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REVIEW

Prevalence and incidence of dementia among indigenous populations: a systematic review

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ABSTRACT

Background: Indigenous populations may be at increased risk, compared with majority populations, for the development of dementia due to lower education levels and socio-economic status, higher rates of diabetes, hypertension, cardiovascular disease and alcohol abuse, an aging population structure, and poorer overall health. This is the first systematic review investigating the prevalence and incidence of dementia in indigenous populations worldwide.

Methods: This systematic review was conducted in accordance with PRISMA guidelines. We searched MEDLINE, Embase, and PsycInfo for relevant papers published up to April 2015. Studies were included if they reported prevalence or incidence, the disease typically occurred after the age of 45, the study population included indigenous people, and the study was conducted in the general population.

Results: Fifteen studies representing five countries (Canada, Australia, the USA, Guam, Brazil) met the inclusion criteria. Dementia prevalence ranged from 0.5% to 20%. Retrospective studies relying on medical records for diagnoses had much lower prevalence rates and a higher risk of bias than population-based prospective studies performing their own diagnoses with culturally appropriate cognitive assessment methods.

Conclusions: The prevalence of dementia among indigenous populations appears to be higher than it is for non-indigenous populations. Despite a building body of evidence supporting the need for dementia research among indigenous populations, there is a paucity of epidemiological research, none of which is of high quality.

Key words: dementia, indigenous, prevalence, incidence, global

Introduction

Dementia is an umbrella term encompassing a variety of symptoms related to a decline in memory, orientation, language, judgment, or reasoning which reduces the ability to accomplish activities of daily living. Alzheimer's Disease (AD) is the most common cause of dementia accounting for approximately 70% of patients (Reitz *et al.*, 2011). Vascular dementia, Lewy Body dementia, and frontotemporal dementia cause the majority of additional dementia cases. While generally not a common cause for dementia, Parkinson's Dementia (PD) was a common cause of dementia among the Chamorros, an indigenous population with Polynesian descent, of Guam prior to World War II (Galasko *et al.*, 2007).

There is no official definition of "indigenous" as the definition varies from country to country. In general, indigenous people self-identify as indigenous and are accepted as indigenous by their community (World Health Organization, 2007; Australian Bureau of Statistics, 2011; Office of Minority Health and Health Equity, 2015). There are approximately 370 million indigenous people worldwide, representing 5% of the world's population (World Health Organization, 2007).

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There is a large degree of variability in cultural practices, spiritual beliefs, languages, and historical experiences between indigenous populations. More than 70 countries have indigenous populations, with many countries having numerous distinct indigenous groups. Indigenous populations in a number of countries, including Canada, Australia Guam, and the USA, suffer from intergenerational trauma as a result of colonization, the associated loss of culture and traditions, and racial discrimination. While not all indigenous populations have experienced the same historical trauma, it is generally accepted that indigenous populations worldwide have a lower socio-economic status, lower levels of education, and poorer overall health (including higher rates of cardiovascular disease, diabetes, and alcohol abuse), increasing their risk for the development of dementia (Chen *et al.*, 2009; Smith *et al.*, 2010).

In Canada, there are three distinct indigenous groups (First Nations, Métis, and Inuit). First Nations people represent approximately 60% of Canada's indigenous population (Statistics Canada, 2011). First Nations people include those who are registered under the Indian Act (also known as Registered Indians or Status Indians) and those who are not registered (also known as non-Status Indians).

In the 2013 USA Census, 5.2 million people self-identified as American Indian or Alaska Native accounting for approximately 2% of the total population (Office of Minority Health and Health Equity, 2015). There are 566 federally recognized (a tribe that has a government-to-government relationship and a special trust relationship with the USA) tribes (US Department of the Interior, 2015). Less than half (approximately 1.9 million people) of the American Indians or Alaska Natives living in the USA are members of these tribes (US Department of the Interior, 2015).

The indigenous population in Australia primarily consists of Aboriginal and Torres Strait Islander people (Australian Bureau of Statistics, 2011). The self-identified indigenous Australian population accounts for roughly 3% (669,900) of the general population (Australian Bureau of Statistics, 2011). Among the indigenous population, 90% identified as Aboriginal, 6% identified as Torres Strait Islander, and 4% identified as both.

In 1960, the Chamorro population was approximately 50% (34,762) of the population in Guam (Plato *et al.*, 2003). By 2000, the Chamorro population had increased to 57,297 and accounted for 37% of the Guam population (Plato *et al.*, 2003).

