INSPQ INSTITUT NATIONAL DE SANTÉ PUBLIQUE DU QUÉBEC

Monitoring of Alzheimer's Disease and Related Disorders: Feasibility Study Based on Health Administrative Databases

BiESP BUREAU D'INFORMATION ET D'ÉTUDES EN SANTÉ DES POPULATIONS

CHRONIC DISEASE SURVEILLANCE

Number 10

Summary

The term *dementia* refers to a group of degenerative diseases that affect cognitive function and lead to loss of functional autonomy. Vascular dementia and Alzheimer's disease (AD) are the most common forms of dementia(1). In this report, the term "*Alzheimer's disease and related disorders*" will be used.

Alzheimer's disease and related disorders generally start appearing from the age of 60 to 65 years of age and onwards(2). They affect individuals' daily functioning by disrupting their memory, judgment, organization, orientation, language or control over their behaviour and emotions. These diseases place a staggering burden on individuals who are affected, their families and caregivers, as well as on professionals and the health system(3).

To date, most estimates of the prevalence and incidence of AD and related disorders in Canada are still based on the Canadian Study of Health and Aging (CSHA), a large population study conducted across Canada between 1991 and 2001. This study provided Canadian results on prevalence in 1994(2), and on incidence in 2000(4). Based on the findings of the CSHA and on studies from Manitoba, the Alzheimer Society of Canada projected the incidence of new cases of AD and other forms of dementia in Canada at 104,000 per year in 2008, and that this number would exceed 250,000 in 2038(1). However, some more recent international population studies appear to have found that the incidence of AD and other forms of dementia may be decreasing(5), which could, for example, be attributable to an improvement in the cerebrovascular health of seniors.

Québec

Consequently, it appears necessary to calculate new estimates of the prevalence and incidence of AD and related disorders. To this end, the Canadian Longitudinal Study on Aging, a population study, is underway in Canada (https://www.clsa-elcv.ca/). However, because of the burden of these diseases, it seems imperative that a surveillance system be developed to monitor Alzheimer's disease and related disorders in Québec as they become manifest within the Québec health system. The Institut national de santé publique du Québec is developing this surveillance through the Québec Integrated Chronic Disease Surveillance System (QICDSS)(6, 7).

The main objective of this report is to demonstrate the feasibility of developing surveillance of AD and related disorders in Québec. Specifically, the study uses the results and definitions identified from the literature, and compares annual prevalence, incidence and mortality estimates of AD and related disorders among Québec seniors aged 65 and over, between April 2000 and March 2011, using three different algorithms or case definitions and based on QICDSS data.

Methodology

Specification

Because AD and related disorders usually affect seniors, the study included all Québec seniors aged 65 and over. This age criterion is consistent with CSHA criteria, and may be used to test case definitions which include prescription drug use, since QICDSS contains pharmaceutical services data for virtually all Québecers aged 65 and over, who are covered by the Régie de l'assurance maladie du Québec's [Québec Health Insurance Board] (RAMQ) public drug insurance plan.

This study surveys cases of AD and related disorders identified using administrative databases from January 1, 1996 to March 31, 2012. However, according to a Canadian consensus, a four-year waiting period has been deemed appropriate for distinguishing incident cases from prevalent cases diagnosed before January 1, 1996. Results are therefore presented starting from the 2000-2001 fiscal year.

Data source

Data on cases of AD and related disorders, as well as data on the non-affected population, were extracted from four QICDSS administrative databases: 1) The RAMQ physician claims database, 2) The hospitalization database (MED-ECHO), 3) The RAMQ pharmaceutical services database, and 4) The RAMQ health insurance registry [Fichier d'inscription des personnes assurées] (FIPA), which also provides death dates.

Case definitions

Several definitions have been tested. Initially, the following criteria were used to choose definitions for this feasibility study: 1) Consensus on the definition among the study research scientists: a neurologist (CB), a demographer (VE), and an epidemiologist (EK), 2) the aim to minimize the impact of undiagnosed cases, 3) agreement between administrative database estimates and CSHA estimates. These three criteria were used to produce definition 1. For comparison purposes, two definitions developed by the Public Health Agency of Canada's (PHAC) Canadian Chronic Disease Surveillance System (CCDSS) Neurological Conditions Working Group were selected. A total of three case definitions are tested in this study to identify cases in the administrative databases.

The diagnostic codes of the 9th and 10th Revisions of the International Classification of Diseases (ICD-9 and ICD-10) used to identify cases of AD and related disorders in the physician claims database and the hospitalization database are: 046.1, 290, 294 and 331.0, 331.1, 331.5 (ICD-9) and G30, F00 to F03 (ICD-10). Drugs used to treat AD are classified under N06 in the *Anatomical Therapeutic Chemical (ATC) Classification System*, and include the following medications: Donepezil (DA02), Rivastigmine (DA03), Galantamine (DA04) and Memantine (DX01). PHAC's CCDSS Neurological Conditions Working Group reached consensus on selection of these codes. These molecules have no other therapeutic indications, and are eligible for reimbursement in Québec as exception drugs.

Thus, to be considered as affected by AD or a related disorder, an individual aged 65 or more had to be eligible for Québec health insurance and have:

Definition 1 (1H1M)[1]

A (primary or secondary) diagnosis of AD or related disorders in the hospitalization database;
OR a diagnosis of AD or related disorders in the physician claims database.

Definition 2 (1H3M2Y)[2]

A (primary or secondary) diagnosis of AD or related disorders in the hospitalization database;
OR at least three diagnoses of AD or related disorders in the physician claims database within a two-year period.

Definition 3 (1H3M2Y1P)[3]

A (primary or secondary) diagnosis of AD or related disorders in the hospitalization database;
OR at least three diagnoses of AD or related disorders in the medical services database within a two-year period;
OR a prescription for a drug to treat AD or related disorders in the pharmaceutical services database.

The case identification date is the date on which the case first meets one of the criteria of the definition. With respect to the criteria regarding three medical services, it is the date of the 3rd service provided to a patient diagnosed with AD or related disorders.

Calculation of incidence, prevalence and the mortality rate

The number of incident cases in a given year is the number of cases that meet the case definition for the first time during the observation period. The incidence rate for a given year is calculated by dividing the number of incident cases for the year by the estimate of the Québec population at risk according to the RAMQ health insurance registry for that particular year. Prevalence for a given year is calculated by dividing the number of prevalent cases by the estimate of the Québec population at risk according to the RAMQ health insurance registry for that particular year.

