Introduction

The proportion of Canadians living with Alzheimer's and related dementias is projected to rise, with an increased burden on the primary health care system in particular.[1] The Canadian Study of Health and Aging reported a prevalence of dementia of 8% in community-dwelling and institutionalized individuals 65 years and older[2] and remains the standard authority for dementia prevalence in the general Canadian population.[3] More recently, the Alzheimer Society of Canada estimated the national prevalence of dementia at14.9%.[4] Ontario-based studies using administrative data provide estimates of dementia prevalence among community-dwelling seniors over 65 at 7.2%.[5,6] The variability in prevalence estimates are likely to derive from heterogeneity in their data sources, as well as in case definition.

Community-based primary care settings are typically the first point of contact for those with symptoms of dementia and their caregivers,[7] and family physicians are vital in achieving effective and efficient diagnosis and management. Improving dementia assessment and management in these settings has major and growing impact throughout the health and social care system, including modifying demand for specialist services and long-term care placement. Enabling primary care physicians and their associated teams of providers to promote and execute early diagnosis and treatment is likely to be a fundamental aspect of emerging pharmaceutical treatments for the disease. It is arguable that the community-based primary health care sector has the capacity to respond to the increasing incidence of dementia associated with population aging,[8] but to do so optimally it must systemically integrate with all relevant health and social care sectors. Understanding the epidemiology and management of dementia among community-dwelling seniors in community-based primary care practices is a crucial component in developing such a system.

The Canadian Primary Care Sentinel Surveillance Network (CPCSSN) began development in 2008 and represents the equivalent of national primary care surveillance systems like the Clinical Practice Research Datalink (CPRD) in the United Kingdom.[9] CPCSSN extracts, cleans and processes de-identified clinical data every three months from the electronic medical records (EMR) of community-based, sentinel family physicians and primary care nurse practitioners.[10] Sentinels are recruited in a strategic manner in order to produce a database that is representative of primary care practitioners and patients across the country.[11] Sentinels must practice full-service family medicine to be included, though need not provide obstetrical care.

CPCSSN data are contemporaneous and more comprehensive than those available through administrative sources. For instance, physicians are often restricted to submitting a limited number of billing codes for payment, irrespective of how many conditions they were actively managing within an encounter. The recording of activity or observations for clinical use, rather than for billing purposes,

creates a wealth of data not available in administrative datasets. Using CPCSSN data for research, surveillance and for clinical quality improvement also has advantages over survey data, as EMR data are extracted regularly and inexpensively, provide opportunities for longitudinal follow-up, and are based on practitioner report, rather than patient self-report. Most notably, EMR data are directly relevant to primary care clinical practice, organization and policy.

This paper provides insight into the epidemiology and pharmacological management of dementia among community-dwelling seniors attending primary care practices across the country.

Method

Data source

For this study, the data derived from 480 sentinel providers from a variety of practice settings and more than 600,000 community-dwelling patients of all ages located in seven provinces across Canada. Data deriving from this period have been used consistently in a series of papers describing the epidemiology and management of the eight CPCSSN "index conditions" in primary care,[12-16] of which this paper is the latest. The CPCSSN data used in this study included patient demographics, diagnoses, medication, physical exam measurements (i.e. body mass index, weight, height) and billing.

Study sample

We employed a case definition for dementia (Table 1) which was specifically developed for use in Canadian primary care EMRs and did not attempt to be applicable in health administrative or other datasets. It included relevant billing codes, diagnostic codes from the patient profile and encounter data, medication data (cholinesterase inhibitor and NMDA medications), as well as text data.[17] Validation of the definition produced a sensitivity of 96.8%, specificity of 98.1%, positive predictive value of 72.8% and negative predictive value of 99.8%.[17] The denominator consisted of all patients in the CPCSSN database aged 65 years or older on December 31, 2012. Patients were considered eligible for inclusion if at least one clinic visit was recorded in their EMR on or after January 1, 2011.

For province-specific sub-analyses (pharmacological treatment and prevalence by province), results are presented for Alberta, Manitoba, Ontario, Newfoundland and Nova Scotia. British Columbia and Quebec were excluded from these sub-analyses because their samples of patients and providers were small and may not reflect broader provincial trends. At the time of this study, CPCSSN did not have data extraction processes in Saskatchewan, New Brunswick, Prince Edward Island or the Territories.

