Senior Director of Medical and Scientific Operations at the Alzheimer’s Association. “Research into new treatments is vital, but we also need to establish a broader understanding of who is at risk for Alzheimer’s, how it’s burdening our health systems, and how to best provide care and support for all who have the disease and their families. The commitment to research by national governments must be increased to match the devastating impact it is having on individuals, families and national economies.”

### **Trends in Dementia Prevalence, Incidence and Health System Costs: A Population-Based Analysis from Ontario, Canada**

Data generated through the routine administration of health care programs, also known as health administrative data, are a valuable resource for monitoring incidence and prevalence trends in Alzheimer’s and other dementias over time and helping to plan effectively for needed increases in health system capacity.

Canadian researchers from the Institute for Clinical Evaluative Sciences (ICES), the Ontario Brain Institute, the University of Toronto and the University of Waterloo aimed to assess trends in dementia prevalence, incidence and related costs over an eight year period in Ontario, Canada.

The researchers used population-based health administrative data to examine trends in yearly Alzheimer’s and dementia prevalence, incidence and publicly funded health system costs from 2004/05 to 2012/13 in older adults by age group, sex and region in the province of Ontario. Annual health system costs included total attributable government healthcare spending associated with one year of health system use; not just costs ascribed to Alzheimer’s and dementia care.

Researchers found that, over the time period of the study:

- Age- and sex-adjusted prevalence of dementia increased by 18.2 percent for individuals aged 66 years and older - from 63.0 to 74.5 per 1,000 persons;  $p < 0.001$ .
- Age- and sex-adjusted incidence decreased slightly - from 18.2 to 17.0 per 1,000 persons;  $p = 0.05$ .
- Although prevalence rates have remained higher among women (97.3 per 1,000 in 2012/13) than men (68.2 per 1,000 in 2012/13), the increase in the rate over time was greater among men.

Median health system costs associated with one year of health system use were CDN\$19,468 (range CDN\$4,490 to CDN\$47,726) for prevalent cases in 2012/13 and CDN\$16,549 (range CDN\$5,070 to CDN\$47,899) for incident cases. Long-term care and hospital care accounted for the largest portion of total costs in both groups.

“The prevalence of Alzheimer’s disease and other dementias has increased in Ontario over the past eight years. Our cost analysis shows a dominance of costs from acute and long-term care sectors, showing the scale of the challenge for publicly financed health systems,” said Susan Bronskill, PhD, from the Institute for Clinical Evaluative Sciences (ICES), Toronto. “Accurately and proactively monitoring incidence and prevalence - and health system use - of persons with Alzheimer’s and other dementias is important to capacity planning for government agencies, local providers and national health systems.”

### **Interpreting Disease Heterogeneity in Alzheimer's and Parkinson's disease**

Alzheimer's disease and Parkinson's disease are two illnesses closely correlated with aging and decrease in brain function. Despite the similarity of these two neurodegenerative disorders, the characteristic brain changes that identify them vary. Parkinson's is primarily associated with dopaminergic decreases in the key brain pathways, while Alzheimer's is primarily associated with abnormal protein folding and aggregation in the brain.

Many people live with elevated levels of Alzheimer's or Parkinson's pathology yet remain cognitively healthy or free from associated motor symptoms. Researchers from Douglas Mental Health University Institute in Montreal sought to better understand how this happens, and how that understanding might be used to improve treatment and prevention.

Researchers used brain imaging technology to map brain communication functions, including a novel technology that maps the different neuroanatomical structures most associated with memory function and motor circuits. They used network-based analysis strategies to determine areas of the brain related to "resilience" in those without cognitive decline yet with elevated pathological burdens.

Findings demonstrated several areas of the brain that appear to be intrinsically related to differences in Alzheimer's and Parkinson's, and also resilience against neurodegenerative disorders. These include preservation of the CA1 region, which is required for memory retrieval, as a resilience mechanism in Alzheimer's, and the enlargement of the striatum and cerebellum, a critical motor region of the brain, in individuals with lower dopamine levels as a potential resilience mechanism in Parkinson's.

