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Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2022-067363
Article Type:	Original research
Date Submitted by the Author:	10-Aug-2022
Complete List of Authors:	Kosteniuk, Julie; University of Saskatchewan College of Medicine, Medicine Osman, Beliz; Saskatchewan Health Quality Council Osman, Meric; Saskatchewan Medical Association Quail, Jacqueline M.; Saskatchewan Health Quality Council Islam, Naorin; University of Saskatchewan O'Connell, Megan; University of Saskatchewan, Psychology Kirk, Andrew; University of Saskatchewan, Medicine Stewart, Norma J.; University of Saskatchewan College of Nursing Morgan, Debra; University of Saskatchewan College of Medicine, Medicine
Keywords:	Dementia < NEUROLOGY, GERIATRIC MEDICINE, HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PRIMARY CARE

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Health service use before and after dementia diagnosis: a retrospective matched case-control study

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Word count: 3800

ABSTRACT

Objectives

This study investigated patterns in health service usage among older adults with dementia and matched controls over a 10-year span from five years before until five years after diagnosis.

Design

Population-based retrospective matched case-control study.

Setting

Administrative health data of individuals in Saskatchewan, Canada from April 1, 2008 to March 31, 2019.

Participants

The study included 2,024 adults aged 65 years and older living in the community at the time of dementia diagnosis from April 1, 2013 to March 31, 2014, matched 1:1 to individuals without a dementia diagnosis on age group, sex, rural vs. urban residence, geographic region, and comorbidity.

Primary and secondary outcome measures

For each 5-yr period before and after diagnosis, we examined usage of health services each year including family physician (FP) visits, specialist visits, hospital admissions, all-type prescription drug dispensations, and short-term care admissions. We used negative binomial regression to estimate the effect of dementia on yearly average health service utilisation adjusting for sex, age group, rural vs. urban residence, geographic region, 1-yr prior health service use, and comorbidity.

Results

Adjusted findings demonstrated that variations in health service usage between persons with and without dementia were greatest in the year before and year after diagnosis, with a higher number of specialist visits and hospitalisations in the year before and higher FP visits and drug prescriptions in the year after. FP contacts and drug prescriptions were higher among persons with dementia during the majority of the 10-yr study period. However, from two years following diagnosis until study end, specialist contacts and hospitalisations were either lower or no different between the two groups.

Conclusions

Findings suggest the time immediately before and after diagnosis presents multiple opportunities to implement quality supports. Family physicians are integral to dementia care and require effective resources to properly serve this population.

Keywords

Dementia, Alzheimer disease, health services research, physicians, hospitals

ARTICLE SUMMARY

Strengths and limitations of this study

- A population-based matched cohort design was used to examine the usage of several health services over a substantial period of time before and after dementia diagnosis, among persons with dementia and persons without dementia.
- The use of administrative data to identify the study population may have resulted in misclassification of cases and controls.
- Group differences in health service usage after diagnosis may be due in part to differences that emerged after the matching date, such as more persons with dementia than without dementia admitted to permanent long-term care.

INTRODUCTION

Dementia is the second leading cause of death in high-income countries and the 7th leading cause of mortality globally.[1] An estimated 58 million people worldwide were living with dementia in 2020, a number that is projected to double by 2040.[2] Aging populations and longer survival after diagnosis account for increasing prevalence.[3, 4] In Canada, more than 670,000 people were estimated to be living with dementia in 2020, including 20,200 people in the province of Saskatchewan.[5, 6] The economic cost of dementia including informal care is an estimated US \$1 trillion annually worldwide.[7] Annual direct costs associated with dementia in Canada (health system costs and out of pocket caregiving expenses) are an estimated 5.5 times greater than for those without dementia and expected to increase from CAD \$12.4 billion in 2021 to \$16.6 billion by 2031.[8]

Most Canadians with dementia live outside long-term care and nursing homes (261,000 or 61%) and may require complex care due to severe cognitive impairment, dependence for activities of daily living, and responsive behaviours.[9] Effectively managing complex long-term conditions such as dementia in primary and community care settings involves addressing cognitive and physical functioning.[10] Information about patterns of health service usage in the time before and after diagnosis can assist with forecasting demand for services, allocating resources, and inform interventions to help alleviate demand. Interventions may improve access to community health and social services, such as an appointed contact person to coordinate services, flexible settings (e.g., for respite care), and health personnel training.[11]

Studies show that the usage of certain health services is greater among persons with dementia than persons without dementia. For example, people with dementia are more likely to be hospitalized [12-20] and admitted to emergency departments than people without dementia.[15, 16, 18, 19] Reports also show more frequent use of certain services among people with dementia, including family physicians [21-24] and hospital admission.[15, 18, 24, 25]

When comparing patterns in health service usage between people with and without dementia, the usage period relative to diagnosis timing is not always specified. A few studies have examined both pre- and post-diagnosis in the same analysis,[15, 22, 23] however the observation period was less than three years. Studies that include both pre- and post-diagnosis and longer timeframes have the potential to account for interactions with the health system that occur over the lengthy course of the diseases that cause dementia and neurodegeneration. The purpose of this study was to use administrative health

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3 data to examine the association between dementia and health service usage over a 10-year period from
4 5 years before until 5 years after an initial dementia diagnosis.
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8 **METHODS**

10 **Design and data sources**

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12 This study used a population-based retrospective matched case-control design and reporting
13 adhered to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)
14 Statement [26]. Administrative health databases from the Canadian province of Saskatchewan
15 (population 1.17 million in 2019) [27] were linked using unique identifiers based on the personal health
16 services numbers of individuals eligible for provincial public health insurance. Saskatchewan residents
17 who hold federal health insurance (<1%) do not also hold provincial health insurance, namely Royal
18 Canadian Mounted Police, Canadian Forces members, and inmates at federal penitentiaries.[28]
19 However, the data of these individuals are captured in Saskatchewan administrative health data.
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26 Linkage and data analysis were conducted at the Saskatchewan Health Quality Council. Data sources
27 included the Medical Services Database, Hospital Discharge Abstract Database, Prescription Drug Plan
28 Database, Person Health Registration System (demographics and geography), and Institutional
29 Supportive Care Home Database. The Medical Services Database includes billing claims by physicians
30 paid on a fee-for-service basis, and shadow billing by primary health sites and practitioners paid under
31 alternate non-fee-for-service methods.[29, 30] The Prescription Drug Plan Database includes
32 information about dispensations to all individuals regardless of the source of funding for the costs (i.e.,
33 public or private insurance, out of pocket). The Institutional Supportive Care Home database is used by
34 special care homes (i.e., nursing or long-term care homes) to maintain records of admission, discharge,
35 and level of care changes.[31]
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45 **Study population**

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47 Individuals aged 65 years or older were identified at their first recorded diagnosis of dementia (i.e.,
48 index date) between April 1, 2013 and March 31, 2014. A lookback period of five years prior to the index
49 date was used to ensure these were incident cases. To identify the cohort, we used the Canadian
50 Chronic Disease Surveillance System (CCDSS) algorithm for dementia [32] that has been previously
51 validated in Ontario, Canada.[33] Recent studies drawing on population-based administrative health
52 data have used this case definition,[24, 34, 35] as has the Public Health Agency of Canada for the
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3 purpose of estimating dementia prevalence and incidence across Canadian provinces and territories.[36]
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5 The algorithm defines dementia based on one or more hospitalisations associated with a diagnosis code
6 for dementia [International Classification of Disease (ICD-9-CM) codes 046.1, 290.0-290.4, 294.1, 294.2,
7 331.0, 331.1, 331.5, 331.82; ICD-10-CA codes F00, F01, F01, F03, G30], three or more physician claims
8 for dementia within two years with at least 30 days between each claim (ICD-9 codes 290, 331), or one
9 or more prescriptions for memantine or a cholinesterase inhibitor (donepezil, galantamine, and
10 rivastigmine). For physician claims, ICD-9 code 298 was also included in the case definition as it has been
11 used as an alternative code in addition to 290 and 331 in Saskatchewan physician billing data since the
12 1970s.
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15 For the purpose of selecting 1:1 matched controls, the index date was set as April 1, 2013. Propensity
16 scores were estimated using a probit model [37] to determine the probability of being a case given the
17 covariates included in the model. The covariates at index date were sex, age group (65-69, 75-74, 75-79,
18 80-84, and ≥ 85), rural versus urban residence (urban defined as postal code outside commuting zone of
19 10,000 or more population), geographic region (northern, central, or southern Saskatchewan), and
20 Charlson Comorbidity Index (CCI) score.[38] Dementia was considered one of 17 comorbidities when
21 calculating the CCI score to truly estimate the burden of diseases on older adults.
22

23
24 A total of 120,915 persons without dementia were identified as potential controls (figure 1). Upon
25 estimation of propensity scores, we used the nearest neighbour matching technique to construct the
26 control group.[39] Individuals residing in permanent long-term care on their index date, per *Institutional*
27 *Supportive Care Home* data, were ineligible for the study. However, individuals admitted to permanent
28 long-term care before or after their index date were eligible for inclusion. Individuals eligible for this
29 study had continuous health insurance coverage or a gap in insurance coverage not exceeding 3 days
30 between April 1, 2008 and the end of the follow-up period (i.e., date of death or study end date of
31 March 31, 2019). Eligible individuals were required to have complete information on all variables used
32 to select the matched controls except for CCI information. Individuals included in dementia cohorts in
33 previous analyses [40, 41] were ineligible to be included as controls.
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49 **Health service use**

50 Health service use measures included family physician visits, specialist visits, hospital admissions,
51 prescription drug dispensations, and admission to short-term institutional care (i.e., adult day
52 programming, respite, and night care). Physicians were separated into two groups based on more than
53 70 categories of certified specialty,[29] namely family medicine [(family physician (FP))] and specialists
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(all specialties other than family medicine). A specialist visit requires a referral from a family physician or nurse practitioner. Physician visits were included in the present study regardless of location (office, home, hospital in-patient, hospital out-patient, emergency room, and other locations). Multiple hospital admissions with less than 1-day gap between discharge and readmission were counted as one hospitalisation. Prescription drug use included all dispensations regardless of drug classification. Individuals may be admitted to institutional supportive care via one of eight streams, one of which is permanent long-term care. The other seven streams constitute short-term care and include temporary care of less than 60 days (respite, convalescence, rehabilitation, geriatric assessment, and palliative care), adult day programming (personal and nursing care, rest, exercise, social and recreational activities), and night care (relief to primary care providers and family).[42]

Statistical analysis

Propensity score matching based on probit regression and all health service use analyses were performed with SAS (version 9.3).