The all-cause mortality rate among people with AD or related disorders in a given year is calculated by dividing the number of deaths during the year among cases meeting the case definition, by the total number of deaths listed in the RAMQ health insurance registry for the given year. The standardized mortality rate ratio is calculated by dividing the all-cause mortality rate among prevalent cases for a given year by the all-cause mortality rate among the unaffected population for the same year.

Standardization

Measurements were adjusted for age using the direct standardization method, with the structure of the Québec population in 2001 as the reference.

Results

About 1.3 million people, corresponding to Québecers aged 65 and over insured by the RAMQ, were included in this study. When identifying cases of AD and related disorders, the criterion regarding the physician claims database was the one most often met, followed by the hospitalization database criterion, and finally by the criterion regarding pharmaceutical services.

Incidence of Alzheimer's disease or related disorders by case definition

Between April 1, 2011 and March 31, 2012, there were 24,580, 19,922, and 21,430 new cases of AD and related disorders among individuals aged 65 and over in Québec based on definitions 1, 2, and 3, respectively. The incidence of AD and related disorders was estimated to be 21.7, 16.5, and 18.1 per 1,000 person-years based on definitions 1, 2, and 3, respectively (Figure 1). The highest incidence rate during the observation period was based on definition 1.

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1 1H1M: indicates that the criteria include 1 diagnosis in the Hospitalization database or 1 diagnosis in the Medical services database.

2 1H3M2Y: indicates that the criteria include 1 diagnosis in the Hospitalization database or 3 diagnoses in the Medical services database within a 2-Year period.

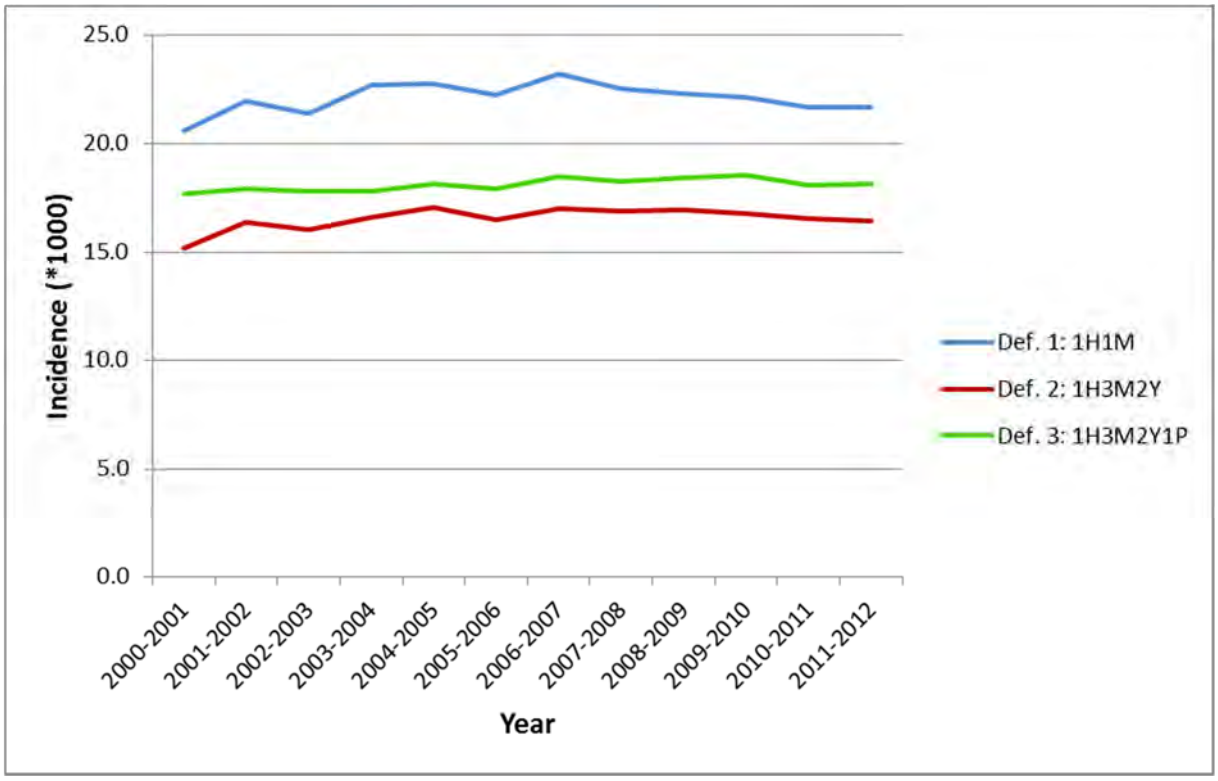
3 1H3M2Y1P: indicates that the criteria include 1 diagnosis in the Hospitalization database, 3 diagnoses in the Medical services database within a 2-Year period, or 1 prescription in the Pharmaceutical services database.

Based on all three definitions, the incidence rate was slightly lower among men than women: the differences were minimal at the beginning of the observation period, but became clearly visible starting in 2007-2008 (Figure 2).

Between 2000-2001 and 2011-2012, the incidence rate trend for the entire study population seemed to fluctuate slightly; the highest incidence rates were observed in 2006-2007 (23.2, 17.0, and 18.5 cases per 1,000 person-years based on definitions 1, 2, and 3, respectively). In men, the highest incidence rate was also observed in 2006-2007, followed by lower rates in subsequent years.

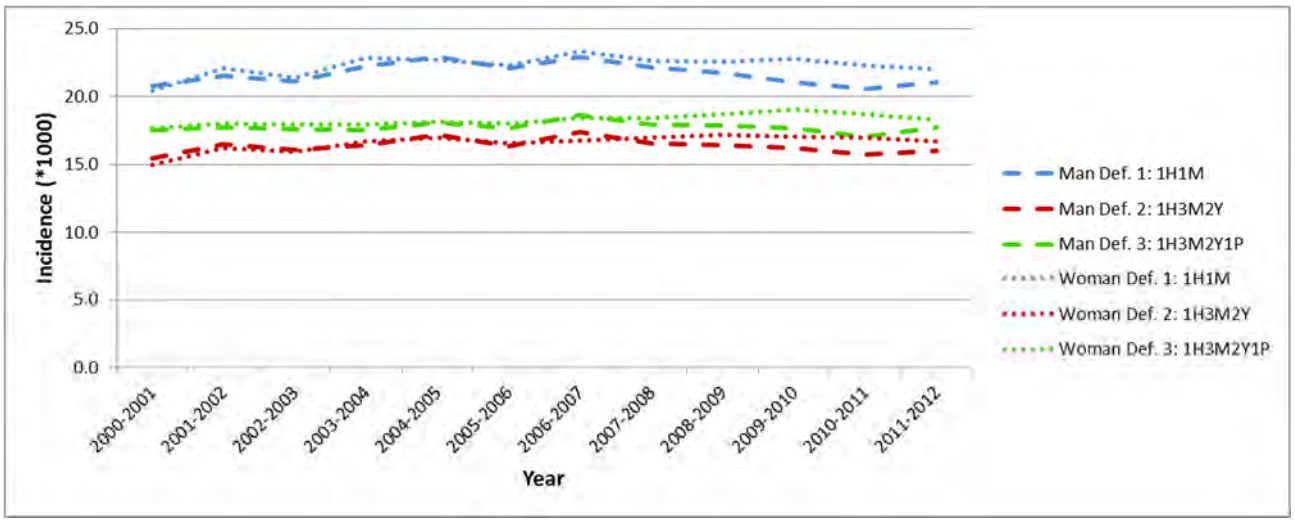
However, among women, the highest incidence rate occurred in 2006-2007 based on definition 1 (23.3 cases per 1000 person-years), whereas based on definitions 2 and 3, the highest rates were observed in 2008-2009 and 2009-2010 respectively.