"Our analysis has the potential to significantly impact the design of novel therapeutic interventions intended to delay disease onset, and could potentially suggest new targets for the prevention of Alzheimer's and Parkinson's," said Mallar Chakravarty, PhD, Douglas Mental Health University Institute. "This work could also provide a robust set of markers to enable the identification of disease trajectory and disease risk for healthy individuals."

### **Considerations in Culturally Safe Care for Indigenous People with Dementia in Canada**

Almost 1.4 million people identified themselves as members of at least one of Canada's Aboriginal groups in the 2011 census, and this population is aging significantly. With prevalence rates rising steadily, Alzheimer's disease and other dementias are becoming a considerable concern for Indigenous populations in Canada.

A group of researchers from Sudbury, Ontario, looked at the framework of "cultural safety" to deliver health services, and specifically dementia care, more effectively in Indigenous communities. Cultural safety is met through actions that recognize and respect the unique cultural identity of a population and appropriately meet their needs and expectations.

Culturally safe approaches to care need to incorporate healthcare provider training on the colonial history of First Nations; Indigenous explanatory models of dementia; appropriate approaches to the encounter with a healthcare provider, care and prevention; and improving access to appropriate care and support.

The research team formed partnerships with several diverse Indigenous communities in Ontario and collected and analyzed a broad spectrum of foundational data concerning dementia and caregiving. From 2011-2014, 168 people were interviewed in six regions of Ontario, including those living with dementia, informal caregivers, Indigenous Knowledge Keepers, seniors and healthcare providers in indigenous communities. These data were examined to elicit specific care and service needs and culturally-grounded approaches to care.

The researchers discovered that labeling symptoms of Alzheimer's and other dementias as disease is relatively new in Indigenous communities. They found cultural beliefs concerning the lifecycle and relationships that have implications for how Indigenous peoples understand and respond to dementia. These beliefs vary among different communities for many reasons, including differing historical and contemporary experiences with governmental bodies.

“As a result of our study, key areas within the healthcare experience have been identified that can be addressed to improve culturally safe care for Indigenous peoples with dementia in Canada,” said Kristen Jacklin, PhD, from Northern Ontario School of Medicine. “The new partnerships have facilitated knowledge translation to better prepare frontline care providers to provide culturally safe dementia care.”

“As the burden of dementia within Indigenous communities grows, we hope the strategies resulting from the study will have direct relevance for policy formation and service design in Canada, and even in other countries, where providing healthcare to Indigenous populations is a focus,” Jacklin added.

### **Evaluation of the Minds in Motion® program: Physical, Mood and Knowledge Outcomes**

Physical and social activity is associated with improved physical function, cognition and quality of life among older adults, including those with dementia. Originally developed in British Columbia, the Alzheimer Society of Ontario launched in 2014 its version of the Minds in Motion® (MIM) program, a physical activity and therapeutic recreation program for older adults with dementia and their caregivers.

The study sought to evaluate the change in physical function, physical activity, perceived self-efficacy (the amount of confidence a person has in their ability to achieve a task), and mood after participation in MIM. The program was delivered once per week for eight weeks to up to 22 participants at 13 Alzheimer Societies across Ontario. Each session consisted of 50 minutes of exercise (cardiovascular, strength, balance, coordination, and flexibility training), a short break and 50 minutes of therapeutic recreation (including social activities meant to invoke memory retrieval, imagination, word formation, and group socialization). Assessments were completed prior to and after the eight week program. Physical function was assessed with the Seniors' Fitness Test. Other outcomes were evaluated using questionnaires.

403 MIM participants completed the follow-up assessment. The average age of participants was 74 with 57% being female. Key findings include:

- Most measures of physical function (endurance, upper/lower body strength, upper/lower body flexibility) improved similarly among people with dementia and their care partners ( $p < 0.001$ ).
- People with dementia demonstrated improved agility ( $p < 0.001$ ) though care partners did not ( $p = 0.52$ ).
- Participants reported a significant increase in weekly frequency, duration and intensity of physical activity ( $p < 0.01$ ). However, participants reported no change in physical activity self-efficacy ( $p = 0.20$ ) and a small but significant decline in mood ( $p = 0.001$ ).