Epidemiology of dementia in primary care

We describe the prevalence of dementia in community-dwelling patients aged 65 years and older who had attended a primary care clinic and examined variations according to patient characteristics, including age, sex, body mass index (BMI) and rural or urban residence, these being important sociodemographic characteristics in relation to the epidemiology and clinical management of chronic disease in primary care. BMI values recorded in the EMR were used; if no BMI value was present, it was calculated using the most recent height and weight values. BMI was classified as underweight (<18), normal (18-24), overweight (25-29), and obese (≥30). Rural or urban residence was determined using the second digit of patients' postal codes (0 indicatesrural; other values indicate urban).[18]

We report comorbidity in relation to other chronic conditions for which CPCSSN has a validated case definition (hypertension, diabetes, chronic obstructive pulmonary disease, osteoarthritis, depression, epilepsy and parkinsonism (including Parkinson's disease)).[17]

Pharmacological treatment of dementia in primary care

We describe the pharmacological treatment for patients aged over 65 years with a diagnosis of dementia in primary care settings by province, including the type and number of dementia-specific medications (donepezil, galantamine, memantine and rivastigmine) prescribed by a primary care practitioner. Medication use for these four dementia-specific drugs was defined as at least one prescription recorded in the EMR. We cannot confirm whether patients had been prescribed medication elsewhere (e.g. from a specialist) or whether the prescription was filled or taken as directed.

Provincial and temporal variation in dementia prevalence

Age and sex-adjusted prevalence rates from 2008 to 2012 for dementia in those over 65 years were calculated and reported for eligible provinces.

Statistical analysis

A combination of descriptive statistics and multivariate modeling using SAS software version 9.3 (Cary, NC, USA) were employed. Two separate log-binomial regression analyses were carried out to calculate prevalence, each adjusting for age and sex of the study population according to national population distributions[19] and to explore associations with residence and BMI categories. The presence of comorbidity was analyzed using the same log binomial approach, adjusted for age and sex, and results expressed using prevalence ratios, 95% confidence intervals (CI) and p-values.

Results

Description of dementia in primary care

Of the 59,177 community-dwelling patients aged 65 years and older about whom we extracted data according to our inclusion criteria, 4552 were identified as having dementia, giving a crude prevalence estimate of 7.7%. Prevalence estimates for dementia rise with increasing age, with females aged 85 or older showing a slightly higher prevalence (22.5%) than males (20.5%) in the same age stratum (Table 2). After adjusting for age and sex, a lower prevalence of dementia was associated with being obese ($p<0.01$), while a greater prevalence of dementia was associated with comorbid diabetes, depression, epilepsy, and parkinsonism (Table 3). The prevalence of dementia was lower for those living in rural settings compared to those in urban locations ($p<0.05$).

Pharmacological treatment of dementia in primary care

Table 4 provides an overview of the treatment of people with a diagnosis of dementia in primary care by province. Many patients had not received a prescription for a dementia-related medication from their primary care provider, though there was an observed decrease in the number of patients without a prescription over time. Of those being prescribed a medication for dementia, most had received a prescription for one drug only and the majority of prescriptions were for donepezil in all provinces except for Nova Scotia, where galantamine was more frequently prescribed in 2009 and 2010.

Provincial and temporal variation in dementia prevalence

Prevalence estimates adjusted for age and sex were calculated at provincial level in order to explore variations across Canada and through time (Figure 1). Alberta, Manitoba, Nova Scotia, and Ontario had considerable observed increases in the prevalence of dementia in primary care from 2008 to 2012. In 2012, the dementia prevalence was highest in Ontario (7.4%) and lowest in Newfoundland (5.7%).

Interpretation

Findings and comparison with other studies

Global estimates of dementia in primary care settings range from 5-10%.[20-22] Our age-standardized prevalence for older adults (7.3%) may be an underestimate, as many physician-specific and system-wide factors preclude swift diagnosis in primary care. It is inevitable that non-diagnosis of some incident cases will occur, especially for a condition such as dementia whose onset is insidious, even in a sample which, by definition, is known to have seen a physician in the last two years. Although the majority of patients experiencing the first signs of dementia initially visit a primary care provider, many, if not most, appear to have their diagnosis confirmed by a specialist.[23] This suggests that in order to meet the rising need,

primary care practitioners need training and experience to undertake routine diagnosis and management without referral. Reasons for dementia diagnoses occurring in specialist practices rather than primary care are multifaceted and include a lack of primary care provider confidence in dementia knowledge and support resources; concern about misdiagnosis; perception of usefulness of diagnosis or treatment options; and lack or mistrust of screening tools.[20,22,23] In recent years, new dementia care models have become widespread in primary care practices,[24] which may facilitate the management of these patients in that setting.

