

The Emergence of Dementia as a Health Concern Among First Nations Populations in Alberta, Canada

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ABSTRACT

OBJECTIVES: Little is known about the prevalence and incidence of dementia in Aboriginal communities in Canada. As with the Canadian population, dementia in Aboriginal people is expected to be an increasing challenge for federal, provincial and community health care systems. To respond to a dearth of information concerning the prevalence of dementia in First Nations, this paper reports population-level data on dementia in the First Nations population in Alberta, Canada.

METHODS: Aggregate data obtained from Alberta Health and Wellness were analyzed. Physician-treated prevalence rates for dementia were calculated for First Nations and non-First Nations populations seeking treatment in Alberta (1998-2009). Trends in age-adjusted rates over time were compared using linear regression models. Age and sex effects were also examined.

RESULTS: In 2009, the age-standardized prevalence of dementia in First Nations in Alberta was 7.5 per 1,000 (95% CI: 6.6 to 8.5 per 1,000) compared to non-First Nations, at 5.6 per 1,000 (95% CI: 5.5 to 5.6). The prevalence of dementia rose more quickly for First Nations ($p=0.032$). The data suggest that dementia disproportionately affects younger age groups and males ($p=0.017$) in First Nations populations compared to non-First Nations.

CONCLUSIONS: Dementia represents an emerging health concern for First Nations. This increase may be driven by parallel trends, such as population aging, changing perceptions of dementia, and disproportionately higher rates of associated risk factors, impacts of the social determinants of health, and co-morbid illnesses. The unique epidemiological profile supports the need for responsive policies, programs and care geared specifically to First Nations.

KEY WORDS: Dementia; Alzheimer disease; First Nations; epidemiology; Canada

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

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In Canada, the number of people with Alzheimer's disease and related dementias is projected to more than double to 1,125,184 over the next 30 years.¹ Little is known about the prevalence and incidence of dementia in Aboriginal communities in Canada but, as is the case for the Canadian population, dementia in Aboriginal people is expected to be an increasing challenge for federal, provincial and community health care systems. The current lack of information makes planning for, and responding to, this emerging health issue difficult for program and policy planners and for those who need to provide services to this population. Aboriginal people gathered to discuss dementia in their communities in 2007. They reported that they believe they are experiencing an increase in the rate of dementia and confirmed that they are concerned that a lack of reliable information and statistics is making it difficult to respond to this emerging health need through current programming and policy.²

Several factors may be contributing to an increase in dementia in Aboriginal communities, including changing perceptions of the illness, demographic transitions, impacts resulting from the social determinants of health, rates of risk factors, increased vulnerability, and co-morbidities. Some evidence suggests dementia was not a significant health issue for Aboriginal people in Canada in the past. While dementia (including Alzheimer's disease, vascular dementia, and other related dementias) may have been present in communities, the phenomenon was often experienced as a non-pathological course of aging.^{3,4} Recent studies suggest that Aboriginal under-

standings of dementia are increasingly diverse and can range from naturalized to medicalized interpretations.^{5,6} Changing perceptions of the illness as a disease may have some impact on diagnosis.

Demographic transitions may also be contributing to an increase in age-related dementias in First Nations. The number of First Nations people in Canada is on the rise and expected to increase 1.4 times between 2006 and 2031. Importantly, the number of First Nations people aged 60 and older is expected to increase in number by 3.4 times from 54,165 in 2006 to 184,334 in 2031.⁷

The risk of dementia for First Nations may also be elevated due to higher rates of associated conditions, such as hypertension, heart disease, stroke, and diabetes,⁸ and higher smoking and obesity rates, all of which increase the risk of dementia.^{9,10} First Nations populations also have an increased vulnerability to the social determi-