We calculated the proportion of older adults with at least one use of each health service during each year of the 5-yr period before the index date, and each year of the 5-yr period after the index date. Among those using a service at least once, we also calculated the annual mean number of services and 95% confidence intervals. Significant differences in the proportion of services used by the two cohorts were identified using the χ^2 test ($p < 0.05$), and significant differences in the mean number of services were established using the Wilcoxon rank sum test ($p < 0.05$). The average number of short-term care admissions was not calculated due to challenges in interpreting this information given variability in the duration of stays across the three types of admission (adult day programming, respite, and night care).

Negative binomial (NB) regression was used to estimate the impact of dementia on mean service utilisation each year of the pre-index and post-index periods. Individuals who died each post-index year were removed from the study the following year. We chose the NB model over another count data model, Poisson regression, due to the presence of overdispersion.[43] The effect of dementia was estimated as the discrete change in the expected mean value of health service utilisation (e.g., average number of hospital admissions) for a change in the dementia variable from 0 to 1. Values of $p < 0.05$ were considered statistically significant. The NB model for each health service was adjusted for sex, age group, rural vs. urban residence, geographic region, 1-yr prior health service use (physician, hospital, and drug), and CCI score. Moreover, varying time spans were adjusted by using each individual's time (number of days) in each period as an offset variable. The other variables in the model were evaluated

by their mean values in expected value calculations.

Patient and public involvement

Neither patients nor members of the public were involved in the study.

RESULTS

Study criteria were met by 2,024 persons with incident dementia matched 1:1 to 2,024 persons without dementia (table 1). At index date, 75.9% of persons with dementia were aged 70 years and older, 39.6% were male, and 69.4% urban. The cohorts were similar in age, sex, rural/urban residence, number of comorbidities, and geographic region. Individuals admitted to permanent long-term care between their index date and end of the 5-yr post-index period were retained in the study, which included 38.8% of persons with dementia (n = 786) and 8.5% of persons without dementia (n = 173) (table 2). Death during the post-index period occurred in 44.6% of persons with dementia (n = 902) and 25.5% of persons without dementia (n = 516); these individuals were removed from the study each year.

Table 1. Descriptives and mean comparison tests between a cohort of persons with dementia and a matched cohort of persons without dementia, at index date between April 1, 2013 and March 31, 2014

Characteristic	Persons with dementia (N = 2024)			Persons without dementia (N = 2024)			p value ^a
	n	% or Mean	SD	n	% or Mean	SD	
Propensity score (mean)	2024	0.024	0.0165	2024	0.024	0.0164	1.00
Age group (%)							
65-69	488	24.11	0.43	488	24.22	0.43	1.00
70-74	276	13.64	0.34	276	13.64	0.34	1.00
75-79	280	13.83	0.35	280	13.83	0.35	1.00
80-84	374	18.48	0.39	375	18.53	0.39	0.97
85+	606	29.94	0.46	605	28.89	0.46	0.97
Male sex (%)	802	39.62	0.49	801	38.58	0.49	0.97
Urban residence (%)	1407	69.42	0.46	1405	69.52	0.46	0.95
Charlson Comorbidity Index score, 1-yr prior (mean)	2024	0.77	1.35	2024	0.77	1.36	0.96
Geographic region (%)							
Northern SK	21	1.04	0.10	21	1.04	0.10	1.00
Central SK	1174	58.0	0.49	1173	58.0	0.49	0.97
Southern SK	829	41.0	0.49	830	41.0	0.49	0.97

^a Chi-square test at 5% level of significance

Table 2. Mortality and admission to permanent LTC in the post-index period

	Post-index ^a					Total n
	1-yr n (%)	2-yr n (%)	3-yr n (%)	4-yr n (%)	5-yr n (%)	
Admitted to permanent LTC ^b						
Persons with dementia	332 (42.2)	155 (19.7)	121 (15.4)	100 (12.7)	78 (9.9)	786
Persons without dementia	33 (19.1)	34 (19.7)	26 (15.0)	40 (23.1)	40 (23.1)	173
Mortality ^c						
Persons with dementia	311 (34.5)	162 (18.0)	158 (17.5)	128 (14.2)	143 (15.9)	902
Persons without dementia	114 (22.1)	102 (19.8)	93 (18.0)	109 (21.1)	98 (19.0)	516

^a Persons with dementia at index date, N=2024; Persons without dementia at index date, N=2024

^b People admitted to permanent LTC each year were retained in the study.

^c People who died each year were removed from the study the following year.

Health service use

Most persons with dementia had at least one FP visit each year and a higher proportion of this group compared to persons without dementia had a FP visit over the study period ($p<0.05$) (figure 2a). Each year, 69.3 to 84.3% of persons with dementia had at least one specialist visit. A greater proportion of persons with dementia had one or more specialist visit during most years until 2-yr post-index ($p<0.05$) (figure 2b). During the pre-index period, the specialties of psychiatry and neurology ranked 7th (5%) and 10th (3%) by visit frequency among persons with dementia, respectively (data not shown). Post-index, psychiatry and neurology ranked 2nd (13%) and 8th (5%), respectively. Among persons without dementia, neurology and psychiatry ranked consistently outside the top ten. Between 29 and 52.5% of persons with dementia were hospitalised at least once annually and a higher proportion compared to persons without dementia were hospitalised between 1-yr pre-index and 2-yr post-index ($p<0.05$) (figure 2c). At least one prescription drug of any type was dispensed annually to 91.0 to 95.8% of persons with dementia and each year this group was more likely than persons without dementia to receive any type of drug ($p<0.05$) (figure 2d). The proportion of older adults with dementia who used short-term institutional care at least once ranged from 0.8% to 7.7% annually and was highest at 1-yr post-index (figure 2e).

The unadjusted mean number of FP and specialist visits by persons with dementia increased over the pre-index period, with the greatest increases at 1-yr pre-index (figure 3a and 3b). After this point, FP visits continued to increase over the post-index period until 4-yr and specialist visits decreased. Each year, hospital admissions ranged between 1.6 and 2.0 visits, peaking one year before and after diagnosis

(figure 3c), and annual drug prescriptions increased until 4-yr post-index (figure 3d).

Regression models for the association between dementia and mean service utilisation each year were adjusted for sex, age group, rural vs. urban residence, geographic region, 1-yr prior health service use (physician, hospital, and drug), and CCI score (tables 3 and 4). At 5-yr pre-index, usage of all health services was lower among persons with dementia than persons without dementia (all $p < 0.001$). At 4-yr pre-index, the pattern changed: FP visits and drug prescriptions were higher among persons with dementia until the end of the 10-yr period ($p < 0.001$), specialist visits were higher from 1-yr pre-index until 1-yr post-index and lower between 2-yr and 5-yr post-index ($p < 0.001$), and hospitalisations were higher at certain points (1-yr and 5-yr pre-index and post-index, $p < 0.001$) but demonstrated no differences otherwise. Differences in specialist visits and hospitalisations between persons with and without dementia were greatest at 1-yr pre-index, and differences in FP visits and drug prescriptions were greatest at 1-yr post-index (all $p < 0.001$).

Table 3. Adjusted^a pre-index differences in the mean number of health services used by persons with dementia and a matched cohort of persons without dementia

Health Service	Pre-index (N = 4038)				
	5-yr	4-yr	3-yr	2-yr	1-yr
Family Physician visits					
Adjusted difference	-1.14	0.69	0.69	1.00	4.07
% difference	12.3	8.5	8.5	11.7	49.3
<i>p</i> value	<0.001	<0.001	<0.001	<0.001	<0.001
Specialist visits					
Adjusted difference	-0.70	0.10	0.06	-0.23	2.43
% difference	16.5	2.7	1.6	-4.9	59.7
<i>p</i> value	<0.001	0.503	0.684	0.203	<0.001
Hospital admissions					
Adjusted difference	-0.04	0.06	0.04	0.02	0.43
% difference	8.3	13.8	8.2	3.3	90.5
<i>p</i> value	0.224	0.035	0.188	0.573	<0.001
Prescription drug dispensations					
Adjusted difference	-9.66	1.40	1.64	1.92	3.99
% difference	32.3	6.0	6.5	7.0	13.6
<i>p</i> value	<0.001	0.009	0.003	0.002	<0.001

^a Adjusted for sex, age group, rural vs. urban residence, geographic region, 1-yr prior health service use (physician, hospital, and prescription drug), and comorbidity score.

Table 4. Adjusted^a post-index differences in the mean number of health services used by persons with dementia and a matched cohort of persons without dementia

Health Service	Post-index ^b				
	1-yr N = 4038	2-yr N = 3614	3-yr N = 3350	4-yr N = 3099	5-yr N = 2862
Family Physician visits					
Adjusted difference	6.42	2.41	3.71	3.26	2.77
% difference	70.0	23.9	38.5	32.2	27.0
<i>p</i> value	<0.001	<0.001	<0.001	<0.001	<0.001
Specialist visits					
Adjusted difference	1.11	-1.23	-0.88	-1.23	-1.18
% difference	23.1	-22.0	-16.2	-22.3	-21.0
<i>p</i> value	<0.001	<0.001	<0.001	<0.001	<0.001
Hospital admissions					
Adjusted difference	0.22	-0.07	-0.05	-0.06	-0.11
% difference	37.7	-10.5	-8.5	-10.5	-18.0
<i>p</i> value	<0.001	0.082	0.117	0.120	0.01
Prescription drug dispensations					
Adjusted difference	8.88	1.65	3.99	2.91	3.05
% difference	29.1	5.0	12.4	8.9	9.0
<i>p</i> value	<0.001	0.031	<0.001	<0.001	<0.001

^a Adjusted for sex, age group, rural vs. urban residence, geographic region, 1-yr prior health service use (physician, hospital, and prescription drug), and comorbidity score.

^b People who died each year were removed from the study the following year.