The discrepancies between diagnosis in primary and specialist care may also provide an explanation for our observation that over half of dementia patients did not have a prescription for an anticholinesterase or NMDAmedication in their EMR. Though the family physician is typically the first point of contact for community-based patients with dementia, prescription of medication is often split between them and specialists.[25,26] Patterns of prescription among primary care physicians are markedly similar across several countries, despite differences in health and insurance systems. The most frequently prescribed medications are cholinesterase inhibitors (e.g. galantamine, donepezil, rivastigmine) and NMDA antagonists (e.g. memantine), reported in ranges of 50-90% of cases.[27-29] Our estimate for the proportion of patients prescribed these medications by their primary care provider is lower than elsewhere and may reflect legitimate uncertainty in Canada about their effectiveness.[30,31] It may also reflect that prescribing by specialists may not be recorded in primary care EMRs. Provincial prescribing policies related to these medications are also likely additional sources of variance.

Our prevalence estimates by province over time indicate expected rates of increase in most provinces associated with the aging population, with Ontario demonstrating the highest prevalence in 2012 (7.4%). Newfoundland was an exception, having the lowest prevalence in 2012 and not showing a steady increase from 2008. The reasons for this require further investigation. We may speculate that dementia patients in Newfoundland and Labrador may be entering long-term care more readily than in other provinces and are being lost to the primary care EMR record for that reason. It may be that they are not being diagnosed in primary care as readily as patients elsewhere. These findings highlight the importance of appropriate health services planning, as most provinces identified in our study have seen rates of dementia in primary care rise by 30-50% from 2008 to 2012.

Across the country, there was a lower prevalence of dementia among those living in rural areas compared to patients in urban settings. This may suggest that patients with dementia are likely to move to urban locations where they can access services related to their condition or reside closer to family.

Though obesity is considered to be moderately associated with dementia,[32] our study found a statistically significant lower prevalence of dementia among obese patients. This may be reflective of lower food consumption among people with dementia.[33]

Additional co-morbidities found to be associated with a higher prevalence of dementia included diabetes, depression, COPD, epilepsy and parkinsonism. In this, our data both supports and diverges from previous research. The most frequent comorbidities previously reported in dementia patients include coronary heart

disease, diabetes, congestive heart failure, and hypertension.[34,35] A U.S. study found that 95% of patients with dementia had one or more comorbidities, with 26% having coronary heart disease and 23% having diabetes.[36] In a Canadian study, 19.5% of dementia patients had a mood disorder compared to 5.3% in a non-demented group of the same age.[37] We found no association with hypertension despite the current recognition of cardiovascular disease as a risk factor for dementia. Further case definition development will be needed to analyze the association with other important comorbidities, such as coronary heart disease and congestive heart failure for which CPCSSN does not at this time have validated case definitions.

Limitations

The CPCSSN database contains only data entered into primary care EMRs. The data also reports only on patients who attend primary care clinics; while this generally excludes residents in long-term care, the majority of community-dwelling Canadians visit their family physician at least once each year[38] and strategic sampling measures were taken to ensure representativeness of the data at national level.[11]

The quality of dementia diagnoses in primary care is considered to be variable, with some family physicians confident to diagnose without referral or imaging while others make use of those supports to varying degrees of appropriateness.[39] Efforts to improve diagnosis and management of the condition in primary care include the implementation of primary care-based memory clinics[24] which attempt to capitalize on the particular expertise of family physicians with specific interest in the disease. Differentiating between different types of dementia is not currently possible within the CPCSSN database for reasons associated with data recording behavior among physicians; nor does CPCSSN data include information on other important aspects of community-based care, such as counseling, homecare or advanced care planning.

Data quality can often be an issue with large primary care EMR databases, as these data are input for clinical purposes and not with research applications in mind. For instance, 30.5% of patients with the diagnosis of dementia in the CPCSSN database were missing BMI values and 3% did not have a postal code to confirm urban or rural status. This may have caused our association between obesity and lower rates of dementia to be invalid, if the BMI data were missing in a non-random pattern. Smoking data are very inconsistently recorded in primary care EMRs, both in form and content, and was excluded from the analysis. A misclassification bias may also exist, as the EMR database may not capture all community-dwelling dementia patients, and our prevalence may thus be underestimated; however, our validity estimates for identifying cases of dementia in primary care EMRs are robust.[17]

Conclusions: implications for practice and future research

The existence of robust health and utilization data in primary care is crucial for primary care development in Canada. Our analysis of dementia data from primary care settings for community-dwelling seniors aged over 65 years across the country provides important insight into the longitudinal prevalence estimates and significant aspects of pharmacological management at a time when prevalence and demand are increasing. Understanding and improving primary care service provision for dementia is essential to maintain standards of care and the health of the nation. Achieving this includes an urgent need for improved undergraduate medical training and continuing medical education in the diagnosis and management of dementia, as well as the development and evaluation of EMR-based care pathways and other innovations for the support of patients and caregivers as well as community-based, primary care providers.