Figure 1 **Age-standardized incidence rate for Alzheimer's disease and related disorders by case definition, Québec, population aged 65 or over, 2000-2001 to 2011-2012**



1H1M: 1 diagnosis in the Hospitalization database or 1 diagnosis in the Medical services database. 1H3M2Y: 1 diagnosis in the Hospitalization database or 3 diagnoses in the Medical services database within a 2-Year period. 1H3M2Y1P: 1 diagnosis in the Hospitalization database, 3 diagnoses in the Medical services database within a 2-Year period, or 1 prescription in the Pharmaceutical services database.

Figure 2 **Age-standardized incidence rate for Alzheimer's disease and related disorders by case definition and sex, Québec, population aged 65 or over, 2000-2001 to 2011-2012**



1H1M: 1 diagnosis in the Hospitalization database or 1 diagnosis in the Medical services database. 1H3M2Y: 1 diagnosis in the Hospitalization database or 3 diagnoses in the Medical services database within a 2-Year period. 1H3M2Y1P: 1 diagnosis in the Hospitalization database, 3 diagnoses in the Medical services database within a 2-Year period, or 1 prescription in the Pharmaceutical services database.

Prevalence of Alzheimer's disease and related disorders by case definition

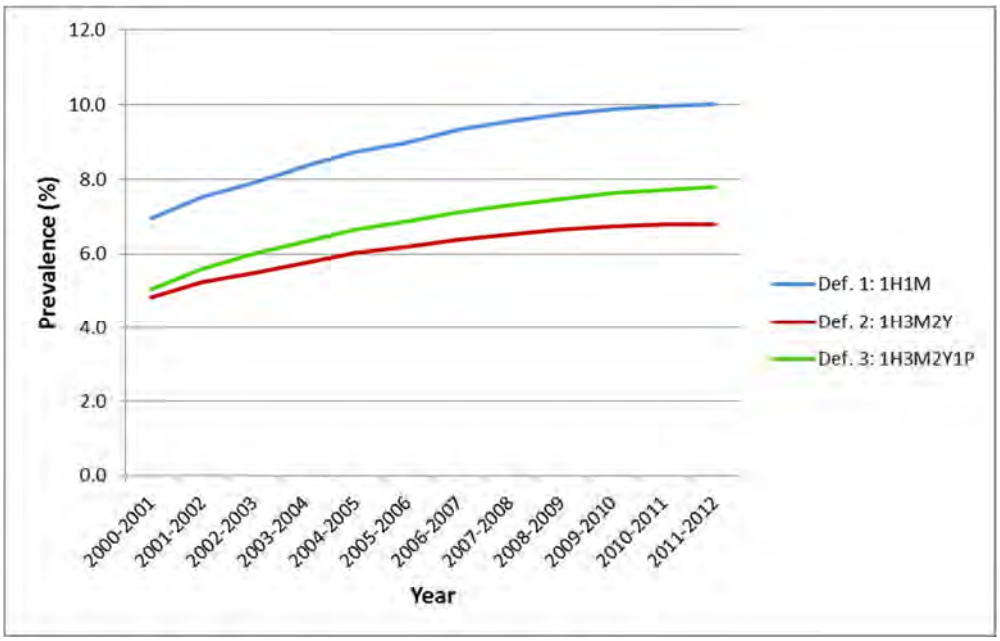
At the beginning of the observation period, 2000-2001 (April 1 to March 31), prevalence of AD and related disorders was estimated at 7.0%, 4.8%, and 5.1% based on definitions 1, 2, and 3, respectively (Figure 3).

Estimated prevalence during the observation period was higher based on definition 1 than on the other two definitions. However, regardless of the definition used, the prevalence trend appeared to be constantly increasing, but the increases diminished over the years, reaching a plateau. These strong increases at the beginning of the monitoring period may be real, but could also be attributable to the shorter wait time (period excluded) used. In fact, the wait time at the beginning of a surveillance study is determined in order to distinguish prevalent cases from incident cases. Longer-term monitoring or an algorithm validation study would provide a better analysis of actual prevalence in the population. At the end of the observation period, prevalence reached 10.0%, 6.8%, and 7.8% based on definitions 1, 2, and 3, respectively. This represented approximately 138,580, 95,502, and 108,865 people aged 65 and over living with the disease in 2011-2012, based on case definitions 1, 2, and 3.

As shown in Figure 4, prevalence was estimated to be higher in women than men, based on all three definitions. According to these three case definitions, prevalence seemed to increase exponentially with age among both men and women (Figures 5 and 6). Among women aged 85 years or older, prevalence reached 37.3% (definition 1), 28.9% (definition 2), and 31.7% (definition 3); prevalence in men of the same age group was 30.5%, 22.9% and 25.5%, respectively. Sex and age group trends were similar for all three definitions.