DISCUSSION

This retrospective study examined patterns in the use of health services among older adults with dementia and matched controls across a 10-year span that included five-year periods before and after first diagnosis of dementia in 2013/2014. Compared to persons without dementia, a higher proportion of persons with dementia experienced at least one FP visit and received at least one all-type drug prescription annually. A higher proportion of persons with dementia also had at least one specialist visit annually during most the pre-diagnosis period until one year after diagnosis, and were hospitalized at least once annually one year before and one year after diagnosis. In adjusted models, usage of all services at the 5-yr point before diagnosis was lower among persons with dementia than persons without dementia. However, within one year the pattern changed and usage of all services except specialists became higher among persons with dementia. Differences in usage were greatest in the year before diagnosis for specialist visits and hospitalisations, and in the year after diagnosis for FP visits and drug prescriptions, with higher usage among persons with dementia.

The pattern of an increasing number of FP visits leading up to diagnosis found in this study is

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3 consistent with the results of previous reports that had similarly lengthy pre-diagnosis periods of three
4 years [23] and five years.[21] These studies found a lower average number of visits each year, namely 4-
5 7 [21] and 6-11 [23] compared to our research (10.3-18.5 visits). Canada has a higher rate of physician
6 consultations per capita than other Commonwealth countries,[44] which may partly explain the higher
7 average in our study. Similar to our findings, previous case-control studies reported more primary care
8 visits among persons with than without dementia in the years leading up to diagnosis and in the year
9 following diagnosis,[22, 23] with particularly large differences 6-12 months before [21, 23] and after
10 diagnosis.[22, 23] More frequent FP visits before diagnosis can reflect a protracted diagnostic process
11 with multiple visits and delays over time,[45, 46] involving an increase in help-seeking as the ability to
12 self-manage declining health and chronic conditions decreases,[47] dementia-related symptoms such as
13 falls increase,[48] and caregiver stress escalates. A pattern of elevated FP visits after diagnosis reflects
14 the central role of FPs in managing the care of older adults with dementia [49] and suggests a need to
15 further support FPs and other primary health care professionals in providing high-quality ongoing post-
16 diagnostic management.[9, 50]

17
18 In terms of specialist visits, the higher number among persons with dementia in the year prior to
19 diagnosis suggests demand for specialist involvement in relation to symptoms of undiagnosed dementia.
20 A similar finding with regard to neurologist and psychiatrist visits was reported in a study using German
21 health insurance data.[22] We also found a higher number of specialist visits among persons with
22 dementia in the year immediately after diagnosis, although the difference was not as great as seen in
23 Chung et al.[51] who reported an 8-fold higher number of psychiatrist visits among persons with
24 dementia in a study of Taiwan health insurants. We considered all specialties rather than subspecialties
25 such as psychiatry, which may partly account for this smaller difference. We also found that apart from
26 the time immediately before and after diagnosis, the number of specialist visits was lower or no
27 different among the two groups. This suggests specialists are consulted to a lesser extent than FPs when
28 seeking a diagnosis and post-diagnostic support. In Saskatchewan, the specialist-to-population ratio is
29 lower than the national average (87 vs. 113 per 100,000),[52] as is the ratio of dementia specialists
30 including psychiatrists, neurologists, and geriatricians (0.1 to 7 vs. 0.8 to 13 per 100,000).[53] It is
31 possible that persons with dementia are less likely than those without dementia to request or receive a
32 specialist referral from their primary care provider, or to follow up on a specialist referral. In the years
33 following a dementia diagnosis, there may be greater challenges accessing specialists who practice
34 mainly in the two major cities of Saskatchewan, and a shift in care responsibility to FPs particularly for
35 less complex cases and persons in permanent long-term care.

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Hospitalisation at least once in the year before diagnosis was more likely among persons with dementia than without dementia (52.5% vs. 29.9%), in line with the findings of Chen et al.[23] (24% AD vs 19% non-AD). This may be partly explained by our inclusion of all dementia subtypes, as there is evidence of higher use of inpatient services before diagnosis among persons with vascular dementia and non-specific dementia compared to AD and other subtypes.[54] Our findings may also suggest undiagnosed and therefore improperly managed symptoms of dementia, inappropriate medication management, or mismanagement of chronic conditions.[14, 55] Similar to other reports, we also found cohort differences in the proportion hospitalised at least once in the first year after diagnosis [15, 23, 56] and two years after diagnosis.[15] The adjusted number of hospitalisations was also higher one year before and one year after diagnosis in persons with dementia, in line with a US study of Medicare beneficiaries.[20] These findings may imply challenges in the short-term following diagnosis, possibly related to learning to manage a greater number of prescriptions, inadequate management of comorbidities,[57, 58] and difficulties communicating symptoms.[59] Later in post-diagnosis, the number of hospitalisations did not vary between the two groups or were lower among persons with dementia, possibly reflecting the admission of a large share to permanent long-term care where conditions were managed on-site.[60]

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Approximately nine in ten older adults received at least one all-type drug prescription each year, in line with 81% of older adults (with and without prevalent dementia) reported in a previous Swedish study.[61] Our findings show that across the study period, the adjusted number of drug prescriptions was higher in persons with dementia compared to without dementia. A recent review noted mixed results in studies comparing the two groups, with an equal number of studies reporting a lower average number as well as a higher average number of medications in persons with prevalent dementia.[62]

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Less than 8% of older adults with dementia were observed to use short-term institutional care annually. Previous studies show that day programs are generally underutilized among persons with dementia.[63-65] Caregivers may lack knowledge of short-term care options, or the options may be limited particularly in rural communities in Saskatchewan.[66] Moreover, low use may be related to low perceived need,[65] feelings of guilt and loneliness in caregivers,[67] and negative perceptions of care programs held by both caregivers and care recipients.[64, 65].

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Future longitudinal investigations could yield further insight into service use variations by considering the causes of use, appropriateness and quality of services, and perceptions and preferences for health services among persons with dementia and their families. Future research should explore how patterns of post-diagnostic service use might be altered, for example by earlier detection of the diseases that

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3 cause dementia. Inequities in health care use before and after dementia diagnosis should be identified
4 and addressed in further research, for instance in relation to age, sex, dementia subtypes, and location
5 of individuals (i.e., rural or urban; community or long-term care).
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10 **Strengths and limitations**

11 The strengths of this study include using a population-based matched cohort design and a lengthy
12 pre- and post-diagnosis observation period relative to comparable studies. As with such studies that use
13 administrative data, it is possible that case identification via diagnosis codes and drug prescription data
14 resulted in misclassification.[68] Missing data is also a limitation of studies using administrative datasets.
15 Although this study excluded individuals living in permanent long-term care at index date, individuals in
16 permanent long-term care before or after their diagnosis were retained in the analysis. As persons with
17 dementia were more likely than persons without dementia to be admitted to permanent long-term care
18 after diagnosis, this may partly explain variations in service use. Also, it may be the case that service use
19 differed among individuals who did not meet the study eligibility criteria. Although sex and other
20 sociodemographic stratification may provide further insight and is warranted, such comparisons were
21 not included in this study given limited time and resources. As this study included the data of older
22 adults living in Saskatchewan, Canada, the generalizability of our results is limited.
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33 **CONCLUSION**

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37 Our study found that differences in health service usage between older adults with dementia and
38 those without dementia depended on the time of use relative to first diagnosis as well as the health
39 service in question. Overall, differences were greatest in the year before and year after diagnosis as
40 persons with dementia had more FP physician, specialist, hospital admissions, and drug prescriptions.
41 This is a critical period with multiple opportunities to implement quality supports and establish effective
42 coordinated care. Our research suggests FPs were a mainstay of care in the years leading up to and
43 following a dementia diagnosis, however, specialists were possibly underutilised in the years after
44 diagnosis. Family physicians require high quality training as well as the necessary resources and
45 community services to provide appropriate care in the pre-diagnosis period and as the disease
46 progresses. The COVID-19 pandemic recently exposed critical weaknesses in the Canadian health care
47 system, particularly for persons with dementia,[69] and these areas must be addressed to strengthen
48 the system for the future.
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Acknowledgements

This project was made possible by the support of Saskatchewan Health Quality Council leadership and staff. We are also grateful to Jagmeet Bajwa for data analysis contributions and to participants of the Annual Summit of the Knowledge Network in Rural and Remote Dementia Care for their feedback on preliminary findings.

Author Contributions

JGK, DGM, BAO, JMQ, and MO formed the research questions, designed the study, and wrote the first draft. BAO, JMQ, MO, and NI performed the analyses. All authors contributed to interpreting the data, revised the manuscript, approved the final version, and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Funding

Funding for the study was provided by a Canadian Institutes of Health Research (CIHR) Foundation Grant to DGM (grant number 148444) and the Canadian Consortium on Neurodegeneration in Aging (CCNA) which is supported by a grant from the Canadian Institutes of Health Research. Funding for CCNA Team 15 is provided by several partners including the Saskatchewan Health Research Foundation, the Alzheimer Society of Canada, and the Centre for Aging and Brain Health. BAO, JMQ, and MO were employed by the Saskatchewan Health Quality Council which contributed, in-kind, portions of their time for this project.

Competing Interests

None declared.

Patient and public involvement

Patients were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication

Not required.

Ethics approval

Ethics approval was granted by the University of Saskatchewan Biomedical Research Ethics Board (Bio 12-339).

Provenance and peer review

Not commission; externally peer reviewed.

Data sharing statement

Administrative health data were accessed for the purposes of this study by the Saskatchewan Health Quality Council under data sharing agreements with the Saskatchewan Ministry of Health and eHealth Saskatchewan. Under these agreements, record-level data are not to be shared outside of the secure data area at the Saskatchewan Health Quality Council.

Disclaimer

This study is based on de-identified data provided by the Saskatchewan Ministry of Health and eHealth Saskatchewan. The interpretation and conclusions contained herein do not necessarily represent those of the Government of Saskatchewan, the Saskatchewan Ministry of Health, or eHealth Saskatchewan.

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Figures

Figure 1. Study population selection

Figure 2. Health service utilisation among persons with dementia compared to a matched cohort of persons without dementia, pre- and post-index; A. Family physician visits; B. Specialist visits; C. Hospital admissions; D. Prescription drug dispensations; E. Short-term care admissions.