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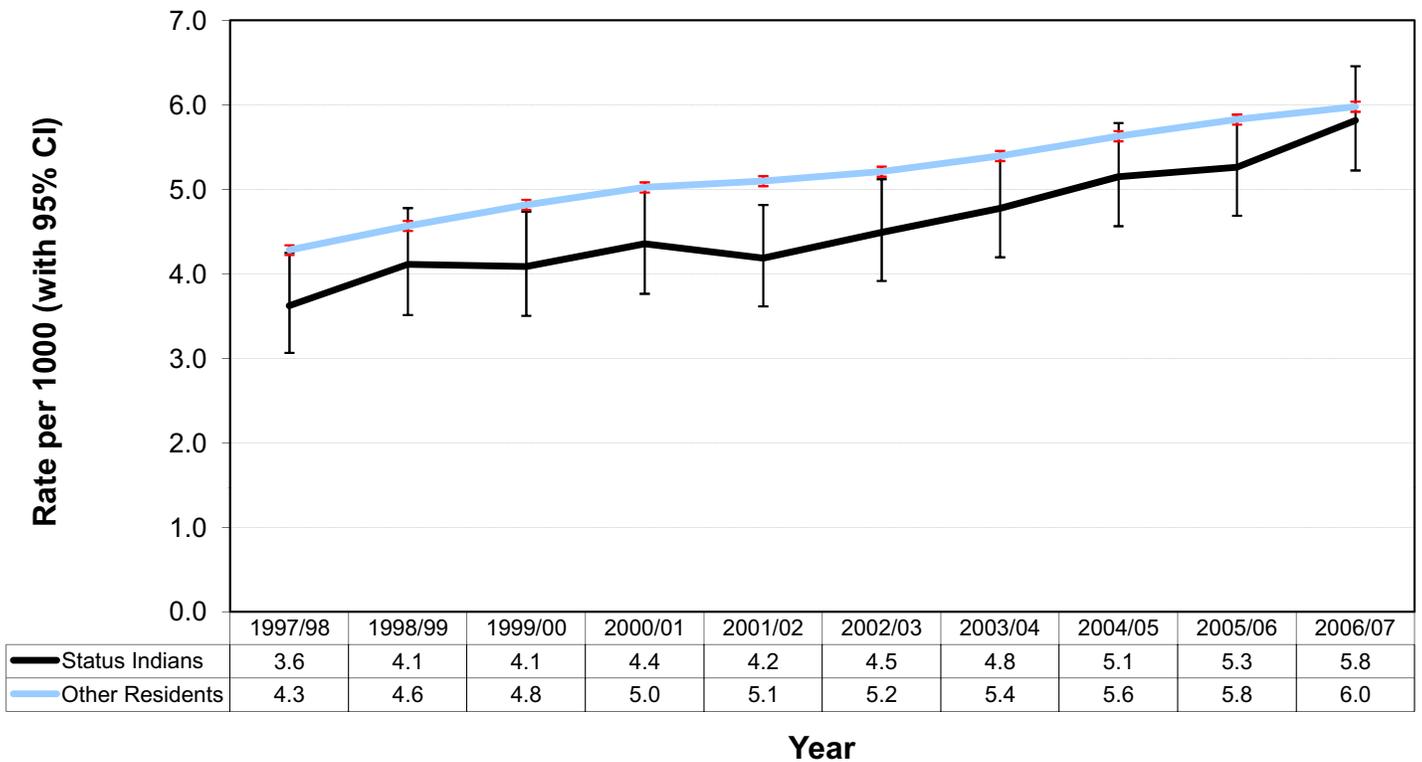
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Figure 1. Age-standardized prevalence rates of dementia, status Indians and other residents, BC, 1997/98 to 2006/07



Source: Population Health Surveillance and Epidemiology, BC Ministry of Health, 2008.

nants of health; most notable for dementia are lower incomes and lower levels of educational attainment.⁹ Recent studies suggest that sufferers of Post-Traumatic Stress Disorder (PTSD) are at an increased risk of dementia.¹¹ As a result of the historical trauma attributed to residential school experience and the ongoing inter-generational effects,¹² PTSD may also contribute to the overall prevalence of dementia for First Nations, Inuit and Métis people. Overall, there are several determinants of health that have the potential to contribute to an increased risk of a dementia diagnosis in this population.