In Brazil, 817,000 people self-identified as indigenous accounting for 0.42% of the total population in 2010 (International Work Group for Indigenous Affairs, 2014). There are 305 indigenous ethnic groups and 274 indigenous languages spoken (International Work Group for Indigenous Affairs, 2014). Regionally, the largest number (approximately 168,000) of indigenous Brazilians live in the Amazonas (International Work Group for Indigenous Affairs, 2014).

Information on the age structure of indigenous populations is limited. While the percentage of indigenous seniors in Canada is relatively small in comparison to non-indigenous seniors, the number of indigenous seniors is increasing at a much faster rate in comparison to non-indigenous seniors (50% vs. 24% from 1996 to 2006) (Statistics Canada, 2006). A similar trend is expected for indigenous seniors in the USA. The non-indigenous senior population is expected to double from 2007 to 2047, while the number of indigenous seniors is expected to more than triple for the same period (Department of Health & Human Services, 2007).

Despite the higher incidence of risk factors indicating that the prevalence for dementia among indigenous populations may be higher than the prevalence among non-indigenous populations and may also be on the rise, dementia among indigenous populations has received minimal research attention. The objective of this systematic literature review was to determine the prevalence and incidence rates for dementia among indigenous populations worldwide.

Methods

This systematic review was conducted in accordance with PRISMA guidelines.

Search sources and searches

Two reviewers (LW and QS) conducted a literature search including grey literature (e.g. conference proceedings and dissertations) of MEDLINE & MEDLINE In-Process & Other Non-Indexed Citations (1946 to April 3, 2015); Embase (1980 to 2015, Week 14); PsycINFO (1806 to April 2015, week 1); and grey literature in April 2015. Government (e.g. Statistics Canada, National Institute of Health, Australian Bureau of Statistics) and non-government (e.g. World Health Organization) websites were searched for relevant publications. There were no restrictions by year of publication or language. Searches based on keywords were conducted. Keywords included dementia, cognition disorders, Alzheimer, neurodegenerative diseases, Aboriginal, Aborigine, Native, First Nation, Indigenous, North American Indians, Oceanic Ancestry Group, odds ratio, prevalence, incidence, risk, and relative odds.