“Overall, our evaluation suggests that Minds in Motion is a promising program for the physical and social health of people with dementia and their care partners,” said Kayla Regan, MSc, from the University of Waterloo. “Participants reported that they did more physical activity after the program than before, reporting more frequent, more intense, and longer bouts of physical activity. Ninety-six percent (96%) of participants indicated that they enjoy the program and 80 percent have returned to the program again. Additionally, 53 percent of participants report that they have developed new relationships through MIM.”

“Because there was a small but significant decline in mood among participants, we recommend further study to better understand whether this change is a result of the program or unrelated changes over time,” Regan added.

### **About AAIC**

The Alzheimer’s Association International Conference (AAIC) is the world’s largest gathering of researchers from around the world focused on Alzheimer’s and other dementias. As a part of the Alzheimer’s Association’s research program, AAIC serves as a catalyst for generating new knowledge about dementia and fostering a vital, collegial research community.

AAIC 2016 home page: [www.alz.org/aaic/](http://www.alz.org/aaic/)

AAIC 2016 newsroom: [www.alz.org/aaic/press.asp](http://www.alz.org/aaic/press.asp)

### **About the Alzheimer’s Association®**

The Alzheimer’s Association is the leading voluntary health organization in Alzheimer’s care, support and research. Our mission is to eliminate Alzheimer’s disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer’s. Visit [alz.org](http://alz.org) or call 800.272.3900.

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- Susan Bronskill, PhD, et al. Trends in Dementia Prevalence, Incidence and Health System Costs: A Population-Based Analysis from Ontario, Canada. (Funder(s): Institute for Clinical Evaluative Sciences, which is funded by the Ontario Ministry of Health and Long-Term Care; Ontario Brain Institute)
- Mallar Chakravarty, PhD, et al. Interpreting Disease Heterogeneity in Alzheimer’s and Parkinson’s Disease. (Funder: Weston Brain Institute)
- Kristen Jacklin, PhD, et al. Considerations in Culturally Safe Care for Indigenous People with Dementia in Canada. (Funder(s): Alzheimer’s Society of Canada; Ontario Mental Health Foundation; Indigenous Health Research Development Program; Canadian Consortium on Neurodegeneration in Aging)
- Kayla Regan, MSc, et al. Evaluation of the Minds in Motion® program: Physical, Mood, and Knowledge Outcomes. (Funder: Alzheimer Society of Ontario)

Proposal ID: 11057

Poster presentation: Monday July 25 2016

Theme selection: Public Health and Psychosocial: Health Economics and Policy

## **Trends in Dementia Prevalence, Incidence and Health System Costs: A Population-Based Analysis from Ontario, Canada**

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**Background:** Surveillance of Alzheimer's and related dementias (ADRD) with health administrative data is a cost-effective tool for describing and monitoring trends in incidence and prevalence over time, and for supporting health system capacity planning. We aimed to assess ADRD trends in prevalence, incidence and related costs over an eight year period in Ontario, Canada.

**Methods:** Using population-based health administrative data and a validated ADRD algorithm based on electronic medical records, we examined trends in yearly ADRD prevalence, incidence and publicly funded health system costs from 2004/05 to 2012/13 in adults aged 66 years and older by age group, sex and region in Ontario, Canada. Annual health system costs included total attributable government health care spending associated with one year of health system use; not just costs ascribed to ADRD.

**Results:** Over time, age- and sex-adjusted prevalence of AD increased by 18.2% for individuals aged 66 years and older (from 63.0 to 74.5 per 1,000 persons; p-value < 0.001) and age- and sex-adjusted incidence decreased slightly (from 18.2 to 17.0 per 1,000 persons; p-value = 0.05). Although prevalence rates have remained highest among women (97.3 per 1,000 in 2012/13) than men (68.2 per 1,000), the increase in the rate over time was greater among men. Median health system costs associated with one year of health system use were \$19,468 (interquartile range (IQR) \$4,490 to \$47,726) for prevalent cases in 2012/13 and \$16,549 (IQR \$5,070 to \$47,899) for incident cases; the median cost varied over 3-fold across age groups. Long-term care and hospital care accounted for the largest portion of total costs in both groups.