Recent research in Australia suggests the prevalence of dementia among the Indigenous peoples in Kimberly, Australia is 12.4% for those over 45, compared to the age-standardized rate of 2.4% for the overall Australian population, making the Indigenous rate in Kimberly 5.2 times higher.¹³ In the Australian study, 53% of diagnoses were “not otherwise specified”, 24% were Alzheimer’s type, 13% vascular, 4% alcohol-induced and 4% due to other conditions. The only population-based estimates available in Canada indicate that the age-standardized rate of all dementia was similar between the First Nations population and the general population of British Columbia (BC) in 2006-07 (Figure 1).¹⁴ The report does not provide information on type of dementia diagnosis. The BC data suggest that First Nations have an earlier onset of dementia and increased risk among males, which is in contrast to non-First Nations trends but consistent with what has been found in Indigenous Australian men who experience dementia at nearly double the rate of Indigenous women.¹³

The dearth of information concerning prevalence and incidence of dementia in Aboriginal peoples in Canada is partially a product of poor and limited health information systems for Aboriginal people¹⁵ and the exclusion of questions concerning dementia and neuro-

logical health on national population health surveys concerning Aboriginal peoples. Administrative health databases often lack the data elements necessary to identify First Nations, Inuit or Métis patients. In a few cases, First Nations people who are registered “Status Indians” can be identified within provincial insurance and billing systems using unique identifiers. For example, this is the case for the Alberta Health and Wellness Surveillance system, which contains an identifier for “Status Indians” and was recently used to assess the epidemiologic profile of diabetes in First Nations in Alberta.¹⁶

To respond to the paucity of information available for dementia planning for First Nations, we report on physician-treated prevalence rates of dementia for First Nations people in Alberta, Canada between 1998 and 2009. “Treated prevalence” refers to the proportion of the population who experienced a physician visit with a primary diagnosis of dementia in a given year. This, coupled with the previously published data from BC, will begin to develop a picture of dementia in First Nations in Canada.

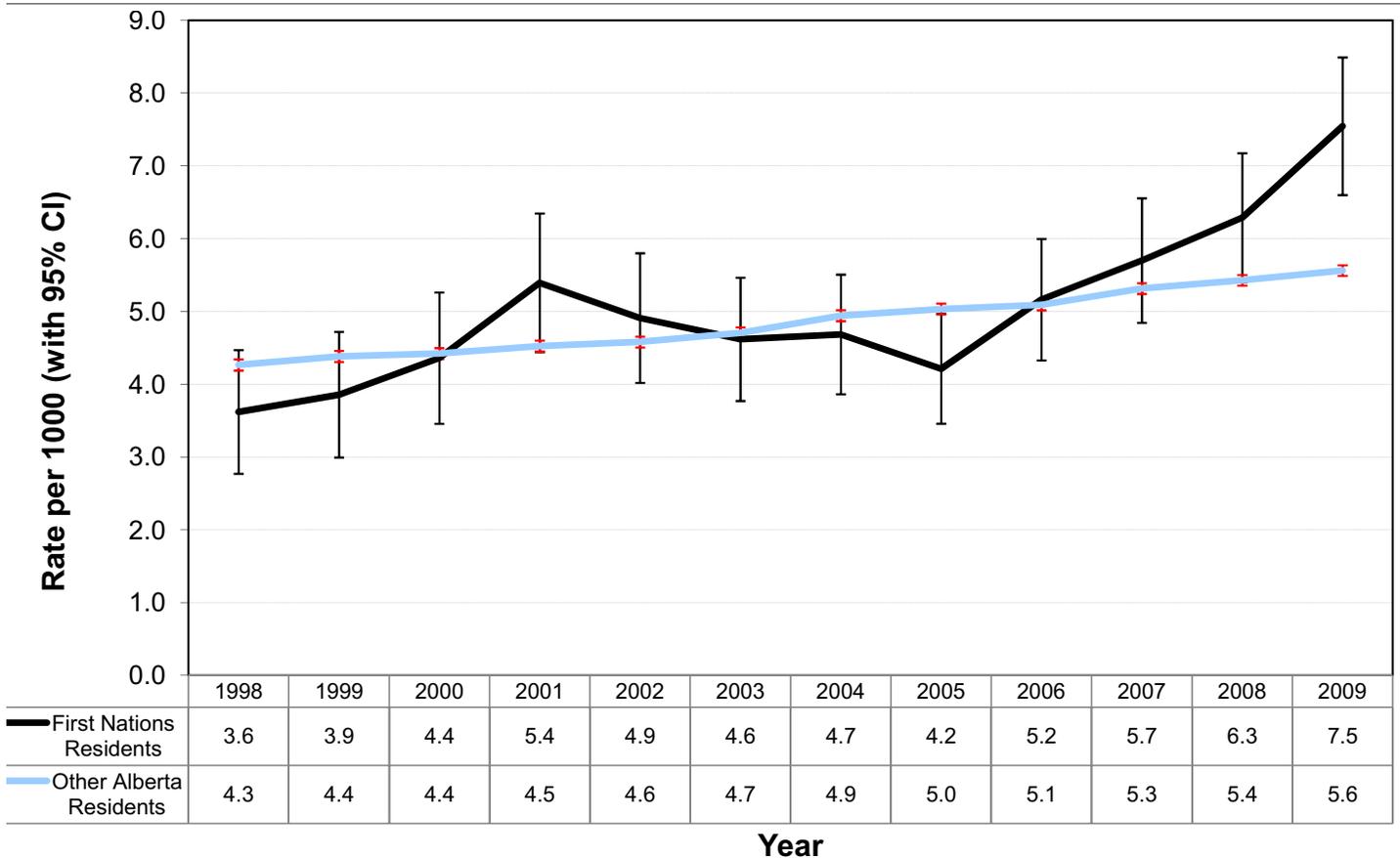
Specifically, we address the following questions: 1) Are physician-treated prevalence rates for dementia increasing more quickly among First Nations compared to non-First Nations populations? 2) Are First Nations populations experiencing dementia at younger ages than the non-First Nations population? 3) Does the sex distribution of dementia differ between First Nations and non-First Nations populations?