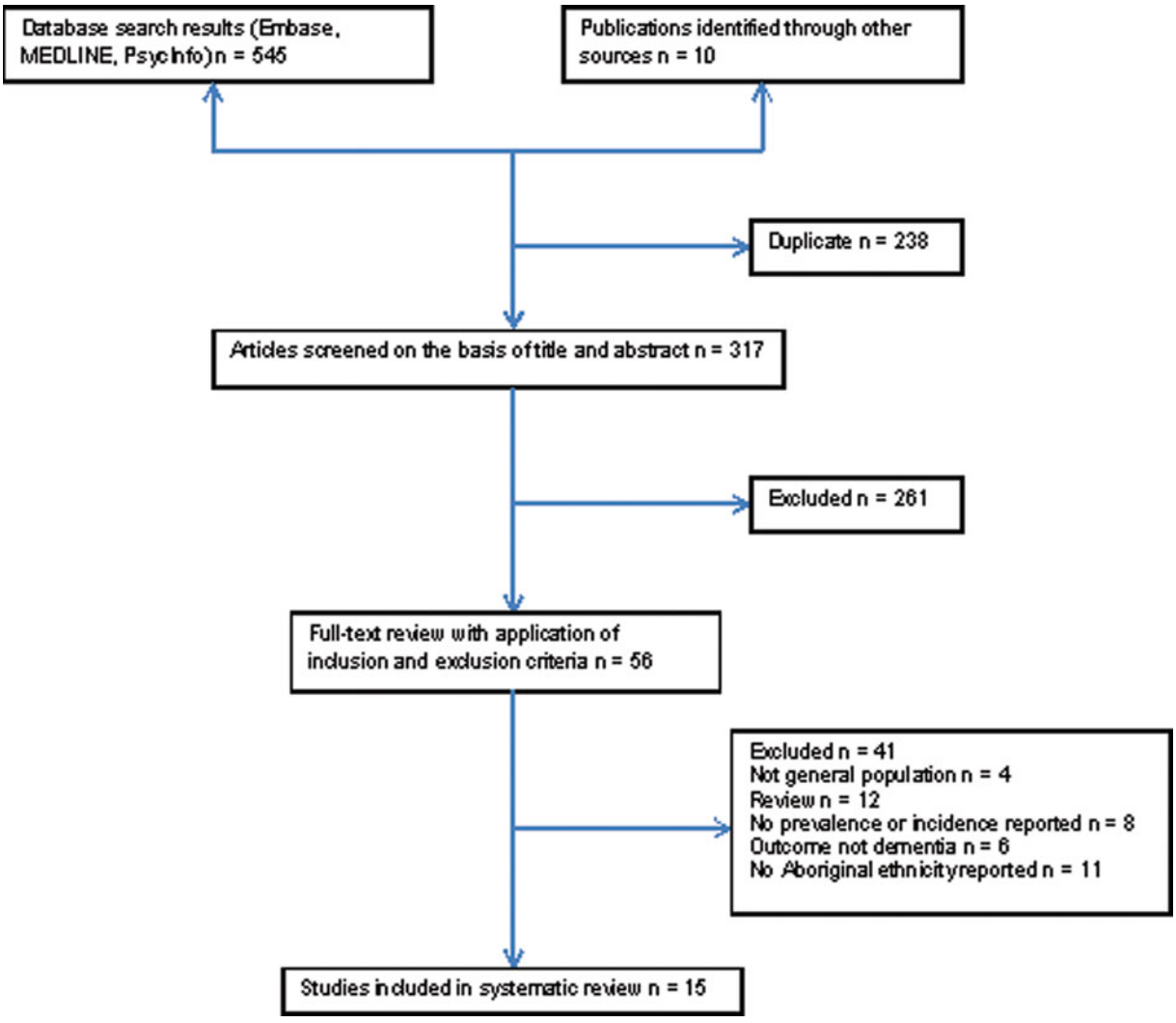

Figure 1. (Colour online) Study search and selection.

References from key papers were also searched. Appendix 1 contains details about the search strategy.

Study selection

Papers investigating dementia among indigenous populations were included for review, if they met the following inclusion criteria: (1) the study included an indigenous population, (2) prevalence or incidence was reported, (3) the study was conducted in the general population, (4) the disease typically occurred after the age of 45. A flow chart of the search is shown in Figure 1.

Data extraction and quality assessment

Data were extracted to a table which included: Authors and date, study location, target population, screening test used, reference test used, mean age, sample size, and the prevalence (Table 1), or incidence (Table 2) of dementia including confidence limits (if available). An assessment of publication bias was not conducted due to the small number and heterogeneity (e.g. prevalence/incidence, AD/dementia/MCI/PD, region, primary/secondary data) of studies. Crude prevalence rates cannot be compared unless we compare them using the same standard population. Prevalence rates for individuals ≥ 65 were age-standardized to the 2014 Canadian population using the direct standardization method, where data permitted (Government of Canada, 2014). Two studies presented data in age increments that began at age 60 (Smith *et al.*, 2008; Jacklin *et al.*, 2013). We applied the prevalence rate of the 60–69 year age group to estimate the prevalence rate of individuals aged 65–69 (Kelly *et al.*, 2008).

Quality assessment was conducted using the Risk of Bias Tool developed for the critical assessment of prevalence studies by Hoy and colleagues (Hoy,

Table 1. Study characteristics of included prevalence publications

AUTHOR AND DATE	STUDY LOCATION	TARGET POPULATION	SCREENING TEST	REFERENCE TEST	MEAN AGE (YEARS)	SAMPLE SIZE	PREVALENCE OF DEMENTIA
Hendrie *et al.*, 1993	Manitoba, Canada	Cree, status FN, individuals ≥65 years	Community Screening Interview for Dementia (CSI 'D')	DSM-III-R	NA	192	Age-standardized 4·2% (95% CI 2·6–5·8%)
Zann, 1994	Northern Queensland, Australia	Aboriginal and Torres Strait Islander peoples ≥65 years	Hospital records, psychogeriatric assessment scale	NA	NA	133	20%
Galasko *et al.*, 2007	Guam	Chamorros, ≥65 years	Cognitive Assessment Screening Intrument (CASI)	DSM-IV	73.8 (±6.0) years	1,984	12.2% (95% CI 11.7–12.9%)
Jervis *et al.*, 2007	Northern Plains Reservation, United States	American Indians, ≥60 years, utilizing senior nutrition program	Mini-Mental State Examination (MMSE) and Mattis Dementia Rating Scale (MDRS)	NA	69.8 (±6.4) years	137	MMSE 14.6%; MDRS 37.2%
Mehta *et al.*, 2008	United States	Diagnosed dementia cases among indigenous and non-indigenous people ≥65 years	MMSE	National Institute of Neurological Diseases and Stroke-Alzheimer's Disease and Related Disorders Association	78·2 (±7.0) years	30,916	0·5%
Smith *et al.*, 2008	Kimberley Region, Australia	Kimberley Aboriginal Communities, individuals ≥45 years	Kimberley Indigenous Cognitive Assessment tool (KICA)	DSM-IV	60.7 (±11.9) years	363	12·4% (95% CI 9·0–15·8%)
British Columbia Provincial Health Officer, 2009	British Columbia, Canada	First Nations residents of British Columbia ≥65 years	Physician diagnosed	NA	NA	357	Age-standardized 0·6%

Table 1. continued.