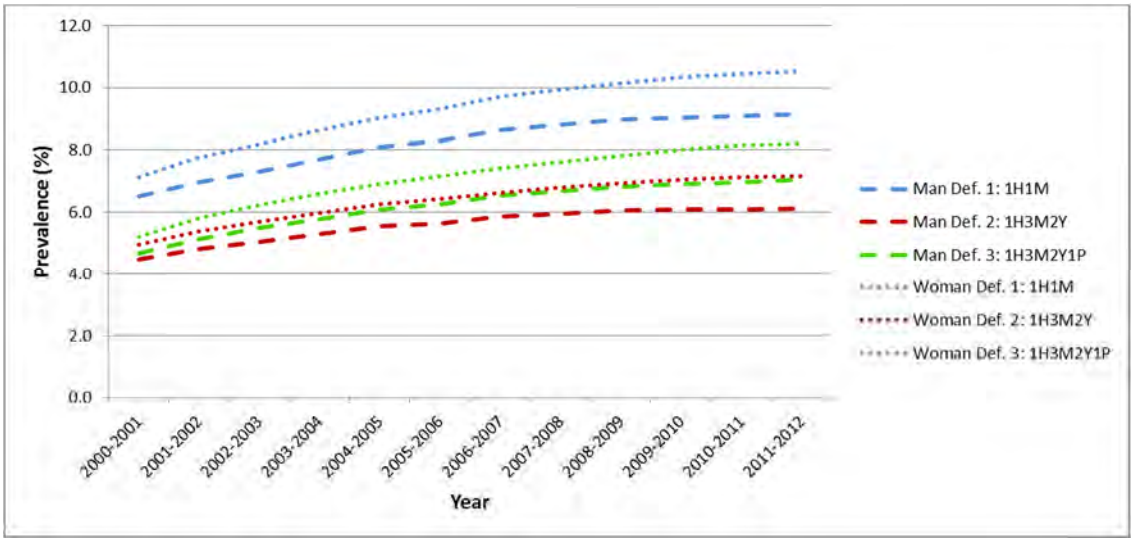
However, Figure 6 indicates that these differences varied by age. Based on all three definitions, estimated prevalence was similar among women and men up to age 75, and then prevalence was higher in women than men in subsequent age groups: the biggest difference between women and men was in the 85 and older age group.

Figure 3 **Age-standardized prevalence of Alzheimer's disease and related disorders by case definition, Québec, population aged 65 or over, 2000-2001 to 2011-2012**



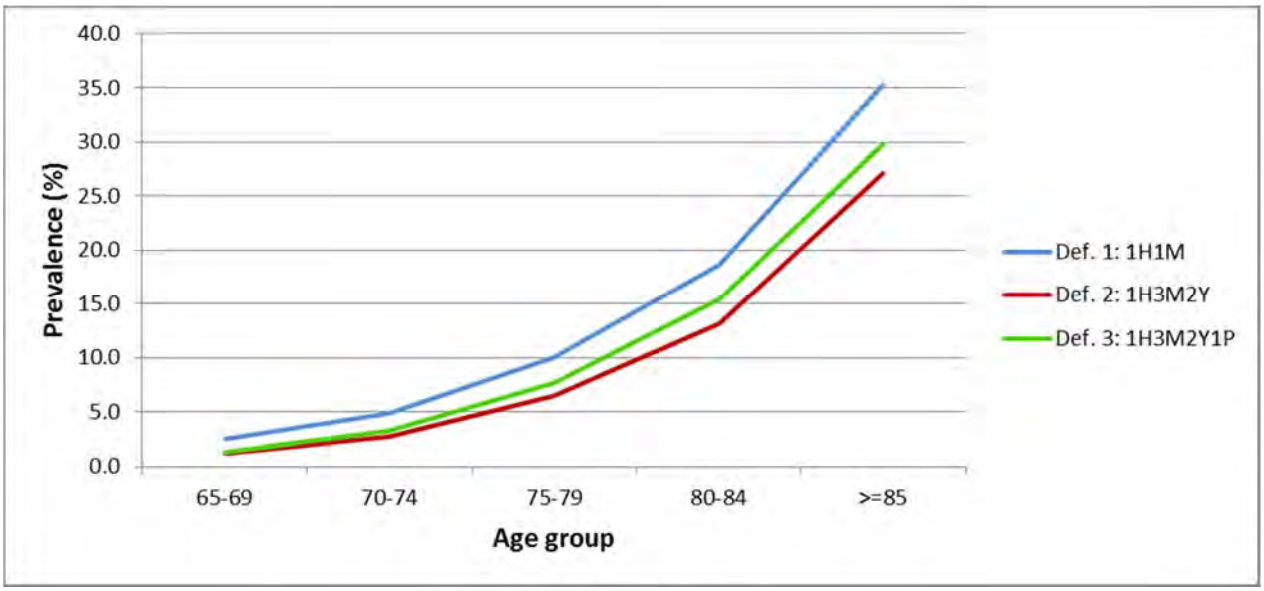
1H1M: 1 diagnosis in the Hospitalization database or 1 diagnosis in the Medical services database. 1H3M2Y: 1 diagnosis in the Hospitalization database or 3 diagnoses in the Medical services database within a 2-Year period. 1H3M2Y1P: 1 diagnosis in the Hospitalization database, 3 diagnoses in the Medical services database within a 2-Year period, or 1 prescription in the Pharmaceutical services database.

Figure 4 **Age-standardized prevalence of Alzheimer's disease and related disorders by case definition and sex, Québec, population aged 65 or over, 2000-2001 to 2011-2012**



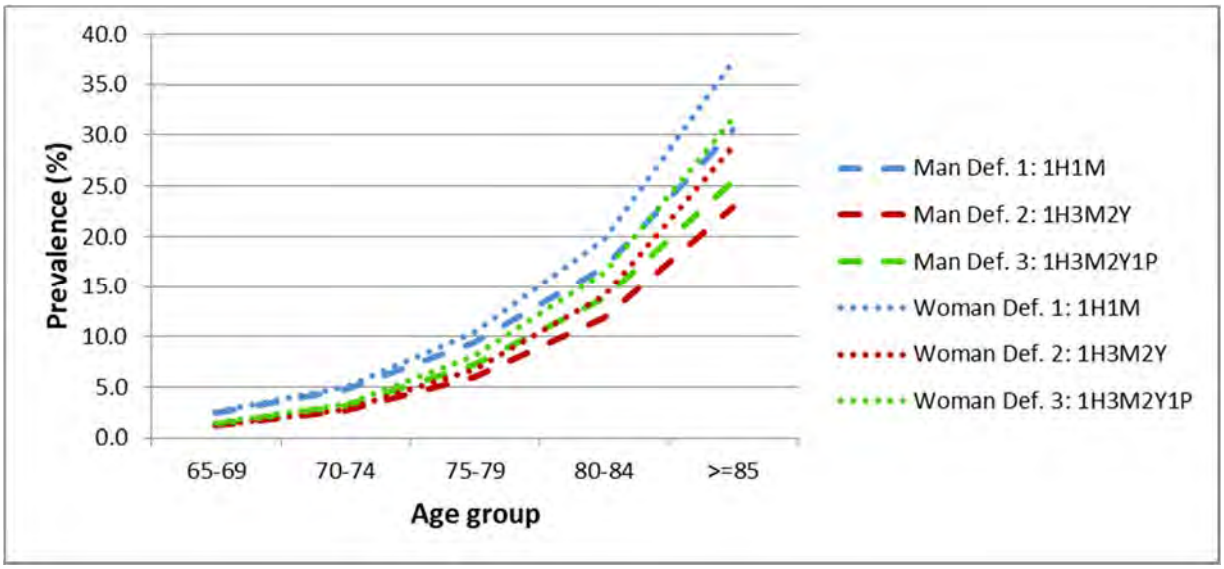
1H1M: 1 diagnosis in the Hospitalization database or 1 diagnosis in the Medical services database. 1H3M2Y: 1 diagnosis in the Hospitalization database or 3 diagnoses in the Medical services database within a 2-Year period. 1H3M2Y1P: 1 diagnosis in the Hospitalization database, 3 diagnoses in the Medical services database within a 2-Year period, or 1 prescription in the Pharmaceutical services database.