METHODS

Study population, data sources and variable definitions

Aggregate data on the physician-treated prevalence of dementia for the First Nations and Non-First Nations populations in Alberta for the 1998 to 2009 calendar years were obtained through a request

Figure 2. Age-adjusted treated prevalence of Alzheimer’s disease and dementia, Alberta, 1998 to 2009



Data sources and notes: Alberta Health Physician Claims Data and Alberta Health Care Insurance Plan Population Registry, Most Responsible Diagnosis of 290 or 331.0.

for information from the Surveillance and Assessment Branch of Alberta Health and Wellness, March, 2011.

Data were extracted from two provincial administrative health databases. The Alberta Health Care Insurance Plan Population Registry provided the population counts for Alberta residents covered by the Alberta Health Care Insurance Plan for each year. This excluded members of the Armed Forces, RCMP, inmates residing in federal penitentiaries and those who had decided not to register with the Alberta Health Care Insurance Plan. The annual First Nations population was estimated based on individuals having a registered band number in the Alberta Health Care Insurance Plan Population Registry at the mid-year point. This definition of First Nations included “Status Indians”, as defined by the Indian Act,¹⁷ living on and off-reserve, but notably excluded non-status Indians and Métis. Groups aggregated by age and sex were also derived from this database.

A second database, the Alberta Health Physician Claims Data, was used to identify First Nations and non-First Nations Alberta residents who experienced fee-for-service physician visits related to dementia within the year. Only the primary diagnosis field was used. If residents had *at least one* physician visit with a primary diagnosis of dementia (International Classification of Disease version 9 [ICD-9 code = 29]) or Alzheimer’s disease (ICD-9 code = 331.0), they were considered to have been treated for dementia.

Analysis

The population counts for First Nations and non-First Nations people in Alberta for each year and the number treated by a physician

for dementia within the year were provided by Alberta Health and Wellness. We used these numbers to calculate crude rates. Alberta Health and Wellness also provided age-adjusted treated prevalence rates for dementia with standard errors, for each year for First Nations and non-First Nations populations. Rates were age-adjusted to the 1991 Alberta population. To test whether the prevalence rates were increasing at different rates for First Nations and non-First Nations populations, a linear regression model was constructed with a slope dummy variable.