* Significantly different between persons with dementia and persons without dementia ($p < 0.05$)

Figure 3. Unadjusted mean number of health services among persons with dementia compared to a matched cohort of persons without dementia, pre- and post-index; A. Family physician visits; B. Specialist visits; C. Hospital admissions; D. Prescription drug dispensations

* Significantly different between persons with dementia and persons without dementia ($p < 0.05$)

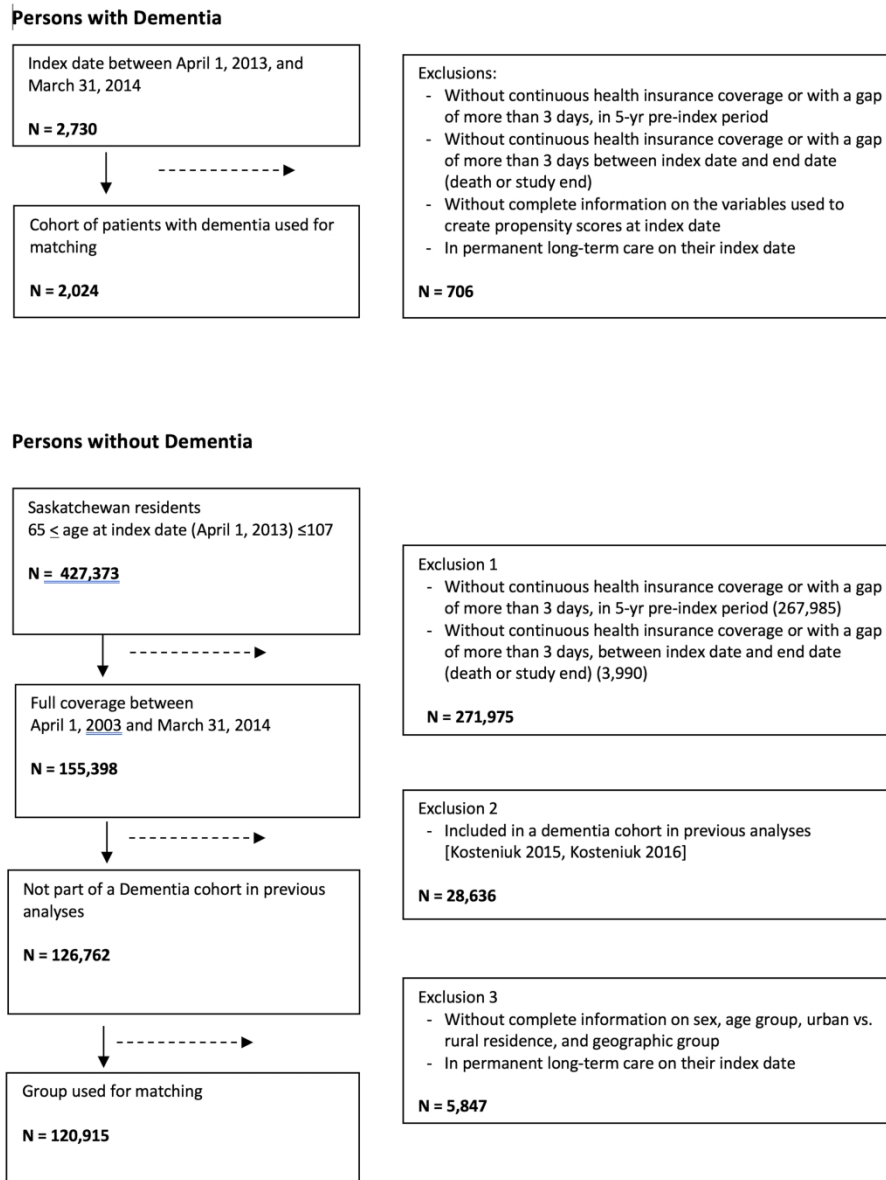


Figure 1. Study population selection

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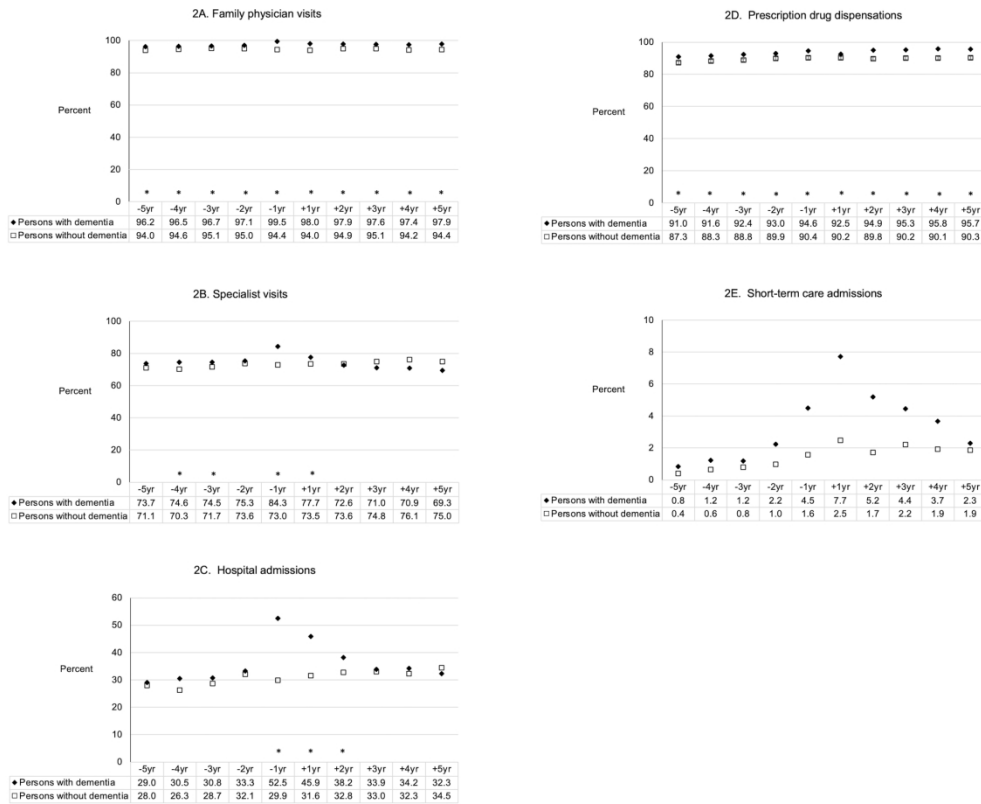


Figure 2. Health service utilisation among persons with dementia compared to a matched cohort of persons without dementia, pre- and post-index; A. Family physician visits; B. Specialist visits; C. Hospital admissions; D. Prescription drug dispensations; E. Short-term care admissions.

* Significantly different between persons with dementia and persons without dementia ($p < 0.05$)

177x143mm (300 x 300 DPI)

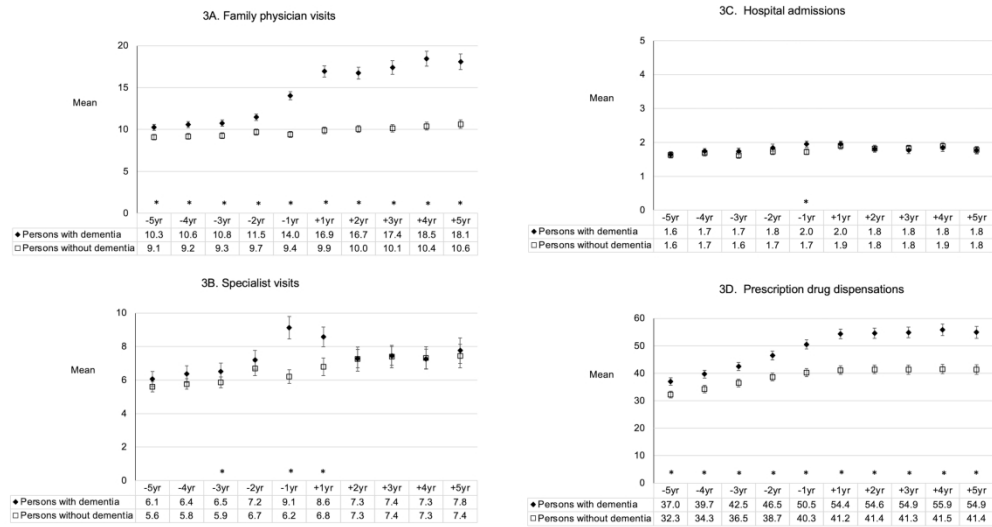


Figure 3. Unadjusted mean number of health services among persons with dementia compared to a matched cohort of persons without dementia, pre- and post-index; A. Family physician visits; B. Specialist visits; C. Hospital admissions; D. Prescription drug dispensations

* Significantly different between persons with dementia and persons without dementia ($p < 0.05$)

253x135mm (300 x 300 DPI)

Reporting checklist for case-control study.

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			Page Number
Title and abstract			
Title	#1a	Indicate the study's design with a commonly used term in the title or the abstract	Title page
Abstract	#1b	Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background / rationale	#2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	#3	State specific objectives, including any prespecified hypotheses	3-4
Methods			
Study design	#4	Present key elements of study design early in the paper	4

1	Setting	#5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
2				
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4	Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls. For matched studies, give matching criteria and the number of controls per case	4-5
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11	Eligibility criteria	#6b	For matched studies, give matching criteria and the number of controls per case	5
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15		#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5-6
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19	Data sources / measurement	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for cases and controls.	5
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26	Bias	#9	Describe any efforts to address potential sources of bias	5
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28	Study size	#10	Explain how the study size was arrived at	5
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31	Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	5
32				
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34	Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	6
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38	Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	n/a
39				
40				
41	Statistical methods	#12c	Explain how missing data were addressed	5
42				
43	Statistical methods	#12d	If applicable, explain how matching of cases and controls was addressed	6
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47	Statistical methods	#12e	Describe any sensitivity analyses	n/a
48				
49	Results			
50				
51	Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for cases and controls.	Fig 1
52				
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58	Participants	#13b	Give reasons for non-participation at each stage	Fig 1
59				
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1	Participants	#13c	Consider use of a flow diagram	Fig 1
2				
3	Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for cases and controls	7
4				
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8	Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	7
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12	Outcome data	#15	Report numbers in each exposure category, or summary measures of exposure. Give information separately for cases and controls	Fig 2 and 3
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16	Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	9-10
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21	Main results	#16b	Report category boundaries when continuous variables were categorized	n/a
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25	Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
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29	Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	n/a
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33	Discussion			
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35	Key results	#18	Summarise key results with reference to study objectives	10
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38	Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	13
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43	Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	13
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48	Generalisability	#21	Discuss the generalisability (external validity) of the study results	13
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Health service use before and after dementia diagnosis: a retrospective matched case-control study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2022-067363.R1
Article Type:	Original research
Date Submitted by the Author:	13-Oct-2022
Complete List of Authors:	Kosteniuk, Julie; University of Saskatchewan College of Medicine, Medicine Osman, Beliz; Saskatchewan Health Quality Council Osman, Meric; Saskatchewan Medical Association Quail, Jacqueline M.; Saskatchewan Health Quality Council Islam, Naorin; University of Saskatchewan O'Connell, Megan; University of Saskatchewan, Psychology Kirk, Andrew; University of Saskatchewan, Medicine Stewart, Norma J.; University of Saskatchewan College of Nursing Morgan, Debra; University of Saskatchewan College of Medicine, Medicine
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Health services research, General practice / Family practice, Neurology
Keywords:	Dementia < NEUROLOGY, GERIATRIC MEDICINE, HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PRIMARY CARE

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Health service use before and after dementia diagnosis: a retrospective matched case-control study

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Word count: 4003

ABSTRACT

Objectives

This study investigated patterns in health service usage among older adults with dementia and matched controls over a 10-year span from five years before until five years after diagnosis.