Figure 5 **Prevalence of Alzheimer's disease and related disorders by case definition and age group, Québec, population aged 65 or over, 2011-2012**



1H1M: 1 diagnosis in the Hospitalization database or 1 diagnosis in the Medical services database. 1H3M2Y: 1 diagnosis in the Hospitalization database or 3 diagnoses in the Medical services database within a 2-Year period. 1H3M2Y1P: 1 diagnosis in the Hospitalization database, 3 diagnoses in the Medical services database within a 2-Year period, or 1 prescription in the Pharmaceutical services database.

Figure 6 **Prevalence of Alzheimer's disease and related disorders by case definition, sex and age group, Québec, population aged 65 or over, 2011-2012**



1H1M: 1 diagnosis in the Hospitalization database or 1 diagnosis in the Medical services database. 1H3M2Y: 1 diagnosis in the Hospitalization database or 3 diagnoses in the Medical services database within a 2-Year period. 1H3M2Y1P: 1 diagnosis in the Hospitalization database, 3 diagnoses in the Medical services database within a 2-Year period, or 1 prescription in the Pharmaceutical services database.

Mortality among people with Alzheimer's disease or related disorders by case definition

The all-cause mortality rate in individuals aged 65 and over was higher among those with AD or related disorders than in persons not suffering from these conditions. In 2011-2012, the rate was 120.6, 148.0, and 132.2 per 1,000 person-years among affected men based on case definitions 1, 2, and 3 respectively, while it was 31.2 among men not suffering from these conditions, based on case definition 1 (Figure 7-A). Since the mortality rate among individuals without these conditions changed very little based on the three definitions of affected cases, it was decided that the mortality rate based on definition 1 would be the only one illustrated. Among women, the mortality rate in 2011-2012 was 82.1, 103.1, and 91.8 per 1,000 person-years based on case definitions 1, 2 and, 3 respectively, while it was 19.5 for women without these conditions (Figure 7-B). Differences in mortality rates among people with these conditions, based on the case definition, were very constant throughout the observation period. Mortality rates were always highest based on definition 2, and lowest based on definition 1.

In addition, mortality rates declined somewhat between 2000-2001 and 2011-2012: based on definition 2 (the most restrictive), the mortality rate among women with these conditions was 119.5 per 1,000 person-years in 2000-2001 compared to 103.1 per 1,000 person-years in 2011-2012; the mortality rate among women without these conditions was 28.3 per 1,000 person-years in 2000-2001, compared to 20.8 per 1,000 person-years in 2011-2012. These differences were more pronounced among men. Mortality rates in men suffering from these conditions were 198.9 in 2000-2001 compared to 148.0 in 2011-2012, whereas mortality rates among men without these conditions were 48.0 in 2000-2001 compared to 32.9 in 2011-2012.

Mortality rate ratios clearly demonstrated the differences in mortality rates among individuals with and without these conditions (Figure 8). In 2011-2012, based on all three definitions, these ratios ranged from 3.9 to 4.5 for men, and 4.2 to 5.0 for women.

Meanwhile, people suffering from these conditions had a shorter life expectancy than people without these conditions (Figures 9 and 10). Among women without these conditions, life expectancy at age 65 was between 24.3 and 24.9 years, based on case definition, but 10.2, 11.0 and 12.0 years in women suffering from these conditions, based on the three case definitions. In other words, depending on the definition used, life expectancy at age 65 decreased between 12 and 14 years in women suffering from these conditions. Among men without these conditions, life expectancy at age 65 was between 20.0 and 20.4 years, based on case definition, and 7.7, 8.3 and 9.2 years in men suffering from AD or related disorders, based on the three case definitions. These differences in life expectancy were significant up to age 80; they ranged from 6.7 to 7.2 years in women with and without these conditions, based on case definitions, and from 5.2 to 5.6 years in men with and without these conditions, based on case definitions.

Figure 7 Age-standardized mortality rate for Alzheimer's disease and related disorders by case definition and sex, Québec, population aged 65 or over, 2000-2001 to 2011-2012