AUTHOR AND DATE	STUDY LOCATION	TARGET POPULATION	SCREENING TEST	REFERENCE TEST	MEAN AGE (YEARS)	SAMPLE SIZE	PREVALENCE OF DEMENTIA
Caixeta and Reis, 2011	Bananal Island, Brazil	Karaja group in Brazilian Amazon ≥60 years	Modified MMSE	DSM-IV; Neuropsychiatric evaluation	72.4 (±1.6) years	108	6.4%
Jacklin *et al.*, 2013	Alberta, Canada	First Nations and non-First Nations Physician-treated dementia cases	Physician diagnosed	NA	NA	129,774	7·5 per 1,000 (95% CI 6·6–8·5 per 1,000)
Li *et al.*, 2014	Northern Territory, Australia	Indigenous and non-indigenous people ≥45 in Northern Territory Health database	Clinical Diagnosis	NA	Median 72 years	784	Age-standardized 6.5 per 100 (95% CI 5.8–6.8 per 100)
Radford *et al.*, 2015	New South Wales, Australia	New South Wales Aboriginal Communities, individuals ≥60 years	Rowland Universal Dementia Assessment Scale (RUDAS); MMSE; modified Kimberley Indigenous Cognitive Assessment Tool (mKICA)	Medical Diagnosis	Median 66·6 (±6.3) years	336	13·4% (95% CI 10·2–17·5%)

Table 2. Study characteristics of included incidence publications

AUTHOR AND DATE	STUDY LOCATION	TARGET POPULATION	SCREENING TEST	REFERENCE TEST	MEAN AGE (YEARS)	SAMPLE SIZE	AGE-ADJUSTED MINIMUM AND MAXIMUM INCIDENCE OF DEMENTIA PER 100,000
Reed and Brody, 1975	Guam	Chamorros	Neurological evaluation	NA	NA	1945: 27,124; 1972: >45,000	Male: 17–55; Female: 0–19
Zhang *et al.*, 1990	Guam	Chamorros	Neurological evaluation	NA	Median: 57	1944: ~27,000 1985: ~47,000	Men 0–68; Female 0–25
Plato *et al.*, 2003	Guam	Chamorros	Neurologic evaluation	NA	NA	1960: 34,762; 2000: 57,297	Male: 4–57; Female: 0–28
Waring *et al.*, 2004	Guam	Chamorros	Neurological evaluation	NA	Male: 51.8–67.5; Female 50.4–63.2	1950: ~28,000 1989: ~50,000	Male 30–63; Female 0–29

2012). The risk of bias tool includes eleven questions; four questions related to external validity, six questions related to internal validity, and an overall summary score based on the risk of bias assessment for internal and external validity. The overall summary score is based on the methods used in Grades of Recommendation, Assessment, Development, and Evaluation (GRADE) and Cochrane (Terracciano *et al.*, 2010; Higgins and Green, 2011). A "low" or "high" risk of bias was assigned to each of the ten questions according to the criteria provided in the tool. Data extraction and quality assessment were conducted by two reviewers (LW and QS). Any discrepancies between the two reviewers' assessments were resolved with a third author.

Results

Search and selection findings

Fifteen publications were included in this systematic review. Four of these studies were conducted in Australia, (Zann, 1994; Smith *et al.*, 2008; Li *et al.*, 2014; Radford *et al.*, 2015) two in the USA, (Jervis *et al.*, 2007; Mehta *et al.*, 2008) five in Guam, (Reed and Brody, 1975; Zhang *et al.*, 1990; Plato *et al.*, 2003; Waring *et al.*, 2004; Galasko *et al.*, 2007) one in Brazil, (Caixeta and Reis, 2011) while the other three (Hendrie *et al.*, 1993; British Columbia Provincial Health Officer, 2009; Jacklin *et al.*, 2013) presented Canadian data.