Design

Population-based retrospective matched case-control study.

Setting

Administrative health data of individuals in Saskatchewan, Canada from April 1, 2008 to March 31, 2019.

Participants

The study included 2,024 adults aged 65 years and older living in the community at the time of dementia diagnosis from April 1, 2013 to March 31, 2014, matched 1:1 to individuals without a dementia diagnosis on age group, sex, rural vs. urban residence, geographic region, and comorbidity.

Outcome measures

For each 5-yr period before and after diagnosis, we examined usage of health services each year including family physician (FP) visits, specialist visits, hospital admissions, all-type prescription drug dispensations, and short-term care admissions. We used negative binomial regression to estimate the effect of dementia on yearly average health service utilisation adjusting for sex, age group, rural vs. urban residence, geographic region, 1-yr prior health service use, and comorbidity.

Results

Adjusted findings demonstrated that 5 years before diagnosis, usage of all health services except hospitalisation was lower among persons with dementia than persons without dementia (all $p < 0.001$). After this point, differences in higher health service usage among persons with dementia compared to without dementia were greatest in the year before and year after diagnosis. In the year before diagnosis, specialist visits were 59.7% higher ($p < 0.001$) and hospitalisations 90.5% higher ($p < 0.001$). In the year after diagnosis, FP visits were 70.0% higher ($p < 0.001$) and all-type drug prescriptions 29.1% higher ($p < 0.001$).

Conclusions

Findings suggest the year before and year after diagnosis offer multiple opportunities to implement quality supports. Family physicians are integral to dementia care and require effective resources to properly serve this population.

Keywords

Dementia, Alzheimer disease, health services research, physicians, hospitals

ARTICLE SUMMARY

Strengths and limitations of this study

- A population-based matched cohort design was used to examine the usage of several health services over a substantial period of time before and after dementia diagnosis, among persons with dementia and persons without dementia.
- The use of administrative data to identify the study population may have resulted in misclassification of cases and controls.
- Group differences in health service usage after diagnosis may be due in part to differences that emerged after the matching date, such as more persons with dementia than without dementia admitted to permanent long-term care.

INTRODUCTION

Dementia is the second leading cause of death in high-income countries and the 7th leading cause of mortality globally.[1] An estimated 58 million people worldwide were living with dementia in 2020, a number that is projected to double by 2040.[2] Aging populations and longer survival after diagnosis account for increasing prevalence.[3, 4] In Canada, more than 670,000 people were estimated to be living with dementia in 2020, including 20,200 people in the province of Saskatchewan.[5, 6] The economic cost of dementia including informal care is an estimated US \$1 trillion annually worldwide.[7] Annual direct costs associated with dementia in Canada (health system costs and out of pocket caregiving expenses) are an estimated 5.5 times greater than for those without dementia and expected to increase from CAD \$12.4 billion in 2021 to \$16.6 billion by 2031.[8]

Most Canadians with dementia live outside long-term care and nursing homes (261,000 or 61%) and may require complex care due to severe cognitive impairment, dependence for activities of daily living, and responsive behaviours.[9] Effectively managing complex long-term conditions such as dementia in primary and community care settings involves addressing cognitive and physical functioning.[10] Information about patterns of health service usage in the time before and after diagnosis can assist with forecasting demand for services, allocating resources, and inform interventions to help alleviate demand. Interventions may improve access to community health and social services, such as an appointed contact person to coordinate services, flexible settings (e.g., for respite care), and health personnel training.[11]

Studies show that the usage of certain health services is greater among persons with dementia than persons without dementia. For example, people with dementia are more likely to be hospitalized [12-20] and admitted to emergency departments than people without dementia.[15, 16, 18, 19] Reports also show more frequent use of certain services among people with dementia, including family physicians [21-24] and hospital admission.[15, 18, 24, 25]

When comparing patterns in health service usage between people with and without dementia, the usage period relative to diagnosis timing is not always specified. A few studies have examined both pre- and post-diagnosis in the same analysis,[15, 22, 23] however the observation period was less than three years. Studies that include both pre- and post-diagnosis and longer timeframes have the potential to account for interactions with the health system that occur over the lengthy course of the diseases that cause dementia and neurodegeneration. The purpose of this study was to use administrative health data to examine the association between dementia and health service usage over a 10-year period from 5 years before until 5 years after an initial dementia diagnosis.

METHODS

Design and data sources

This study used a population-based retrospective matched case-control design and reporting adhered to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement.[26] Administrative health data in the Canadian province of Saskatchewan (population 1.17 million in 2019) [27] routinely capture the health system interactions of Saskatchewan residents. For this study, population-based administrative health data from April 1, 2008 to March 31, 2019 were linked using unique identifiers based on the personal health services numbers of individuals eligible for provincial public health insurance. Saskatchewan residents who hold federal health insurance (<1%) do not also hold provincial health insurance, namely Royal Canadian Mounted Police, Canadian Forces members, and inmates at federal penitentiaries.[28] However, the data of these individuals are captured in Saskatchewan administrative health data.

Linkage and data analysis were conducted at the Saskatchewan Health Quality Council. Data sources included the Medical Services Database, Hospital Discharge Abstract Database, Prescription Drug Plan Database, Person Health Registration System (demographics and geography), and Institutional Supportive Care Home Database. The Medical Services Database includes billing claims by physicians paid on a fee-for-service basis (maximum of 1 diagnosis per claim), and shadow billing by primary health sites and practitioners paid under alternate non-fee-for-service methods.[29, 30] The Hospital Discharge Abstract Database consists of hospital admission and discharge dates, diagnosis codes (up to 25 codes per abstract), and other information submitted on a mandatory basis by all provinces and territories in Canada.[31] The Prescription Drug Plan Database includes information about dispensations to all individuals regardless of the source of funding for the costs (i.e., public or private insurance, out of pocket). The Institutional Supportive Care Home database is used by special care homes (i.e., nursing or long-term care homes) to maintain records of admission, discharge, and level of care changes.[32]

Study population

Individuals aged 65 years or older were identified at their first recorded diagnosis of dementia (i.e., index date) between April 1, 2013 and March 31, 2014. Study eligibility criteria are described in Figure 1. A lookback period of five years prior to the index date was used to ensure these were incident cases. To identify the cohort, we used the Canadian Chronic Disease Surveillance System (CCDSS) algorithm for dementia [33] that has been previously validated in Ontario, Canada.[34] Recent studies drawing on population-based administrative health data have used this case definition,[24, 35, 36] as has the Public Health Agency of Canada for the purpose of estimating dementia prevalence and incidence across Canadian provinces and territories.[37] The algorithm defines dementia based on one or more hospitalisations associated with a diagnosis code for dementia [International Classification of Disease

(ICD-9-CM) codes 046.1, 290.0-290.4, 294.1, 294.2, 331.0, 331.1, 331.5, 331.82; ICD-10-CA codes F00, F01, F03, G30], three or more physician claims for dementia within two years with at least 30 days between each claim (ICD-9 codes 290, 331), or one or more prescriptions for memantine or a cholinesterase inhibitor (donepezil, galantamine, and rivastigmine). For physician claims, ICD-9 code 298 was also included in the case definition as it has been used as an alternative code in addition to 290 and 331 in Saskatchewan physician billing data since the 1970s.

For the purpose of selecting 1:1 matched controls, the index date was set as April 1, 2013. Propensity scores were estimated using a probit model [38] to determine the probability of being a case given the covariates included in the model. The covariates at index date were sex, age group (65-69, 75-74, 75-79, 80-84, and ≥ 85), rural versus urban residence (urban defined as postal code outside commuting zone of 10,000 or more population), geographic region (northern, central, or southern Saskatchewan), and Charlson Comorbidity Index (CCI) score. A CCI score for each person was calculated based on 17 clinical conditions derived from ICD-9 and ICD-10 diagnoses in the Medical Services Database and Hospital Discharge Abstract Database [39, 40] during the 1-yr period prior to each person's index date. A previous Saskatchewan study found the CCI demonstrated good predictive performance of hospital utilisation and mortality.[41] Dementia was considered one of 17 comorbidities when calculating the CCI score to truly estimate the burden of diseases on older adults.

A total of 120,915 persons without dementia were identified as potential controls (figure 1). Upon estimation of propensity scores, we used the nearest neighbour matching technique to construct the control group.[42] Individuals residing in permanent long-term care on the day of their index date, per Institutional Supportive Care Home data, were ineligible for the study. However, individuals discharged from permanent long-term care before their index date were eligible for inclusion, as were individuals admitted after their index date. Individuals eligible for this study had continuous health insurance coverage or a gap in insurance coverage not exceeding 3 days between April 1, 2008 and the end of the follow-up period (i.e., date of death or study end date of March 31, 2019). Eligible individuals were required to have complete information on all variables used to select the matched controls except for CCI information. Individuals included in dementia cohorts in previous analyses [43, 44] were ineligible to be included as controls.

Health service use

Health service use measures included family physician visits, specialist visits, hospital admissions, prescription drug dispensations, and admission to short-term institutional care (i.e., adult day programming, respite, and night care). Physicians were separated into two groups based on more than 70 categories of certified specialty,[29] namely family medicine [(family physician (FP))] and specialists

(all specialties other than family medicine). A specialist visit requires a referral from a family physician or nurse practitioner. Physician visits were included in the present study regardless of location (office, home, hospital in-patient, hospital out-patient, emergency room, and other locations). Multiple hospital admissions with less than 1-day gap between discharge and readmission were counted as one hospitalisation. Prescription drug use included all dispensations regardless of drug classification. Individuals may be admitted to institutional supportive care via one of eight streams, one of which is permanent long-term care. The other seven streams constitute short-term care and include temporary care of less than 60 days (respite, convalescence, rehabilitation, geriatric assessment, and palliative care), adult day programming (personal and nursing care, rest, exercise, social and recreational activities), and night care (relief to primary care providers and family).[45]

Statistical analysis

Propensity score matching based on probit regression and all health service use analyses were performed with SAS (version 9.3).