Figure 7-A. Men

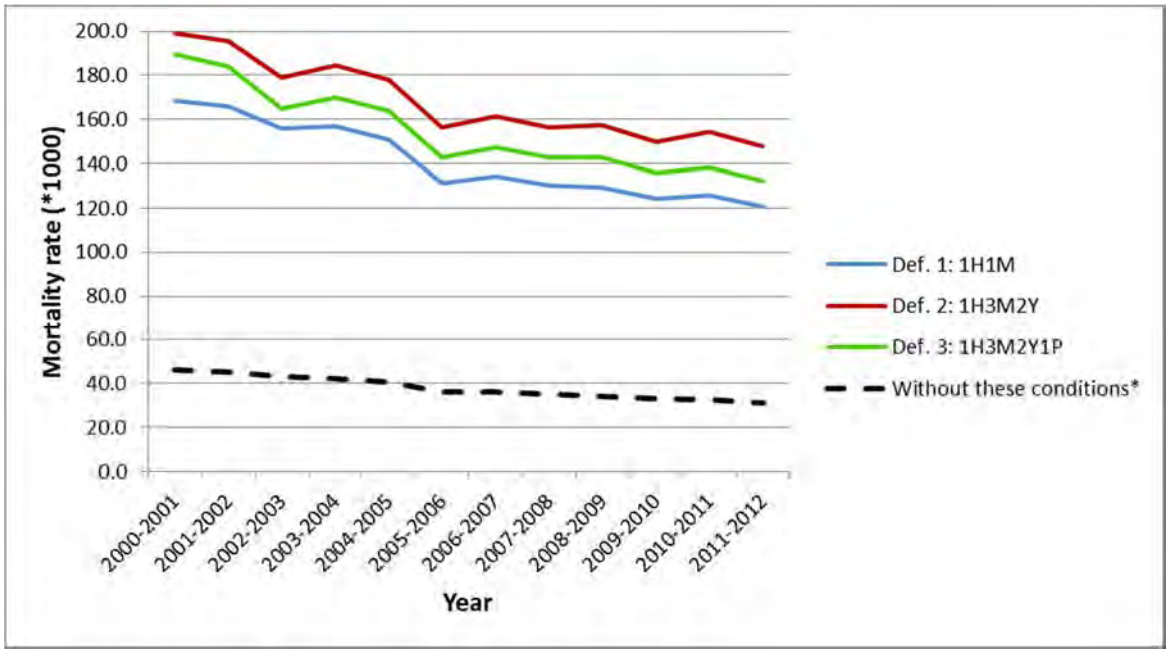
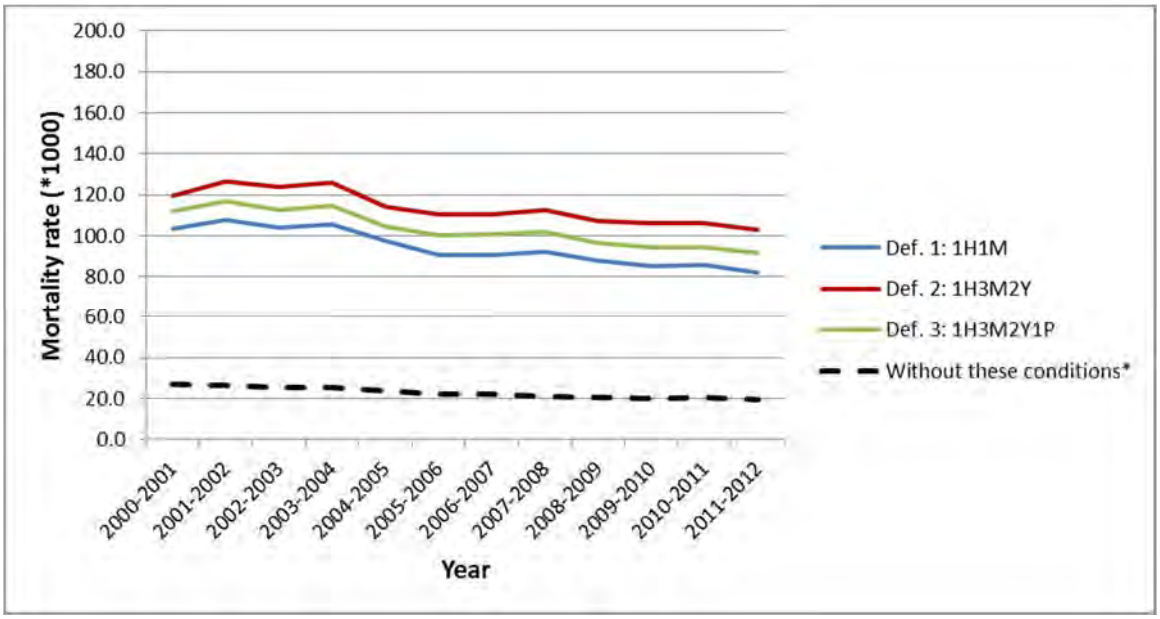


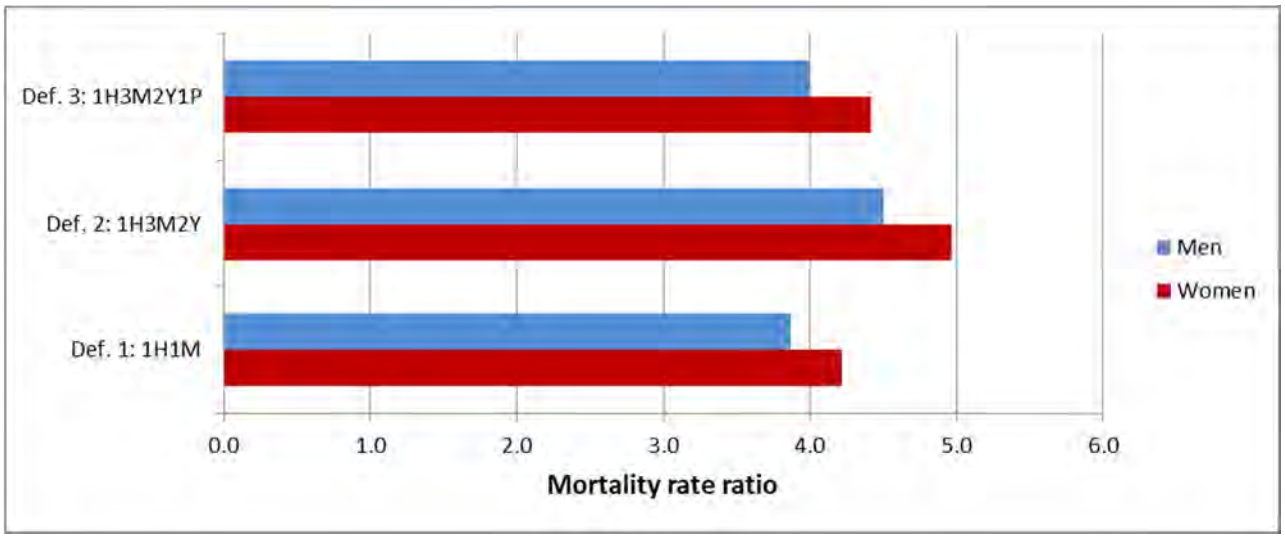
Figure 7-B. Women



1H1M: 1 diagnosis in the Hospitalization database or 1 diagnosis in the Medical services database. 1H3M2Y: 1 diagnosis in the Hospitalization database or 3 diagnoses in the Medical services database within a 2-Year period. 1H3M2Y1P: 1 diagnosis in the Hospitalization database, 3 diagnoses in the Medical services database within a 2-Year period, or 1 prescription in the Pharmaceutical services database.