Study quality

Table 3 displays the risk of bias for the external validity, internal validity, and overall. There were no disagreements in overall study quality assessment between the two reviewers. All included publications except one received high risk of bias scores for external validity as a result of their small, region/province-specific samples (Reed and Brody, 1975; Zhang *et al.*, 1990; Hendrie *et al.*, 1993; Zann, 1994; Plato *et al.*, 2003; Waring *et al.*, 2004; Jervis *et al.*, 2007; Mehta *et al.*, 2008; Smith *et al.*, 2008; British Columbia Provincial Health Officer, 2009; Caixeta and Reis, 2011; Jacklin *et al.*, 2013; Li *et al.*, 2014; Radford *et al.*, 2015). A census was used to give a complete enumeration of permanent residents on Guam in the study conducted by Galasko and colleagues, which was the only study to receive a low risk of bias for external validity (Galasko *et al.*, 2007). Three studies (British Columbia Provincial Health Officer, 2009; Jacklin *et al.*, 2013; Li *et al.*, 2014) received a high risk of bias for internal validity because diagnostic criteria were not standardized and the sample represented the treated prevalence, which is likely different than the true prevalence.

Characteristics of studies

Seven of the studies reported only the prevalence of dementia, (Zann, 1994; Galasko *et al.*, 2007; British Columbia Provincial Health Officer, 2009; Caixeta and Reis, 2011; Jacklin *et al.*, 2013; Li *et al.*, 2014;

Table 3. Quality assessment of included publications

AUTHOR	EXTERNAL VALIDITY	INTERNAL VALIDITY	OVERALL RISK OF BIAS
British Columbia Provincial Health Officer	High risk	High	High
Caixeta and Reis	High risk	Low risk	Moderate
Galasko *et al.*	Low risk	Low risk	Moderate
Hendrie *et al.*	High risk	Low risk	Moderate
Jacklin *et al.*	High risk	High risk	High
Jervis *et al.*	High risk	Low risk	Moderate
Li *et al.*	High risk	High risk	High
Mehta *et al.*	High risk	Low risk	High
Plato *et al.*	High risk	Low risk	Moderate
Radford *et al.*	High risk	Low risk	Moderate
Reed and Brody	High risk	Low risk	Moderate
Smith *et al.*	High risk	Low risk	Moderate
Waring *et al.*	High risk	Low risk	Moderate
Zann	High risk	Low risk	Moderate
Zhang *et al.*	High risk	Low risk	Moderate

Radford *et al.*, 2015) four of the studies conducted in Guam presented incidence data on PD, (Reed and Brody, 1975; Zhang *et al.*, 1990; Plato *et al.*, 2003; Waring *et al.*, 2004) one study presented the prevalence of AD, (Mehta *et al.*, 2008) one study defined patients with cognitive impairment, (Jervis *et al.*, 2007) one study presented the prevalence of both AD and dementia, (Hendrie *et al.*, 1993) and in one study participants were classified as having dementia, cognitive impairment but not dementia or no cognitive impairment (Smith *et al.*, 2008).

The study conducted among Cree residents of Manitoba provided a breakdown of participants by age category (Hendrie *et al.*, 1993). While Zann acknowledged the much younger age distribution in the indigenous population compared to the non-indigenous population individuals who were aged ≥ 65 years and individuals who were identified as being at high risk for dementia or showing signs of dementia by health workers were surveyed to be consistent with sampling methodology used in dementia studies in the non-indigenous Australian population (Zann, 1994).

The prevalence of dementia among indigenous people ranged from 0.5% (Mehta *et al.*, 2008) to 20% (Zann, 1994) (Table 1). Four studies also included data from the non-indigenous population (Mehta *et al.*, 2008; British Columbia Provincial Health Officer, 2009; Jacklin *et al.*, 2013; Li *et al.*, 2014). The age-standardized prevalence rate was the same (0.6%) for Status First Nations and other residents in the British Columbia study, (British Columbia Provincial Health Officer, 2009) whereas the age-standardized prevalence of dementia was 34% higher for First Nations (0.75%, 95% CI 0.66–0.85) in comparison to non-First Nations (0.56%, CI 0.55–0.56) in the study led by Jacklin (Jacklin *et al.*, 2013). Consistent with the study by Jacklin and colleagues, Li and colleagues found the age-adjusted prevalence in the indigenous population aged 45 years or older (6.5 per 100 population, 95% CI 5.8–6.8) was much higher than the age-adjusted prevalence found in the non-indigenous population ≥ 45 (2.6 per 100 population, 95% CI 2.3–2.8) (Li *et al.*, 2014). Indigenous people represented 0.5% of the 30,916 patients with possible or probable AD seen at an AD Center in the USA between 1984 and 2005 (Mehta *et al.*, 2008). The vast majority (81%) of the patients with possible or probable AD were Caucasian (Mehta *et al.*, 2008).