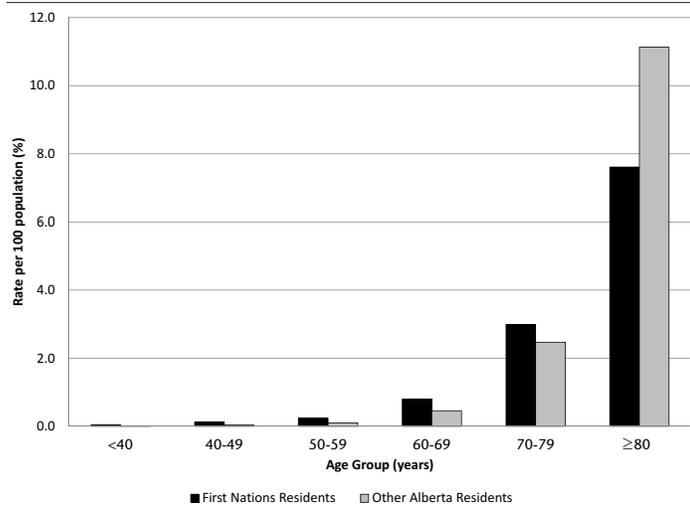
Alberta Health and Wellness also provided age-specific prevalence for the following age groups: 0 to 39, 40 to 49, 50 to 59, 60 to 69, 70 to 79, 80 and older, and sex-specific counts, rates and standard errors for each year. Because the counts by age group were low for each year, age-specific counts, rates and standard errors were aggregated over all the study years. Thus, we were not able to examine age-specific trends over time. To determine whether the relationship between sex and dementia prevalence differed for First Nations and non-First Nations populations, a second linear regression model was constructed with a sex by First Nations interaction variable, controlling for year.

We used the standard errors provided to construct approximate confidence intervals (calculated as +/- 2*standard error) around the prevalence estimates. For all analyses, STATA statistical analysis software was used and significance levels were set at alpha = 0.05.

RESULTS

The population of Alberta grew by 27% between 1998 and 2009. Similarly, the number of registered First Nations people in Alberta

Figure 3. Age-specific treated prevalence of Alzheimer's disease and dementia, Alberta, 1998-2009



Data sources and notes: Alberta Health Physician Claims Data and Alberta Health Care Insurance Plan Population Registry, Most Responsible Diagnosis of 290 or 331.0.

increased by 31% from 99,204 to 129,774. Over the same period, the number of First Nations people who were treated for dementia tripled from 101 to 316, an average increase of 26 treated individuals per year. The crude prevalence rates for this population increased from 1.0 per 1,000 to 2.4 per 1,000.

Because the age distribution of the First Nations population was notably younger than the non-First Nations population, rates were age-standardized. The rates over time are presented in Figure 2. The age-standardized prevalence of dementia in the First Nations population in 2009 was 34% higher than the rate for non-First Nations (7.5 per 1,000 [95% CI: 6.6 to 8.5 per 1,000] compared to 5.6 per 1,000 [95% CI: 5.5 to 5.6]).

Over time, the prevalence in First Nations rose with an observed minor peak in 2001 and a more recent increasing trend since 2006. While most of the annual variation is not likely different from the general population (that is, the 95% confidence interval includes the non-First Nations rate), the 2008 and 2009 First Nations rates appear to be more substantially different. Statistical testing showed that, despite the year-over-year variation, the age-adjusted prevalence rates rose significantly more quickly among First Nations than among non-First Nations populations ($p=0.032$).

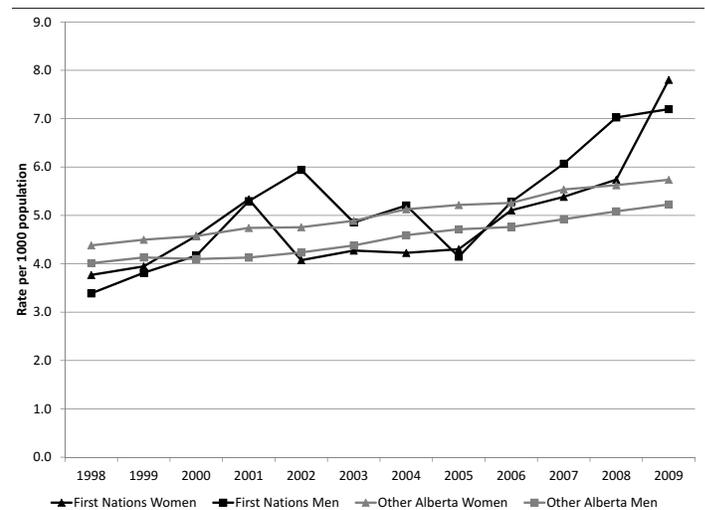
Figure 3 displays the age-specific treated prevalence estimates for all years and demonstrates a younger age distribution for First Nations compared with non-First Nations populations.