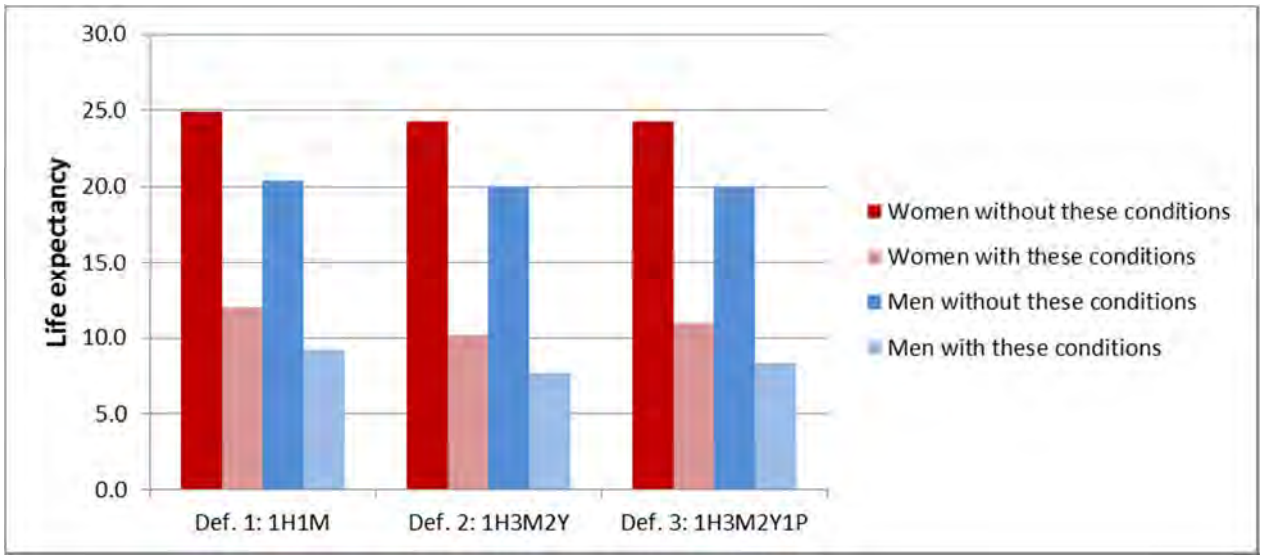
* Since the mortality rate among individuals without these conditions changed very little based on the three definitions, it was decided that the mortality rate based on definition 1 would be the only one illustrated.

Figure 8 **Age-standardized mortality rate among individuals with or without Alzheimer's disease and related disorders, by sex, Québec, 2011-2012**



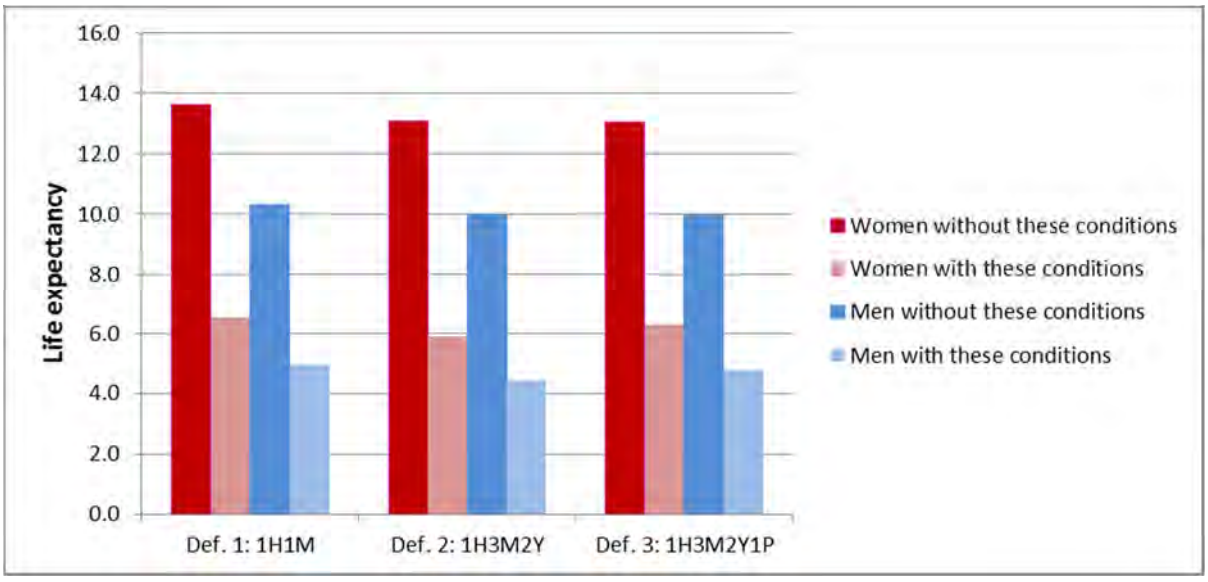
1H1M: 1 diagnosis in the Hospitalization database or 1 diagnosis in the Medical services database. 1H3M2Y: 1 diagnosis in the Hospitalization database or 3 diagnoses in the Medical services database within a 2-Year period. 1H3M2Y1P: 1 diagnosis in the Hospitalization database, 3 diagnoses in the Medical services database within a 2-Year period, or 1 prescription in the Pharmaceutical services database.

Figure 9 **Life expectancy at age 65, among individuals with or without Alzheimer's disease and related disorders, by sex, Québec, 2006-2012**



1H1M: 1 diagnosis in the Hospitalization database or 1 diagnosis in the Medical services database. 1H3M2Y: 1 diagnosis in the Hospitalization database or 3 diagnoses in the Medical services database within a 2-Year period. 1H3M2Y1P: 1 diagnosis in the Hospitalization database, 3 diagnoses in the Medical services database within a 2-Year period, or 1 prescription in the Pharmaceutical services database.

Figure 10 **Life expectancy at age 80, among individuals with or without Alzheimer's disease and related disorders, by sex, Québec, 2006-2012**



1H1M: 1 diagnosis in the Hospitalization database or 1 diagnosis in the Medical services database. 1H3M2Y: 1 diagnosis in the Hospitalization database or 3 diagnoses in the Medical services database within a 2-Year period. 1H3M2Y1P: 1 diagnosis in the Hospitalization database, 3 diagnoses in the Medical services database within a 2-Year period, or 1 prescription in the Pharmaceutical services database.

Discussion

This feasibility study showed that several analyses can be performed on key surveillance indicators, such as incidence, prevalence and mortality, among people aged 65 or over in Québec affected by AD or related disorders between 2000-2001 and 2011-2012. In sum, prevalence results for AD and related disorders varied by case definition, but as expected, indicated that these diseases markedly increased mortality, and significantly reduced the life expectancy of individuals suffering from these conditions.