**Conclusions:** The prevalence of ADRD has increased in Ontario, Canada over the past eight years and, given slightly declining incidence rates over this time period, is likely attributable to declining mortality. The skewed distribution of costs associated with one year of health system use by both prevalent and incident cases were dominated by acute and long-term care services and reflect a significant challenge for publically financed health systems.

Proposal ID: F4-04-02

Featured Research Session, Wednesday, July 27, 2016

Topic Selection: Biomarkers Across Neurodegenerative Diseases: Uncovering the Similarities and Differences in Alzheimer's and Parkinson's Disease Brain Changes

### **Interpreting Disease Heterogeneity in Alzheimer's and Parkinson's Disease**

**Presenting author: Mallar Chakravarty, Ph.D.**

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**Senior author: Min Tae Park**

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**Background:** Alzheimer's (AD) and Parkinson's disease (PD) are the two most prevalent neurodegenerative disorders. Our population is set to age at a rapid pace, as the oldest generations are some of the fastest growing segments of the population. Not surprisingly, the oldest members of society are most likely to be afflicted with AD or PD; and the severity of these two neuropsychiatric disorders is tightly correlated with the age of the patient. However, the pathologies most commonly associated with AD and PD (amyloid aggregation and dopaminergic decreases in the nigrostriatal pathways) are heterogeneous. For example, one may suffer from elevated levels of amyloid and be completely cognitively healthy; while others may experience dopaminergic depletion through the nigrostriatal pathway but experience no motor symptom associated with PD. The question central to this work is how do certain individuals live with elevated levels of pathology, yet remain cognitively and functionally healthy?

**Methods:** To answer this question used data from the publically Alzheimer's Disease Neuroimaging Initiative (ADNI) and the Parkinson's Progression Marker Initiative (PPMI). We will use 18F-Fluorobetair positron emission tomography data to determine amyloid load in ADNI and DaTSCAN single photon emission tomography to determine presynaptic dopamine transporter affinity (henceforth known as dopamine) in PPMI. We will use structural magnetic resonance images (MRI) available in both databases to determine if there are neuroanatomical signatures of resilience in normal controls with elevated amyloid burden and low striatal dopamine levels. We will use novel technology developed by our group that maps the different neuroanatomical structures of the memory (the hippocampus and its subfields, fimbria, fornix, anterior nucleus of the thalamus, and the thickness of the entorhinal cortex and parahippocampal gyrus) and the motor (the striatum, pallidum, thalamus, cerebellum and its lobules, and the cortical motor areas) circuits and we will use network-based analysis strategies to determine a "resilience" network topography in normal controls with elevated pathological burdens (based on levels elucidated in the AD, prodromal AD, and PD sample in ADNI and PPMI).

**Results:** Our results demonstrate several interesting and regionally specific areas that appear to be intrinsically related to disease heterogeneity and resilience against neurodegenerative disorders. This includes the preservation of the CA1 region as a resilience mechanism in Alzheimer's disease and the coordinated enlargement of the striatum and cerebellum in individuals with lower dopamine in Parkinson's disease.

**Conclusions:** The results of our analysis will have significant impact of the design of novel therapeutic interventions intended to delay disease onset and could potentially suggest novel therapeutic targets for the prevention of AD and PD. This work could also provide a robust set of biomarkers that could enable the identification of disease trajectory and disease risk for healthy individuals.

Proposal ID: F3-02-01

Featured Research Session #1953: Tuesday, July 26, 2016: 8:00-9:30 AM

Theme selection: International Perspectives on Dementia and Aging in Indigenous Populations

### **Considerations in Culturally Safe Care for Indigenous People with Dementia in Canada**

**Presenting author: Kristen Jacklin, PhD**

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**Background:** Rates of dementia and Alzheimer's disease are now a considerable concern for Indigenous populations in Canada. The prevalence of these illnesses increased quickly in this population leaving most health care providers and Indigenous health services searching for ways to provide adequate or appropriate care. As dementia is now more firmly established as a health concern for an aging Indigenous population it is recognized that education, training, services and programs must shift to meet the needs of Indigenous people with dementia and their families. It is increasingly recognized that cultural safety provides an appropriate framework for how health services, including dementia care, in Indigenous communities can be delivered more effectively.