Figure 4 illustrates that the consistently higher dementia rates among females observed in the non-First Nations population were not observed for the First Nations population. In general, First Nations males had a disproportionately higher risk of dementia than non-First Nations males. Statistical testing confirmed that, controlling for year, the relationship between sex and dementia was significantly different for First Nations compared with non-First Nations populations ($p=0.017$).

DISCUSSION

The results show several distinct epidemiological trends in the First Nations population. The rate of dementia in the Alberta First Nation population grew from 3.9 per 1,000 to 7.5 per 1,000

Figure 4. Age-adjusted treated prevalence of Alzheimer's disease and dementia by gender, Alberta, 1998 to 2009



Data sources and notes: Alberta Health Physician Claims Data and Alberta Health Care Insurance Plan Population Registry, Most Responsible Diagnosis of 290 or 331.0.

between 1998 and 2009, surpassing rates of dementia for the non-First Nations population in the most recent years. Dementia rates increased at a faster rate in comparison to non-First Nations. Other distinct characteristics for First Nations include a younger age profile and trend data showing that First Nations men on average have had a higher rate of dementia than females over time.

Our findings are similar to those reported in BC showing an increasing trend in the number of First Nations individuals living with dementia between 2002/2003 and 2006/2007 where the rate of dementia increased from 4 to 6 per 1,000.¹⁴ However, unlike BC, the Alberta data show that the rate of treated dementia in First Nations has clearly surpassed that of the non-First Nation population and was calculated to be 34% higher in 2009. While the BC data showed a more gradual increase in the prevalence of dementia, the Alberta First Nations data showed a sharp increase only since 2006, with prior years being less consistent. While this may be a reflection of a sudden increase in dementia presentation, it could also be attributed to inconsistencies in reporting due to disruptions to services and programs affecting only First Nations residents.

The findings concerning the younger age profile in Alberta is consistent with the BC data showing First Nations people are diagnosed in younger age categories (60-69 and 70-79) compared to non-First Nations. Our finding that over time men had, on average, higher rates of dementia compared to women is distinct to this population and consistent with the BC and the Australian research.^{13,14}

The increasing prevalence of dementia found in the Alberta First Nations may be partially attributable to the demographic shift occurring in this population. It would not be unreasonable to assume that a growing elderly population would result in more cases of dementia. However, growth in rates of dementia outpaces population growth, suggesting that population growth alone does not account for either the sharp increase in dementia or the finding of higher rates of dementia in First Nations.

It may also be speculated that higher rates of associated diseases such as cardiovascular and cerebrovascular disease in First Nations

populations may account for higher rates of dementia. However, our gender analysis suggests that more First Nations men than women are being diagnosed with dementia, despite higher rates of diabetes and hypertension in First Nations women.^{16,18,19} This indicates that co-morbidity alone likely does not account for the increased prevalence of dementia found in First Nations.

Factors associated with higher prevalence of dementia in First Nations compared to non-First Nations people are more likely a complex blend of physiological and social determinants. The Australian research is the only study that addresses the question of factors associated with increased risk of dementia in Indigenous peoples, although it is specific to Aboriginal Australians.^{13,20} This study has most recently found that among demographic factors, older age, male gender, and no formal education were associated with a diagnosis of dementia; and lifestyle and clinical factors with an association included current smoking, previous stroke, epilepsy, head injury and various geriatric conditions. Notably, neither alcohol consumption nor diabetes was found to be associated with a diagnosis of dementia.²⁰ Similar physiological (co-morbid illness) and social determinants of health between Aboriginal Australians and First Nations in Canada as well as a shared colonial history suggest that factors associated with an elevated risk of dementia in First Nations may share similarities with those found in Australia.