Incidence and prevalence results were somewhat lower than estimates based on the Canadian Study of Health and Aging, the last large population study of AD and dementia. According to data collected by the CSHA in 1991, age-standardized prevalence among people 65 and older was 8.4% in Québec(2) compared to 4.8%, 5.1%, and 7.0% for 2000-2001 respectively, based on case definitions 2, 3, and 1 of our study. The CSHA estimates for 2001, the end of the study, indicated that prevalence of dementia in Canada (8% of people aged 65 and over) had changed little since 1991(8). However, the prevalence of AD and dementia may have increased between 1991 and 2000 in Québec, Canada and elsewhere(9-11), which would accentuate the difference observed in our study compared to the CSHA.

The validity of case definitions used by PHAC (definitions 2 and 3) was assessed in Ontario by the Institute for Clinical Evaluative Sciences (ICES), and was deemed to be satisfactory. Electronic medical records from community-based family physician practices in Ontario were used to assess prevalence of dementia in people aged 65 and older. 150 cases of AD and dementia were identified (out of 3,404 charts). Sensitivity was assessed at 65.3% and 80.7% respectively, based on definitions 2 and 3. The specificity of case detection algorithms for these two definitions was respectively 98.8% and 98.7%, and positive predictive value (PPV) was 71.0% and 74.7%(12). Despite lower sensitivity, meaning that several people were not identified by the algorithm, definition 2 was used to make comparisons between provinces and territories. It is useful to include among the tested definitions one that does not include pharmaceutical services (definition 2) because pharmaceutical services data are not available in all provinces and territories. This type of definition could also be used to study cases of AD or related disorders

among people under age 65 for whom public plans are often unable to provide any prescription drug data.

According to our observations, results based on definition 1 seem closest to prevalence results published by the CSHA. However, the ICES validation study indicated that the definition's PPV was low (41.0%), sensitivity was 85.3%, and specificity was 94.3%. If specificity is lowered to increase sensitivity, many persons not suffering from these conditions are identified by the algorithm. As a result, this definition was not used. PHAC's Canadian Chronic Disease Surveillance System has decided to use case definitions with greater specificity (identification of individuals not affected by these conditions), taking into account that the algorithm underestimates the true number of people suffering from these conditions.

Based on the preliminary results presented, definition 2 (1H3M2Y) has the lowest incidence rate, lowest prevalence, and highest mortality rates. We can infer that cases not identified by definition 2, but identified by definition 3, may be cases with less serious conditions, because AD and related disorders often develop undetected for up to 20 years. The selected algorithms' potential underestimation [of the true number of people suffering from these conditions], compared to CSHA findings, may not be random and may also influence mortality results.

Limitations

The variation in incidence and prevalence results presented here, and the fact that they are lower than predictions based on the CSHA, can be explained by several findings or assumptions concerning, for example, administrative data limitations.

First, it is known that AD and related disorders are under-diagnosed in Canada(1). Diagnosing these diseases is relatively complex, especially at the onset of the disease. It is a diagnosis of exclusion and there are no validated biological indicators for AD and most related disorders(13). The fact that Québec family physicians can only enter one diagnosis per visit on the claim form, even if they make two or more during the same visit, restricts the number of diagnoses of AD or related disorders listed in the physician claims database. In addition, physicians working in memory clinics, local community service centres (CLSCs) or long-term care facilities are not necessarily paid on a fee-for-service basis, and their diagnoses are therefore not listed in the medical services database. This represents a particular limitation for seniors and individuals with multiple diseases or a debilitating disease, such as AD, which increases the likelihood of institutionalization.

Also, it may be that a too short follow-up period (4 years) to distinguish new cases (incident cases) from subsequently identified cases (prevalent cases) is causing prevalence to be underestimated (mainly at the start of the observation period). A validation study of case detection algorithms, including a review of physician records, would provide a better assessment of this issue. In addition, longer term surveillance of AD and related disorders will reduce the impact of insufficient follow-up duration.

For further reflection

Differences in the incidence and prevalence noted here between men and women are in agreement with observations and assumptions reported in the literature(14). Life expectancy is higher for women than men in Québec. Women are therefore at greater risk than men of developing AD or a related disorder during their lives. In addition, men and women have different morbidity profiles and health behaviours(15). It is therefore possible that AD and related disorders are diagnosed more often in women than men.

In fact, the CSHA did not find any association between sex and the risk of developing AD or dementia(16). However, a recent review of the influence of sex and gender, i.e., biological and sociocultural differences between men and women, found a higher incidence of AD and related disorders in women whereas men were more at risk of mild cognitive impairment(17). Because sociocultural influences in the lives of men and women continue to evolve in Québec, it is important that incidence, prevalence, mortality and life expectancy be considered separately in men and women when studying the epidemiology of AD and related disorders(4). In-depth analyses of health care service utilization profiles may subsequently help us understand these differences.

Based mainly on definition 1, the results presented also appear to indicate some level of change in the incidence of AD and related disorders: incidence was highest in 2006-2007 (23.2, 18.5, and 17.0 per 1,000 person-years, based on definitions 1, 3, and 2 respectively), and decreased slightly until 2009-2010, with stable estimates in the last two years of observation. Recent literature has shown that the incidence may be slowing down in Europe(5, 18, 19) and North America(20). Several explanations for this change were considered: reduction of vascular risk factors, increased levels of physical activity among seniors, higher levels of education or intellectual activity among seniors, etc.(5, 18-20)

Conclusion

Estimates of the incidence, prevalence and mortality of Alzheimer's disease and related disorders tend to vary depending on the definition used to identify cases in health administrative databases. ICES found the highest sensitivity, specificity, and positive predictive values for definition 3, which combines criteria related to the physician claims database, hospitalization database, and the pharmaceutical services database(12). This definition is therefore being used to perform neurological disease surveillance work in Canada. Because no validation studies have been performed using Québec data, and none are under consideration at this time, Québec public health agencies and the Ministry of Health and Social Services will use this definition to monitor AD and related disorders.

Although estimates based on the QICDSS may tend to underestimate the true burden caused by these diseases, time trends in these estimates seem consistent with observations made in the United States(20). Case definition number 3 can now be used to develop a current picture of the burden of these neurodegenerative diseases as they manifest within the Québec health system, taking into account their geographical distribution and, where possible, distinctive features of primary care, such as Family Medicine Groups. The results of this feasibility study support the idea that health administrative databases can be used to estimate the burden of these diseases, particularly within the context of the Québec chronic disease and associated determinants surveillance system.

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Monitoring of Alzheimer's Disease and Related Disorders: Feasibility Study Based on Health Administrative Databases

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