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Table 1. CPCSSN case definition for dementia

Text-based Definition

- Includes: Alzheimer's disease, frontotemporal dementia, Pick's disease, senile degeneration of the brain, corticobasal degeneration, cerebral degeneration, dementia with Lewy bodies, mild cognitive impairment, senile dementia, presenile dementia, vascular dementia, senility without mention of psychosis.

Operational Definitions

Classification can occur by meeting criteria in any of the sections (Billing, Problem List / Encounter Diagnosis, Medication), unless otherwise specified:

Billing	Profile / Encounter Diagnosis	Medication
Any occurrence of the following ICD9 codes: • 290.* - dementias psychosis • 331.* - other cerebral degenerations • 294.1 - dementia in conditions classified elsewhere • 294.8 - other persistent mental disorders due to conditions classified elsewhere • 797.* - senility without mention of psychosis • 438.* - late effects of cerebrovascular disease psychosis The following are excluded: • 290.8 - other specified senile psychotic condition • 290.9 - unspecified senile psychotic condition • 331.3 - communicating hydrocephalus • 331.4 - obstructive hydrocephalus • 331.5 - idiopathic normal pressure hydrocephalus • 331.81 - Reye's syndrome	Any occurrence of the following ICD9 codes: • 290.* - dementias psychosis • 331.* - other cerebral degenerations • 294.1 - dementia in conditions classified elsewhere • 294.8 - other persistent mental disorders due to conditions classified elsewhere • 797.* - senility without mention of psychosis • 438.* - late effects of cerebrovascular disease psychosis The following are excluded: • 290.8 - other specified senile psychotic condition • 290.9 - unspecified senile psychotic condition • 331.3 - communicating hydrocephalus • 331.4 - obstructive hydrocephalus • 331.5 - idiopathic normal pressure hydrocephalus • 331.81 - Reye's syndrome	**Drug Name** **ATC Code** MEMANTINE N06DX01 RIVASTIGMINE N06DA03 GALANTAMINE N06DA04 DONEPEZIL N06DA02 Medication criteria is required for the following diagnoses to be classified: • 797.* - senility without mention of psychosis • 438.* - late effects of cerebrovascular disease psychosis

Table 2. Prevalence of dementia, by age and sex

	Prevalence of dementia % (n/N), 95% CI	
Age Group	**Males**	**Females**
65-74 years	2.4 (336/13,964), 2.2-2.7	2.5 (426/16,914), 2.3-2.8
75-84 years	9.0 (745/8,243), 8.4-9.7	9.7 (1,067/10,978), 9.2-10.3
85 years & older	20.5 (648/3,158), 8.4-9.7	22.5 (1,330/5,920), 21.4-23.5
Total prevalence (observed)	7.7 (4,552/59,177), 7.5-7.9	
Total prevalence (age and sex standardized)	7.3, 7.1-7.5	

Table 3. Characteristics influencing the prevalence of dementia, adjusted for age and sex

Characteristics	N	Prevalence Ratio	95% CI
Location			
Urban = ref	42,940	1.00	--
Rural	14,438	0.93	0.87-1.00
Missing	1,799	1.50	1.36-1.67
BMI group			
Normal (18-24) = ref	12,246	1.00	--
Underweight (<18)	1,552	1.13	0.98-1.33
Overweight (25-29)	14,510	0.94	0.87-1.03
Obese (>= 30)	12,843	0.89	0.81-0.97
Missing	18,026	1.03	0.96-1.11
Comorbidity			
Hypertension	59,177	0.97	0.95-1.00
Diabetes	59,177	1.10	1.04-1.16
Depression	59,177	2.40	2.29-2.52
COPD	59,177	1.08	1.00-1.17
Osteoarthritis	59,177	1.01	0.97-1.06
Epilepsy	59,177	2.89	2.32-3.60
Parkinsonism	59,177	2.93	2.47 -3.47