We calculated the proportion of older adults with at least one use of each health service during each year of the 5-yr period before the index date, and each year of the 5-yr period after the index date. Among those using a service at least once, we also calculated the annual mean number of services and 95% confidence intervals. Significant differences in the proportion of services used by the two cohorts were identified using the χ^2 test ($p < 0.05$), and significant differences in the mean number of services were established using the Wilcoxon rank sum test ($p < 0.05$). The average number of short-term care admissions was not calculated due to challenges in interpreting this information given variability in the duration of stays across the three types of admission (adult day programming, respite, and night care).

Negative binomial (NB) regression was used to estimate the impact of dementia on mean service utilisation each year of the pre-index and post-index periods. Individuals who died each post-index year were removed from the study the following year. We chose the NB model over another count data model, Poisson regression, due to the presence of overdispersion.[46] The effect of dementia was estimated as the discrete change in the expected mean value of health service utilisation (e.g., average number of hospital admissions) for a change in the dementia variable from 0 to 1. Values of $p < 0.05$ were considered statistically significant. The NB model for each health service was adjusted for sex, age group, rural vs. urban residence, geographic region, 1-yr prior health service use (physician, hospital, and drug), and CCI score. Moreover, varying time spans were adjusted by using each individual's time (number of days) in each period as an offset variable. The other variables in the model were evaluated by their mean values in expected value calculations.

Patient and public involvement

None.

RESULTS

Study criteria were met by 2,024 persons with incident dementia matched 1:1 to 2,024 persons without dementia (table 1). At index date, 75.9% of persons with dementia were aged 70 years and older, 39.6% were male, and 69.4% urban. The cohorts were similar in age, sex, rural/urban residence, number of comorbidities, and geographic region. Individuals admitted to permanent long-term care between their index date and end of the 5-yr post-index period were retained in the study, which included 38.8% of persons with dementia (n = 786) and 8.5% of persons without dementia (n = 173) (table 2). Death during the post-index period occurred in 44.6% of persons with dementia (n = 902) and 25.5% of persons without dementia (n = 516); these individuals were removed from the study each year.

Table 1. Descriptive data and mean comparison tests between a cohort of persons with dementia and a matched cohort of persons without dementia, at index date between April 1, 2013 and March 31, 2014

Characteristic	Persons with dementia (N = 2024)			Persons without dementia (N = 2024)			p value ^a
	n	% or Mean	SD	n	% or Mean	SD	
Propensity score (mean)	2024	0.024	0.0165	2024	0.024	0.0164	1.00
Age group (%)							
65-69	488	24.11	0.43	488	24.22	0.43	1.00
70-74	276	13.64	0.34	276	13.64	0.34	1.00
75-79	280	13.83	0.35	280	13.83	0.35	1.00
80-84	374	18.48	0.39	375	18.53	0.39	0.97
85+	606	29.94	0.46	605	28.89	0.46	0.97
Male sex (%)	802	39.62	0.49	801	38.58	0.49	0.97
Urban residence (%)	1407	69.42	0.46	1405	69.52	0.46	0.95
Charlson Comorbidity Index score, 1-yr prior (mean)	2024	0.77	1.35	2024	0.77	1.36	0.96
Geographic region (%)							
Northern SK	21	1.04	0.10	21	1.04	0.10	1.00
Central SK	1174	58.0	0.49	1173	58.0	0.49	0.97
Southern SK	829	41.0	0.49	830	41.0	0.49	0.97

^a Chi-square test at 5% level of significance

Table 2. Mortality and admission to permanent LTC in the post-index period

	Post-index ^a					Total n
	1-yr n (%)	2-yr n (%)	3-yr n (%)	4-yr n (%)	5-yr n (%)	
Admitted to permanent LTC ^b						
Persons with dementia	332 (42.2)	155 (19.7)	121 (15.4)	100 (12.7)	78 (9.9)	786
Persons without dementia	33 (19.1)	34 (19.7)	26 (15.0)	40 (23.1)	40 (23.1)	173
Mortality ^c						
Persons with dementia	311 (34.5)	162 (18.0)	158 (17.5)	128 (14.2)	143 (15.9)	902
Persons without dementia	114 (22.1)	102 (19.8)	93 (18.0)	109 (21.1)	98 (19.0)	516

^a Persons with dementia at index date, N=2024; Persons without dementia at index date, N=2024

^b People admitted to permanent LTC each year were retained in the study.

^c People who died each year were removed from the study the following year.

Health service use

Most persons with dementia had at least one FP visit each year and a higher proportion of this group compared to persons without dementia had a FP visit over the study period ($p<0.05$) (figure 2a). Each year, 69.3 to 84.3% of persons with dementia had at least one specialist visit. A greater proportion of persons with dementia had one or more specialist visit during most years until 1-yr post-index ($p<0.05$) (figure 2b). During the pre-index period, the specialties of psychiatry and neurology ranked 7th (5%) and 10th (3%) by visit frequency among persons with dementia, respectively (data not shown). Post-index, psychiatry and neurology ranked 2nd (13%) and 8th (5%), respectively. Among persons without dementia, neurology and psychiatry ranked consistently outside the top ten. Between 29.0 and 52.5% of persons with dementia were hospitalised at least once annually and a higher proportion compared to persons without dementia were hospitalised between 1-yr pre-index and 2-yr post-index ($p<0.05$) (figure 2c). At least one prescription drug of any type was dispensed annually to 91.0 to 95.8% of persons with dementia and each year this group was more likely than persons without dementia to receive any type of drug ($p<0.05$) (figure 2d). The proportion of older adults with dementia who used short-term institutional care at least once ranged from 0.8% to 7.7% annually and was highest at 1-yr post-index (figure 2e).

The unadjusted mean number of FP and specialist visits by persons with dementia increased over the pre-index period, with the greatest increases at 1-yr pre-index (figure 3a and 3b). After this point, FP visits continued to increase over the post-index period until 4-yr and specialist visits decreased. Each year, hospital admissions ranged between 1.6 and 2.0 visits, peaking one year before and after diagnosis (figure 3c), and annual all-type drug prescriptions increased until 4-yr post-index (figure 3d).

Regression models for the association between dementia and mean service utilisation each year were adjusted for sex, age group, rural vs. urban residence, geographic region, 1-yr prior health service use (physician, hospital, and drug), and CCI score (tables 3 and 4). At 5-yr pre-index, usage of all health services except hospitalisation was lower among persons with dementia than persons without dementia (all $p < 0.001$). After 5-yr pre-index, the pattern changed: FP visits ($p < 0.001$) and all-type drug prescriptions ($p = 0.031$ to $p < 0.001$) were higher among persons with dementia until the end of the 10-yr period, specialist visits were higher from 1-yr pre-index until 1-yr post-index and lower between 2-yr and 5-yr post-index ($p < 0.001$), and hospitalisations were higher from 1-yr pre-index until 1-yr post-index ($p < 0.001$) but demonstrated no significant difference for the majority of the study period. After 5-yr pre-index, differences in specialist visits and hospitalisations between persons with and without dementia were greatest at 1-yr pre-index, and differences in FP visits and all-type drug prescriptions were greatest at 1-yr post-index (all $p < 0.001$).

Table 3. Adjusted^a pre-index differences in the mean number of health services used by persons with dementia and a matched cohort of persons without dementia

Health Service	Pre-index (N = 4038)				
	5-yr	4-yr	3-yr	2-yr	1-yr
Family Physician visits					
Adjusted difference	-1.14	0.69	0.69	1.00	4.07
% difference	-12.3	8.5	8.5	11.7	49.3
<i>p</i> value	<0.001	<0.001	<0.001	<0.001	<0.001
Specialist visits					
Adjusted difference	-0.70	0.10	0.06	-0.23	2.43
% difference	-16.5	2.7	1.6	-4.9	59.7
<i>p</i> value	<0.001	0.503	0.684	0.203	<0.001
Hospital admissions					
Adjusted difference	-0.04	0.06	0.04	0.02	0.43
% difference	-8.3	13.8	8.2	3.3	90.5
<i>p</i> value	0.224	0.035	0.188	0.573	<0.001
Prescription drug dispensations					
Adjusted difference	-9.66	1.40	1.64	1.92	3.99
% difference	-32.3	6.0	6.5	7.0	13.6
<i>p</i> value	<0.001	0.009	0.003	0.002	<0.001

^a Adjusted for sex, age group, rural vs. urban residence, geographic region, 1-yr prior health service use (physician, hospital, and prescription drug), and comorbidity score.

Table 4. Adjusted^a post-index differences in the mean number of health services used by persons with dementia and a matched cohort of persons without dementia

Health Service	Post-index ^b				
	1-yr N = 4038	2-yr N = 3614	3-yr N = 3350	4-yr N = 3099	5-yr N = 2862
Family Physician visits					
Adjusted difference	6.42	2.41	3.71	3.26	2.77
% difference	70.0	23.9	38.5	32.2	27.0
p value	<0.001	<0.001	<0.001	<0.001	<0.001
Specialist visits					
Adjusted difference	1.11	-1.23	-0.88	-1.23	-1.18
% difference	23.1	-22.0	-16.2	-22.3	-21.0
p value	<0.001	<0.001	<0.001	<0.001	<0.001
Hospital admissions					
Adjusted difference	0.22	-0.07	-0.05	-0.06	-0.11
% difference	37.7	-10.5	-8.5	-10.5	-18.0
p value	<0.001	0.082	0.117	0.120	0.01
Prescription drug dispensations					
Adjusted difference	8.88	1.65	3.99	2.91	3.05
% difference	29.1	5.0	12.4	8.9	9.0
p value	<0.001	0.031	<0.001	<0.001	<0.001

^a Adjusted for sex, age group, rural vs. urban residence, geographic region, 1-yr prior health service use (physician, hospital, and prescription drug), and comorbidity score.

^b People who died each year were removed from the study the following year.