We age-standardized the prevalence rates of five studies (Hendrie *et al.*, 1993; Galasko *et al.*, 2007; Smith *et al.*, 2008; Jacklin *et al.*, 2013; Li *et al.*, 2014) to the 2014 Canadian population. Two of the studies were conducted in Canada, (Hendrie *et al.*, 1993; Jacklin *et al.*, 2013) two were conducted in Australia, (Smith *et al.*, 2008; Li *et al.*, 2014) and one was conducted in Guam (Galasko *et al.*, 2007). The age-standardized dementia prevalence rates for individuals 65 years of age or older were the same (Hendrie: 3.5% ± 2.5%, Jacklin: 3.5% ± 0.2%) for the two Canadian studies (Hendrie *et al.*, 1993; Jacklin *et al.*, 2013). The age-standardized prevalence rate for those ≥65 was higher (27.2% ± 6.6% compared to 14.6% ± 2.5%) for the prevalence study by Smith and colleagues than it was for the study by Li and colleagues, which was based on treated dementia patients (Smith *et al.*, 2008; Li *et al.*, 2014). The age-standardized

prevalence rate in Guam was 15.6% ± 1.8% (Galasko *et al.*, 2007).

All incidence studies were based on the same population for different time periods. Despite using the same data sources, the average annual age-adjusted incidence rates varied slightly between studies for the same time periods (Table 2). The incidence of PD was consistently higher (approximately 3:1) for men in comparison to women across all studies (Reed and Brody, 1975; Zhang *et al.*, 1990; Plato *et al.*, 2003; Waring *et al.*, 2004). Peak incidence, ~63 per 100,000, occurred between 1960 and 1964 for men and from 1970 to 1974 for women (~28 per 100,000) (Reed and Brody, 1975; Zhang *et al.*, 1990; Plato *et al.*, 2003; Waring *et al.*, 2004).

Seven of the prevalence studies were based on primary data collection and developed or modified cognitive assessment tools to be more culturally appropriate for indigenous populations, (Hendrie *et al.*, 1993; Zann, 1994; Galasko *et al.*, 2007; Jervis *et al.*, 2007; Smith *et al.*, 2008; Caixeta and Reis, 2011; Radford *et al.*, 2015) while the other four were based on pre-existing data (Mehta *et al.*, 2008; British Columbia Provincial Health Officer, 2009; Jacklin *et al.*, 2013; Li *et al.*, 2014). In three studies, dementia diagnoses were confirmed by neurologists, psychiatrists, or geriatricians using DSM-III (Hendrie *et al.*, 1993) or DSM-IV (Galasko *et al.*, 2007; Smith *et al.*, 2008) criteria. The data from the British Columbia study were based on existing provincial-level hospitalization data and physician billings (Kim Reimer, personal communication, May 7 2014). Patients with dementia were diagnosed by physicians in the study led by Jacklin (Jacklin *et al.*, 2013). The sample size for indigenous populations ranged from 108 (Caixeta and Reis, 2011) to 129,774 (Jacklin *et al.*, 2013).

Discussion

Globally, indigenous populations have a much lower life expectancy than non-indigenous populations, up to 20 years lower in some countries, which may account for the paucity of research on dementia among indigenous populations. The majority of researchers studying dementia in indigenous populations investigated genetic factors, health, social and cultural factors, and environmental risk factors (Borenstein *et al.*, 2007; Butler *et al.*, 2010; Dingwall *et al.*, 2013). However, to date, there are only 15 studies published on the prevalence or incidence of dementia among indigenous populations worldwide.

Due to the small number of studies in combination with the high degree of heterogeneity between study sample sizes, locations, screening and diagnostic methods, outcome definitions, and data sources, (medical records compared to population sampling), the large range in the prevalence rates of dementia are not surprising. Galasko and colleagues conducted an island-wide prevalence survey among all permanent residents of Guam aged ≥65 years. All registered First Nations people in Alberta were counted in the denominator for the study led by Jacklin which accounts for the much larger sample size (n = 129,774) and the low prevalence rates (Jacklin *et al.*, 2013). Cases were obtained from previous dementia diagnoses (ICD-9 or ICD-10 diagnostic code recorded by hospital or physician visit) in the study conducted in British Columbia (British Columbia Provincial Health Officer, 2009). All of the studies, except for the study led by Galasko, were conducted in relatively small populations which are likely not representative of the national populations they were drawn from. All of the Canadian studies did not include information from non-status First Nations, Métis, and Inuit populations (Hendrie *et al.*, 1993; British Columbia Provincial Health Officer, 2009; Jacklin *et al.*, 2013). The three provinces represented were all from Western or Central Canada; there were no studies from Eastern Canada or the territories. Three of the Australian studies were conducted in rural regions in Northern Australia, (Zann, 1994; Smith *et al.*, 2008; Li *et al.*, 2014) while the fourth study was conducted in indigenous communities in New South Wales with a significant urban indigenous population (Radford *et al.*, 2015). The study by Jervis and colleagues recruited cases from a senior nutrition program in a Northern Plains Reserve in Colorado, USA (Jervis *et al.*, 2007). Data for the study conducted by Mehta and colleagues was obtained from more than 30 AD Centers nation-wide (Mehta *et al.*, 2008).