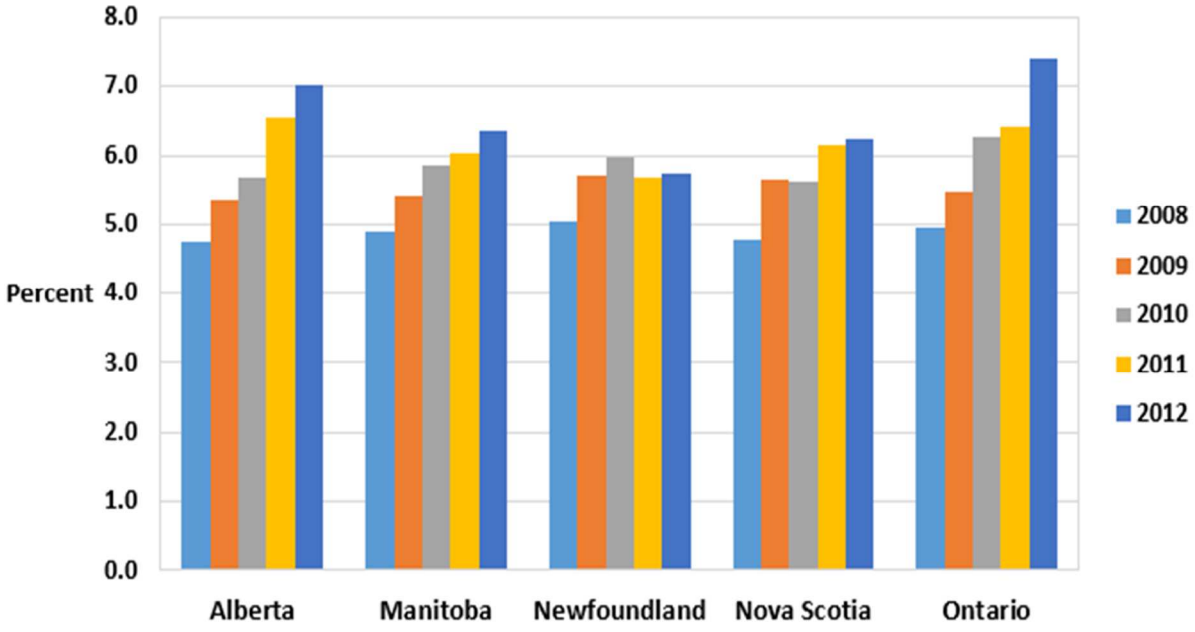
Table 4. Number and type of dementia medications prescribed by primary care providers to patients with dementia, by year and province

	2008	2009	2010	2011	2012
Alberta					
Number of dementia medications* prescribed to dementia patients, n (%)					
0 drugs	658 (94.8)	632 (91.1)	615 (88.6)	616 (88.8)	609 (87.8)
1 drug	33 (4.8)	60 (8.7)	77 (11.1)	75 (10.8)	85 (12.3)
2 drugs	3 (0.4)	2 (0.3)	1 (0.1)	3 (0.4)	0 (0.0)
3-4 drugs	0 (0.0)	0 (0.0)	1 (0.1)	0 (0.0)	0 (0.0)
Number of dementia patients prescribed specific dementia medications, n (%)**					
Donepezil	21 (60.0)	21 (65.6)	28 (62.2)	29 (72.5)	57 (67.1)
Galantamine	13 (37.1)	7 (21.9)	17 (37.8)	12 (30.0)	24 (28.2)
Memantine	4 (11.4)	2 (6.3)	1 (2.2)	1 (2.5)	7 (8.2)
Rivastigmine	4 (11.4)	4 (12.5)	3 (6.7)	7 (17.5)	9 (10.6)
Manitoba					
Number of dementia medications* prescribed to dementia patients, n (%)					
0 drugs	466 (94.1)	456 (92.1)	446 (90.1)	445 (89.9)	445 (89.0)
1 drug	28 (5.7)	38 (7.7)	48 (9.7)	49 (9.9)	49 (9.9)
2 drugs	1 (0.2)	1 (0.2)	1 (0.2)	1 (0.2)	1 (0.2)
3-4 drugs	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.0)	0 (0.0)
Number of dementia patients prescribed specific dementia medications, n (%)**					
Donepezil	11 (91.7)	11 (84.6)	14 (82.4)	17 (77.3)	47 (94.0)
Galantamine	1 (8.3)	4 (30.8)	2 (11.8)	7 (31.8)	4 (8.0)
Memantine	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (2.0)
Rivastigmine	1 (8.3)	0 (0.0)	1 (5.9)	1 (4.6)	3 (6.0)
Newfoundland					
Number of dementia medications* prescribed to dementia patients, n (%)					
0 drugs	271 (92.8)	253 (86.6)	227 (77.7)	207 (70.9)	207 (70.9)
1 drug	20 (6.9)	34 (11.6)	62 (21.2)	83 (28.4)	83 (28.4)
2 drugs	0 (0.0)	4 (1.4)	3 (1.0)	1 (0.3)	2 (0.7)
3-4 drugs	1 (0.3)	1 (0.3)	0 (0.0)	1 (0.3)	0 (0.0)
Number of dementia patients prescribed specific dementia medications, n (%)**					