DISCUSSION

This retrospective study examined patterns in the use of health services among older adults with dementia and matched controls across a 10-year span that included five-year periods before and after first diagnosis of dementia in 2013/2014. Compared to persons without dementia, a higher proportion of persons with dementia experienced at least one FP visit and received at least one all-type drug prescription annually. A higher proportion of persons with dementia also had at least one specialist visit annually during most the pre-diagnosis period until one year after diagnosis, and were hospitalized at least once annually between one year before and two years after diagnosis. In adjusted models, usage of all services except hospitalisation was lower at 5-yr pre-diagnosis among persons with dementia than persons without dementia. However, within one year the pattern changed. After 5-yr pre-diagnosis, differences in usage were greatest in the year before diagnosis for specialist visits and hospitalisations, and in the year after diagnosis for FP visits and all-type drug prescriptions, with higher usage among persons with dementia.

The pattern of an increasing number of FP visits leading up to diagnosis found in this study is consistent with the results of previous reports that had similarly lengthy pre-diagnosis periods of three years [23] and five years.[21] These studies found a lower average number of visits each year, namely 4-

7 [21] and 6-11 [23] compared to our research (10.3-18.5 visits). Canada has a higher rate of physician consultations per capita than other Commonwealth countries,[47] which may partly explain the higher average in our study. Similar to our findings, previous case-control studies reported more primary care visits among persons with than without dementia in the years leading up to diagnosis and in the year following diagnosis,[22, 23] with particularly large differences 6-12 months before [21, 23] and after diagnosis.[22, 23] More frequent FP visits before diagnosis can reflect a protracted diagnostic process with multiple visits and delays over time,[48, 49] involving an increase in help-seeking as the ability to self-manage declining health and chronic conditions decreases,[50] dementia-related symptoms such as falls increase,[51] and caregiver stress escalates. A pattern of elevated FP visits after diagnosis reflects the central role of FPs in managing the care of older adults with dementia [52] and suggests a need to further support FPs and other primary health care professionals in providing high-quality ongoing post-diagnostic management.[9, 53]

In terms of specialist visits, the higher number among persons with dementia in the year prior to diagnosis suggests demand for specialist involvement in relation to symptoms of undiagnosed dementia. A similar finding with regard to neurologist and psychiatrist visits was reported in a study using German health insurance data.[22] We also found a higher number of specialist visits among persons with dementia in the year immediately after diagnosis, although the difference was not as great as seen in Chung et al.[54] who reported an 8-fold higher number of psychiatrist visits among persons with dementia in a study of Taiwan health insurants. We considered all specialties rather than subspecialties such as psychiatry, which may partly account for this smaller difference. We also found that apart from the time immediately before and after diagnosis, the number of specialist visits was lower or no different among the two groups. This suggests specialists are consulted to a lesser extent than FPs when seeking a diagnosis and post-diagnostic support. In Saskatchewan, the specialist-to-population ratio is lower than the national average (87 vs. 113 per 100,000),[55] as is the ratio of dementia specialists including psychiatrists, neurologists, and geriatricians (0.1 to 7 vs. 0.8 to 13 per 100,000).[56] It is possible that persons with dementia are less likely than those without dementia to request or receive a specialist referral from their primary care provider, or to follow up on a specialist referral. In the years following a dementia diagnosis, there may be greater challenges accessing specialists who practice mainly in the two major cities of Saskatchewan, and a shift in care responsibility to FPs particularly for less complex cases and persons in permanent long-term care.

Hospitalisation at least once in the year before diagnosis was more likely among persons with dementia than without dementia (52.5% vs. 29.9%). Chen et al.[23] also found persons with dementia were more likely to be hospitalized during this timeframe, however compared to our study the reported proportions were lower (24% AD vs 19% non-AD). The higher proportions in our study may be partly

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3 explained by our inclusion of all dementia subtypes, as there is evidence of higher use of inpatient
4 services before diagnosis among persons with vascular dementia and non-specific dementia compared
5 to AD and other subtypes.[57] Our findings may also suggest undiagnosed and therefore improperly
6 managed symptoms of dementia, inappropriate medication management, or mismanagement of
7 chronic conditions.[14, 58] Similar to other reports, we also found cohort differences in the proportion
8 hospitalised at least once in the first year after diagnosis [15, 23, 59] and two years after diagnosis.[15]
9 The adjusted number of hospitalisations was also higher one year before and one year after diagnosis in
10 persons with dementia, in line with a US study of Medicare beneficiaries.[20] These findings may imply
11 challenges in the short-term following diagnosis, possibly related to learning to manage a greater
12 number of prescriptions, inadequate management of comorbidities,[60, 61] and difficulties
13 communicating symptoms.[62] Later in post-diagnosis, the number of hospitalisations did not vary
14 between the two groups for the most part, possibly reflecting the admission of a large share to
15 permanent long-term care where conditions were managed on-site.[63]

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Approximately nine in ten older adults received at least one all-type drug prescription each year, in line with 81% of older adults (with and without prevalent dementia) reported in a previous Swedish study.[64] Our findings show that across the majority of the study period, the adjusted number of all-type drug prescriptions was higher in persons with dementia compared to without dementia. A recent review noted mixed results in studies comparing the two groups, with an equal number of studies reporting a lower average number as well as a higher average number of medications in persons with prevalent dementia.[65]

Less than 8% of older adults with dementia were observed to use short-term institutional care annually. Previous studies show that day programs are generally underutilized among persons with dementia.[66-68] Caregivers may lack knowledge of short-term care options, or the options may be limited particularly in rural communities in Saskatchewan.[69] Moreover, low use may be related to low perceived need,[68] feelings of guilt and loneliness in caregivers,[70] and negative perceptions of care programs held by both caregivers and care recipients.[67, 68].

Future longitudinal investigations could yield further insight into service use variations by considering the causes of use, appropriateness and quality of services, and perceptions and preferences for health services among persons with dementia and their families. Future research should explore how patterns of post-diagnostic service use might be altered, for example by earlier detection of the diseases that cause dementia. Inequities in health care use before and after dementia diagnosis should be identified and addressed in further research, for instance in relation to age, sex, dementia subtypes, and location of individuals (i.e., rural or urban; community or long-term care).

Strengths and limitations

The strengths of this study include using a population-based matched cohort design and a lengthy pre- and post-diagnosis observation period relative to comparable studies. As with such studies that use administrative health data, it is possible that case identification via diagnosis codes and drug prescription data resulted in misclassification.[71] It should be noted that income was not one of the five matched factors as individual-level income was not available in the administrative health data; it is possible that differences in health service use were partly due to income differences. Although this study excluded individuals living in permanent long-term care on the day of their index date, individuals living in permanent long-term care before or after this point were retained in the analysis. As persons with dementia were more likely than persons without dementia to be admitted to permanent long-term care after diagnosis, this may partly explain variations in service use. Also, it may be the case that service use differed among individuals who did not meet the study eligibility criteria. Sex and other sociodemographic stratification may provide further insight and is warranted, however such comparisons were not included in this study given limited time and resources. As this study included the data of older adults living in Saskatchewan, Canada, the generalizability of our results is limited.

CONCLUSION

Our study found that differences in health service usage between older adults with dementia and those without dementia depended on the time of use relative to first diagnosis as well as the health service in question. Overall, differences were greatest in the year before and year after diagnosis as persons with dementia had more FP physician, specialist, hospital admissions, and drug prescriptions. This is a critical period with multiple opportunities to implement quality supports and establish effective coordinated care. Our research suggests FPs were a mainstay of care in the years leading up to and following a dementia diagnosis, however, specialists were possibly underutilised in the years after diagnosis. Family physicians require high quality training as well as the necessary resources and community services to provide appropriate care in the pre-diagnosis period and as the disease progresses. The COVID-19 pandemic recently exposed critical weaknesses in the Canadian health care system, particularly for persons with dementia,[72] and these areas must be addressed to strengthen the system for the future.

Acknowledgements

This project was made possible by the support of Saskatchewan Health Quality Council leadership and staff. We are also grateful to Jagmeet Bajwa for data analysis contributions and to participants of the

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3 Annual Summit of the Knowledge Network in Rural and Remote Dementia Care for their feedback on
4 preliminary findings.
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8 **Contributors**

9 JGK, BAO, MO, JMQ, and DGM formed the research questions, designed the study, and wrote the first
10 draft. BAO, JMQ, MO, and NI performed the analyses. JGK, BAO, MO, JMQ, NI, MEO, AK, NJS, and DGM
11 contributed to interpreting the data, revised the manuscript, approved the final version, and agree to be
12 accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of
13 any part of the work are appropriately investigated and resolved.
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18 **Funding**

19 Funding for the study was provided by a Canadian Institutes of Health Research (CIHR) Foundation Grant
20 to DGM (grant number 148444) and the Canadian Consortium on Neurodegeneration in Aging (CCNA)
21 which is supported by a grant from the Canadian Institutes of Health Research. Funding for CCNA Team
22 15 is provided by several partners including the Saskatchewan Health Research Foundation, the
23 Alzheimer Society of Canada, and the Centre for Aging and Brain Health. BAO, JMQ, and MO were
24 employed by the Saskatchewan Health Quality Council which contributed, in-kind, portions of their time
25 for this project.
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33 **Competing interests**

34 None declared.
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38 **Patient consent for publication**

39 Not applicable.
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42 **Ethics approval**

43 Ethics approval was granted by the University of Saskatchewan Biomedical Research Ethics Board (Bio
44 12-339).
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48 **Provenance and peer review**

49 Not commission; externally peer reviewed.
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53 **Data availability statement**

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Administrative health data were accessed for the purposes of this study by the Saskatchewan Health Quality Council under data sharing agreements with the Saskatchewan Ministry of Health and eHealth Saskatchewan. Under these agreements, record-level data are not to be shared outside of the secure data area at the Saskatchewan Health Quality Council.

Disclaimer

This study is based on de-identified data provided by the Saskatchewan Ministry of Health and eHealth Saskatchewan. The interpretation and conclusions contained herein do not necessarily represent those of the Government of Saskatchewan, the Saskatchewan Ministry of Health, or eHealth Saskatchewan.

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Figure titles and legends

Figure 1. Study population selection

Figure 2. Health service utilisation among persons with dementia compared to a matched cohort of persons without dementia, pre- and post-index

A. Family physician visits; B. Specialist visits; C. Hospital admissions; D. Prescription drug dispensations; E. Short-term care admissions. *Significantly different between persons with dementia and persons without dementia ($p < 0.05$).