The diagnostic methods for all 15 studies were different; however, all of the studies completed exclusively in indigenous communities attempted to use culturally appropriate cognitive assessment tools. Seven of the studies identified patients through physician diagnoses (Reed and Brody, 1975; Waring *et al.*, 2004; British Columbia Provincial Health Officer, 2009; Caixeta and Reis, 2011; Jacklin *et al.*, 2013; Li *et al.*, 2014; Radford *et al.*, 2015).

In 1966, PD among the Chamorro population of Guam was identified as a clinically and pathologically distinct disease from Parkinson's disease (Steele, 2005). PD is typically familial, may have a long latent period and has only occurred in three Pacific regions. Due to the large number

of studies relative to the number of cases, its limited geographic region, familial nature, and short exposure window studies on PD are more comprehensive than studies on the other dementias covered in this review. The study led by Galasko was the only study to receive a low risk of bias for external validity due to the complete enumeration of the permanent residents of Guam (Galasko *et al.*, 2007).

Four Guam studies reported age-adjusted incidence rates. The oldest study, conducted by Reed and Brody in 1975, used cases of PD to calculate average age-adjusted annual incidence rates for five year periods from 1950 to 1972 (Reed and Brody, 1975). The entire population of Guam was used for the denominator in the annual incidence rate calculations which included non-Chamorro residents of Guam (Reed and Brody, 1975). The incidence rates reported in the study by Waring and colleagues are likely more accurate as only Chamorros residents were included in the denominator (Waring *et al.*, 2004).

While the incidence rates varied slightly between studies, the quadratic pattern was consistent across studies with peak incidence occurring in the early 1960s for males and 1970s for females. The difference in incidence rates was likely related to environmental and cultural changes that took place in Guam after World War II (1945) with a shift away from traditional lifestyles. Cycad, plant indigenous to the tropics, was a staple of the traditional Chamorros diet and has been associated with a higher prevalence of PD (Borenstein *et al.*, 2007).

The greatest difference in the prevalence of dementia between studies was likely due to different types of data sources and cognitive assessment methods. Three of the four studies that used medical records to identify cases reported much lower prevalence rates (0.5%–6.5%) (Mehta *et al.*, 2008; British Columbia Provincial Health Officer, 2009; Jacklin *et al.*, 2013) than studies that screened older (≥45, ≥60, or ≥65) individuals in indigenous communities (dementia prevalence: 4.2%–37.2%) (Hendrie *et al.*, 1993; Galasko *et al.*, 2007; Jervis *et al.*, 2007; Smith *et al.*, 2008; Caixeta and Reis, 2011; Radford *et al.*, 2015). Using dementia diagnoses from medical records yielded treated prevalence rates as opposed to studies using primary data collection methods, which attempt to capture true prevalence. The treated prevalence rate is often not reflective of the true prevalence as a number of factors affect the probability of an individual accessing healthcare (e.g. socio-economic status, region of residence), especially in the USA, where healthcare is predominantly funded privately. Within the same study, the prevalence of dementia more than doubled (37.2% vs. 14.6%) when the Mattis Dementia Rating Scale (MDRS) was used to identify dementia cases in comparison to the Mini-Mental State Examination (MMSE) (Jervis *et al.*, 2007).

In general, indigenous populations have a lower socio-economic status, lower education levels, and a lower level of overall health, including a higher prevalence of HIV/AIDS, diabetes, hypertension, alcohol abuse, obesity, cardiovascular disease, and mental health disorders, (Waldram *et al.*, 2006; Statistics Canada, 2011; Cunningham and Paradies, 2012) which are all risk factors for the development of dementia. It is difficult to generalize studies conducted in specific populations/regions to the national level as there is a large degree of variation in risk profiles between indigenous communities, even within the same region (Cunningham and Paradies, 2012). Basic demographics and co-morbidities that may increase the risk for dementia were only provided for participants in two studies (Smith *et al.*, 2010; Radford *et al.*, 2015). No formal education, smoking, previous stroke, epilepsy, and prior head injury were associated with increased odds of dementia (Smith *et al.*, 2010). Radford and colleagues provided the number of participants with risk factors (e.g. previous stroke, head injury, depression) for the entire sample with no comparisons between individuals who were and were not diagnosed with dementia (Radford *et al.*, 2014).