Limitations

Dementia is often under-reported in recorded diagnoses²¹ and even less likely to be the primary diagnosis. Our results use only the primary diagnosis, likely underestimating the rates overall but not leading to inconsistencies between First Nations compared to non-First Nations populations. Underdiagnosis of dementia in the First Nations population is probable and often attributed to: reduced access to health services in remote reserve locations, especially to provincial health care services and long-term care facilities,^{22,23} questions concerning the cultural validity of screening tools,^{24,25} general cross-cultural care barriers,^{26,27} and differing and diverse understandings of dementia.²⁻⁶ Jurisdictional issues in the delivery of health care to First Nations in general also influence our ability to capture a comprehensive picture of any diagnosis using administrative databases since First Nations may obtain services through provincially or federally funded programs such as community-based health centres funded by First Nations and Inuit Health.

The availability of cholinesterase inhibitors used in the treatment of mild to moderate Alzheimer’s disease may increase the likelihood of reporting Alzheimer’s disease. However, cholinesterase inhibitors were not an approved federal health benefit for First Nations until December 2008²⁸ and therefore are not likely a strong contributing factor to the increase in dementia observed in this study.

CONCLUSIONS

Although many limitations with the data are noted, the findings from this work are found to be consistent with the only two other known studies reporting on dementia in Indigenous populations. Our results demonstrate that diagnosed dementia is increasing in First Nations in Alberta at a faster rate than in the non-First Nations population. It is likely that the actual number of cases is greater than estimated here. Several plausible explanations for the recent increase exist, including changing perceptions of the illness, access

to care, the demographic changes occurring in First Nations, higher rates of co-morbid conditions, greater prevalence of social and physiological risk factors, and other social determinants of health. With the prevalence of dementia having surpassed that of non-First Nations and prevalence rates rising more quickly for First Nations, we suggest there is a need for research concerning contributing factors using appropriate Aboriginal determinants of health models.^{9,29}

The results also demonstrate important differences in the presentation of dementia in First Nations useful to health care practitioners, planners and communities; that is, the likelihood of an earlier onset of dementia among First Nations and a greater risk in men. These findings will be helpful in supporting responsive policy enhancements and program planning within all health programs providing dementia services and care to First Nations.

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RÉSUMÉ

OBJECTIFS : On sait peu de choses sur la prévalence et l'incidence de la démence dans les communautés autochtones au Canada. Comme dans la population canadienne, on s'attend à ce que la démence chez les Autochtones présente un défi croissant pour les systèmes de santé fédéral, provinciaux et locaux. Pour combler le manque d'information sur la prévalence de la démence chez les Premières Nations, nous présentons des données populationnelles sur la démence dans la population des Premières Nations de l'Alberta, au Canada.

MÉTHODE : Nous avons analysé les données globales du ministère albertain de la Santé et du Bien-être. Les taux de prévalence de la démence traitée par un médecin ont été calculés pour les populations des Premières Nations et hors Premières Nations en quête de soins en Alberta (1998-2009). À l'aide de modèles de régression linéaire, nous avons comparé l'évolution dans le temps des taux ajustés selon l'âge. Nous avons aussi examiné les effets selon l'âge et le sexe.

RÉSULTATS : En 2009, la prévalence de la démence, standardisée pour l'âge, chez les Premières Nations de l'Alberta était de 7,5 p. 1 000 (IC de 95 % : 6,6 à 8,5 p. 1 000), tandis qu'hors des Premières Nations, elle était de 5,6 p. 1 000 (IC de 95 % : 5,5 à 5,6). La prévalence de la démence a augmenté plus rapidement chez les Premières Nations ($p=0,032$). Les données montrent que la démence touche les jeunes et les hommes de façon démesurée ($p=0,017$) dans les populations des Premières Nations comparativement aux populations hors Premières Nations.

CONCLUSION : La démence est un problème de santé émergent pour les Premières Nations. Son augmentation pourrait être alimentée par des tendances parallèles, comme le vieillissement de la population, l'évolution des perceptions à l'égard de la démence, ainsi que les taux démesurément plus élevés des facteurs de risque associés, les impacts des déterminants sociaux de la santé et les comorbidités. Ce profil épidémiologique singulier appelle à des politiques, des programmes et des soins plus spécifiquement adaptés aux Premières Nations.

MOTS CLÉS : démence; maladie d'Alzheimer; Premières Nations; épidémiologie; Canada