Figure 3. Unadjusted mean number of health services among persons with dementia compared to a matched cohort of persons without dementia, pre- and post-index

A. Family physician visits; B. Specialist visits; C. Hospital admissions; D. Prescription drug dispensations. *Significantly different between persons with dementia and persons without dementia ($p < 0.05$).

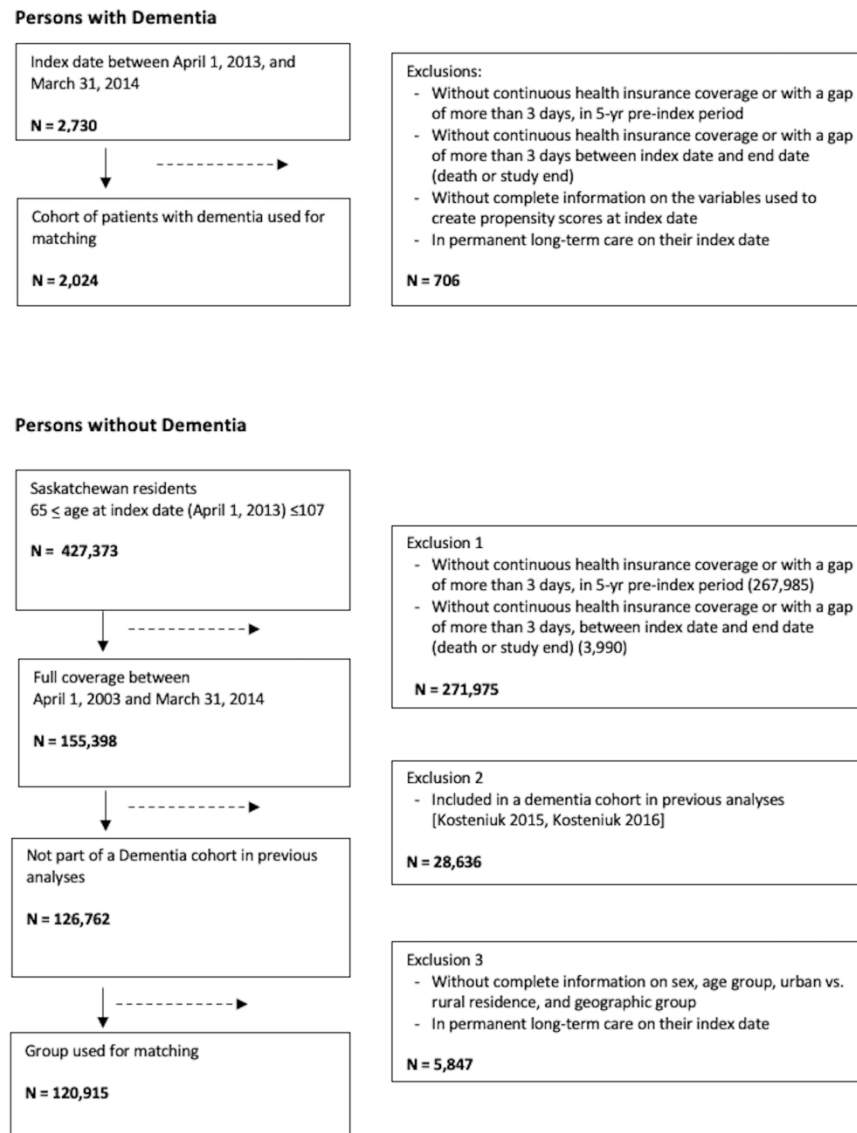


Figure 1. Study population selection

245x311mm (300 x 300 DPI)

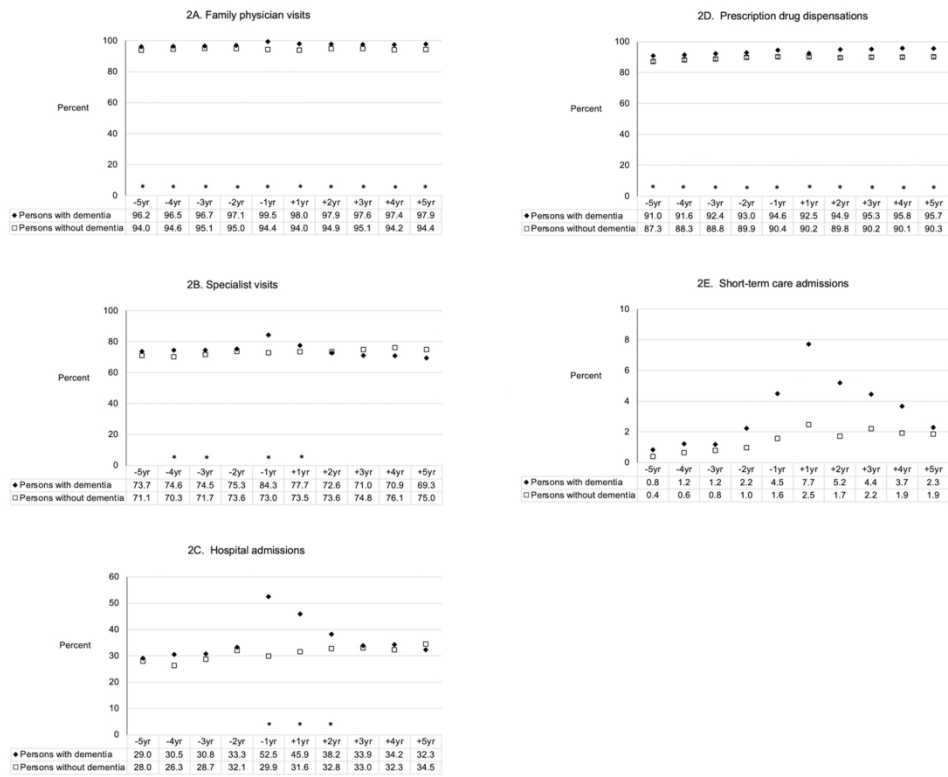


Figure 2. Health service utilisation among persons with dementia compared to a matched cohort of persons without dementia, pre- and post-index; A. Family physician visits; B. Specialist visits; C. Hospital admissions; D. Prescription drug dispensations; E. Short-term care admissions.

* Significantly different between persons with dementia and persons without dementia (p<0.05)

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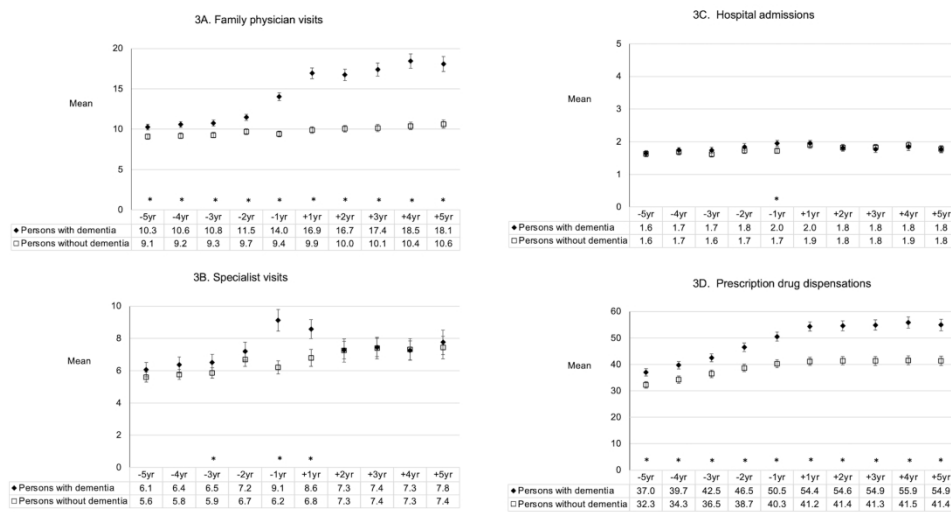


Figure 3. Unadjusted mean number of health services among persons with dementia compared to a matched cohort of persons without dementia, pre- and post-index; A. Family physician visits; B. Specialist visits; C. Hospital admissions; D. Prescription drug dispensations

* Significantly different between persons with dementia and persons without dementia ($p < 0.05$)

673x368mm (300 x 300 DPI)

Reporting checklist for case-control study.

Based on the STROBE case-control guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE case-control reporting guidelines, and cite them as:

von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies.

			Page Number
Title and abstract			
Title	#1a	Indicate the study's design with a commonly used term in the title or the abstract	Title page
Abstract	#1b	Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background / rationale	#2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	#3	State specific objectives, including any prespecified hypotheses	3-4
Methods			
Study design	#4	Present key elements of study design early in the paper	4

1	Setting	#5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
2				
3				
4	Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls. For matched studies, give matching criteria and the number of controls per case	4-5
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11	Eligibility criteria	#6b	For matched studies, give matching criteria and the number of controls per case	5
12				
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15		#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5-6
16				
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19	Data sources / measurement	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for cases and controls.	5
20				
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26	Bias	#9	Describe any efforts to address potential sources of bias	5
27				
28	Study size	#10	Explain how the study size was arrived at	5
29				
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31	Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	5
32				
33				
34	Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	6
35				
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38	Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	n/a
39				
40				
41	Statistical methods	#12c	Explain how missing data were addressed	5
42				
43	Statistical methods	#12d	If applicable, explain how matching of cases and controls was addressed	6
44				
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47	Statistical methods	#12e	Describe any sensitivity analyses	n/a
48				
49	Results			
50				
51	Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for cases and controls.	Fig 1
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58	Participants	#13b	Give reasons for non-participation at each stage	Fig 1
59				
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1	Participants	#13c	Consider use of a flow diagram	Fig 1
2				
3	Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for cases and controls	7
4				
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8	Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	7
9				
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12	Outcome data	#15	Report numbers in each exposure category, or summary measures of exposure. Give information separately for cases and controls	Fig 2 and 3
13				
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16	Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	9-10
17				
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21	Main results	#16b	Report category boundaries when continuous variables were categorized	n/a
22				
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25	Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
26				
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29	Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	n/a
30				
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33	Discussion			
34				
35	Key results	#18	Summarise key results with reference to study objectives	10
36				
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38	Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	13
39				
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43	Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	13
44				
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48	Generalisability	#21	Discuss the generalisability (external validity) of the study results	13
49				
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51	Other			
52	Information			
53				
54	Funding	#22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	14
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