The prevalence of dementia doubles with every 5.5 year increase in age from the age of 60 years onwards (Brookmeyer *et al.*, 2007). We age-standardized the prevalence rates of five studies to the same general population to account for different age structures between studies (Hendrie *et al.*, 1993; Galasko *et al.*, 2007; Smith *et al.*, 2008; Jacklin *et al.*, 2013; Li *et al.*, 2014). Age-standardized prevalence rates for individuals 65–69 were estimated using the prevalence rates for individuals in the 60–69 age category for the studies led by Jacklin and Smith (Smith *et al.*, 2008; Jacklin *et al.*, 2013). The estimated prevalence rates may be slightly lower than the true prevalence rates as the estimate was based on a younger age demographic. In general, treated prevalence rates underestimate the true prevalence. As such, we expected the age-standardized prevalence rate to be higher in the prevalence study conducted by Hendrie and colleagues than in the study based on administrative data led by Jacklin (Hendrie *et al.*, 1993; Jacklin *et al.*, 2013). Twenty years elapsed between the studies led by Hendrie and Jacklin. Broader definitions of dementia used in current-day diagnostic criteria in comparison to criteria in the early 1990s may account for the relatively low prevalence rate in the study led by Hendrie

(Wu *et al.*, 2014). As expected, the age-standardized prevalence rate for those ≥65 was higher (27.2% compared to 14.6%) for the prevalence study by Smith and colleagues than it was for the study by Li and colleagues based on treated dementia cases (Smith *et al.*, 2008; Li *et al.*, 2014). The prevalence rates may be artificially higher in Australia than they are in Canada due to differences in the quality and quantity of administrative data used in the studies led by Jacklin and Li (Jacklin *et al.*, 2013; Li *et al.*, 2014). The study by Jacklin and colleagues only included individuals who received a primary diagnosis of dementia at a physician visit, whereas four databases, including all public hospitals in the northern territory, health centers in remote communities, and records of specialized dementia care, were used to identify dementia cases in the study by Li and colleagues which may account for the higher prevalence rate found in Australia. The age-standardized prevalence rate in Guam, 15.6%, was more consistent with the prevalence rates found in the studies conducted in Australia. The Australian studies and the Guam study were all conducted in the 2000s, and followed DSM-IV criteria, as opposed to DSM-III criteria in the study led by Hendrie, for dementia diagnoses.

It is now widely accepted that standard cognitive assessment tools, such as the MMSE, which are based on the English language and western education systems may not be appropriate for use in all populations (Hatfield *et al.*, 2009; LoGiudice *et al.*, 2011). A large number of culturally appropriate cognitive assessment tools have been developed for use in a variety of ethnic groups (Hendrie *et al.*, 1988; Chen *et al.*, 2002; Koski, 2013). To date, the Kimberley Indigenous Cognitive Assessment Tool (KICA-cog) is the only validated cognitive assessment tool specific to indigenous populations (LoGiudice *et al.*, 2011). The Montreal Cognitive Assessment tool (MoCA) was modified for use in indigenous populations in Canada; however, this tool has not yet been validated (Rose, 2010).

Almost 50 years have elapsed between the first study (Reed and Brody, 1975) and the most recent study (Radford *et al.*, 2015) included in this review. The age structure, risk profile, and attitude toward dementia of the indigenous population have all changed over the past 50 years. In addition to the diagnostic criteria mentioned above, the changes in age, risk profile, and attitude toward dementia may have influenced the dementia prevalence rates found in these studies (Hulko *et al.*, 2010; Statistics Canada, 2011; Lindeman *et al.*, 2012).

Family physicians are less comfortable making dementia diagnoses than geriatricians or other clinicians with dementia-specific training (Baloch *et al.*, 2010). This may partially explain the lower prevalence rates of dementia found in the studies which relied on physician diagnoses or hospital records for case ascertainment in comparison to the studies which relied on geriatricians or neuropsychiatrists for diagnoses (Cummings *et al.*, 2011).

Conclusions

The existing literature on the prevalence of dementia among indigenous populations globally is extremely limited with a large degree of variation between study designs and findings. The prevalence rates of dementia ranged from a low of 0.5% to a high of 20%. Given the increased number of indigenous seniors, in combination with their unique culture and history, additional studies involving more representative samples, covering a broader geographic region, and culturally appropriate cognitive assessment methods are necessary to gain a better understanding of dementia among indigenous populations.

Conflict of interest

None.

Description of authors' roles

All authors contributed to the study topic and design, review and critical revision. L. Warren and Q. Shi conducted the literature search and assessment of study quality. L. Warren wrote the paper and completed the statistical analysis.

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