**Methods:** Community-based participatory methods facilitated partnerships with several diverse Indigenous communities in Ontario to collect and analyze a broad spectrum of foundational data concerning dementia and caregiving. From 2011-2014, we interviewed 168 people with dementia, informal caregivers, Indigenous knowledge keepers, seniors, and health care providers in Indigenous communities in six regions in Ontario. These data were examined using a cultural safety framework to elicit specific care and service needs and culturally-grounded approaches to care.

**Results:** The labeling of symptoms of dementia and Alzheimer's as an illness is relatively new in Indigenous communities. Several cultural beliefs concerning the lifecycle and relationships have implications for how Indigenous peoples understand and respond to the illness. These beliefs can vary among Indigenous people, owing to cultural diversity and to varying historical and contemporary experiences with the Government. Culturally safe approaches to care need to incorporate health care provider training on the colonial history of Indigenous peoples; Indigenous explanatory models of dementia; appropriate approaches to the clinical encounter, care and prevention; reducing barriers and improving access to appropriate care and support.

**Conclusions:** We have identified key areas within the health care experience that can be addressed to improve culturally safe care for Indigenous people with dementia. The community-based methodology resulted in several partnerships that have facilitated knowledge translation activities that will better prepare frontline care providers to provide culturally safe dementia care to Indigenous people in Canada.



Proposal ID: O3-07-06

Oral session: Tuesday, July 26, 2016: 4:15-5:45 PM

Topic selection: Dementia Care Practice: The Journey of Dementia -- Caring and Deciding

### **Evaluation of the Minds in Motion<sup>®</sup> program: Physical, Mood, and Knowledge Outcomes**

**Presenting author: Kayla Regan, MSc**  
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Background: Physical and social activity is associated with improved physical function and quality of life among older adults, including those with dementia. Consequently, the Alzheimer's Society of Ontario launched the Minds in Motion<sup>®</sup> program (MIM), a physical activity and therapeutic recreation program for older adults with dementia and their care partners.

Methods: The objective of this study was to evaluate the change in physical function, physical activity, physical activity self-efficacy, mood, and knowledge of physical and social activity health benefits after participation in MIM. The program was delivered once per week for 8 weeks to up to 22 participants at 13 Alzheimer Societies across Ontario. Each session consisted of 50 minutes of exercise (cardiovascular, strength, balance, coordination, and flexibility training), a short break, and 50 minutes of therapeutic recreation (including social activities meant to invoke memory retrieval, imagination, word formation, and group socialization). Assessments were completed prior to and after the 8 week program. Physical function was assessed with the Seniors' Fitness Test. Other outcomes were evaluated using questionnaires.

Results: Of the 585 participants who participated in the evaluation of this program, 403 were present and completed the follow up assessment. Most measures of physical function improved similarly among people with dementia and their care partners (endurance, upper and lower body strength, upper and lower body flexibility) ( $p < 0.001$ ). In contrast, people with dementia demonstrated improved agility ( $p < 0.001$ ) whereas care partners did not ( $p = 0.52$ ). Participants also reported a significant increase in weekly frequency, duration and intensity of physical activity ( $p < 0.01$ ). However, participants reported no change in physical activity self-efficacy ( $p = 0.20$ ) and a small but significant decline in mood ( $p = 0.001$ ) and knowledge of the health-implications of physical and social activity ( $p = 0.002$ ).

Conclusion: Participation in MIM was associated with significant improvements in physical function and physical activity for both people with dementia and their care partners. However, participants reported poorer mood after the program. Whether this change is a result of the program or unrelated changes over time is unclear. MiM is a promising program for the physical health of people with dementia and their care partners.

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