Donepezil	6 (66.7)	7 (77.8)	16 (64.0)	29 (65.9)	75 (88.2)
Galantamine	3 (33.3)	2 (22.2)	9 (36.0)	22 (50.0)	16 (18.8)
Memantine	1 (11.1)	1 (11.1)	5 (20.0)	1 (2.3)	0 (0.0)
Rivastigmine	2 (22.2)	0 (0.0)	1 (4.0)	2 (4.6)	1 (1.2)
Nova Scotia					
Number of dementia medications* prescribed to dementia patients, n (%)					
0 drugs	491 (89.9)	468 (85.7)	429 (78.6)	383 (70.2)	397 (72.7)
1 drug	51 (9.3)	73 (13.4)	110 (20.2)	154 (28.2)	139 (25.5)
2 drugs	4 (0.7)	5 (0.9)	7 (1.3)	8 (1.5)	10 (1.8)
3-4 drugs	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.2)	0 (0.0)
Number of dementia patients prescribed specific dementia medications, n (%)**					
Donepezil	7 (53.9)	2 (18.2)	14 (53.9)	38 (56.7)	90 (60.4)
Galantamine	4 (30.8)	9 (81.8)	16 (61.5)	29 (43.3)	62 (41.6)
Memantine	1 (7.7)	0 (0.0)	1 (3.9)	3 (4.5)	8 (5.4)
Rivastigmine	1 (7.7)	0 (0.0)	2 (7.7)	7 (10.5)	17 (11.4)
Ontario					
Number of dementia medications* prescribed to dementia patients, n (%)					
0 drugs	1934 (92.8)	1812 (86.9)	1678 (80.5)	1589 (76.2)	1557 (74.7)
1 drug	135 (6.5)	248 (11.9)	357 (17.1)	432 (20.7)	459 (22.0)
2 drugs	14 (0.7)	23 (1.1)	49 (2.4)	62 (3.0)	66 (3.2)
3-4 drugs	2 (0.1)	2 (0.1)	1 (0.1)	2 (0.1)	3 (0.1)
Number of dementia patients prescribed specific dementia medications, n (%)**					
Donepezil	25 (67.6)	30 (63.8)	68 (58.6)	138 (60.3)	343 (62.9)
Galantamine	8 (21.6)	18 (38.3)	49 (42.2)	81 (35.4)	191 (35.1)
Memantine	4 (10.8)	5 (10.6)	15 (12.9)	45 (19.7)	95 (17.4)
Rivastigmine	3 (8.1)	7 (14.9)	12 (10.3)	27 (11.8)	59 (10.8)

**Dementia medications: donepezil, galantamine, memantine, rivastigmine.*
***Total may exceed 100%, as some patients were prescribed multiple medications.*

Figure 1: Provincial variation in the prevalence of dementia from 2008 to 2012, age & sex standardized



2008	4.7 (4.3-5.2)	4.9 (4.4-5.4)	5.0 (4.3-5.8)	4.8 (4.2-5.4)	5.0 (4.6-5.3)
2009	5.4 (4.9-5.8)	5.4 (4.9-6.0)	5.7 (5.0-6.4)	5.7 (5.1-6.2)	5.5 (5.2-5.8)
2010	5.7 (5.2-6.1)	5.8 (5.3-6.4)	6.0 (5.3-6.7)	5.6 (5.1-6.2)	6.3 (6.0-6.6)
2011	6.5 (6.1-7.0)	6.0 (5.5-6.6)	5.7 (5.0-6.3)	6.1 (5.6-6.6)	6.4 (6.1-6.7)
2012	7.0 (6.5-7.5)	6.4 (5.8-6.9)	5.7 (5.1-6.3)	6.2 (5.7-6.7)	7.4 (7.1-7.7)
Provincial N 2011 (65+ years)	405,720	172,450	82,115	153,370	1,878,330