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Epidemiological evolution and healthcare services utilization in elderly dementia patients of Catalonia

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Abstract

Background Assessing the dynamics and burden of dementia is necessary to improve healthcare plans. This study aimed to describe the epidemiology and characteristics of dementia diagnoses in Catalonia (North-East of Spain) and evaluate healthcare services utilization and associated expenditures in people with dementia compared with people without.

Methods Retrospective study including all the dementia population (2013–2020) using data from an administrative database, the Catalan Health Surveillance System, covering a 7.5–7.7-million population. Data included demographic, clinical, healthcare services utilization, and morbidity-associated risk variables, and was analyzed according to dementia type, including Alzheimer's disease (AD), vascular dementia (VD), frontotemporal dementia (FTD), dementia with Lewy bodies (LBD), and unspecified dementia (UD). We compared comorbidities and morbidity-associated risk, healthcare services utilization and associated expenditures, and mortality rates between people with dementia and the population without dementia adjusted for age, sex, and income level.

Results During the study period, dementia prevalence remained stable, and incidence modestly decreased. AD and VD incidence rates decreased, whereas UD modestly increased, being the highest in 2019. Patients with dementia had a higher prevalence of comorbidities, morbidity-associated risk, healthcare services utilization, specially admissions in nursing homes and intermediate care, healthcare-associated expenditures, and mortality than people without dementia adjusted by age, sex, and income level in 2019. An expenditure €1311.7 per person per year was attributable to dementia, representing an increase of 44.1% of total healthcare costs. Compared to other dementia types, AD and VD had increased admissions, and VD had the highest expenditures. The use of antidepressants and benzodiazepines progressively decreased.

Conclusions Using a population dataset, this study showed that dementia is associated with a high burden and healthcare needs, providing useful information to design improved healthcare plans.

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Keywords Dementia, Cognitive impairment, Healthcare services utilization, Dementia expenditures, Mortality, Epidemiology, Prevalence, Incidence

Background

Dementia is a syndromic disorder affecting 5% of the population over 65 years worldwide and it is projected to increase from 50.2 million in 2019 to 75 and 132 million in 2030 and 2050, respectively [1]. The risk of dementia progressively increases with age, resulting in a higher prevalence among older people [2]. In Catalonia (North-East of Spain), with 7.7 million inhabitants in 2020, 18.96% is currently ≥ 65 years and 3.2% is ≥ 85 years [3]. These proportions are projected to increase to 22.3% and 3.7% in 2030, and to 29.83% and 8% in 2060, respectively [4]. Consequently, owing to populations' aging resulting from longer life expectancies and demographic changes, the absolute and relative numbers of people with dementia are projected to increase, similar to other high-income countries [5].

Dementia is characterized by impaired memory, cognitive abilities, and behavior and it is classified into several subtypes, the most known being Alzheimer's disease (AD), dementia with Lewy bodies (LBD), frontotemporal dementia (FTD), vascular dementia (VD), and mixed dementia [1, 6]. The impact of dementia symptoms on patients' daily functioning leads to disability and dependency, raising the need for assistance to carry out their daily activities [1, 2]. Hence, besides direct medical care, dementia patients require home (formal and informal), nursing, and community care to meet their needs and those unable to live independently, residential care, generating a significant burden to health and social care systems. In addition, long-term care of older people with dementia impacts the daily lives of caregivers at the practical and psychological level, resulting in additional expenses incurred by patients' relatives [1]. The overall burden of dementia is expected to increase worldwide with the progressive absolute and relative increase in people with dementia, reaching overwhelming figures for long-term health and social care systems [5, 7].

In this scenario, international organizations and administrations have developed different initiatives to meet the care demands of patients with dementia and other chronic conditions [1, 8]. The "Pla director sociosanitari" (Sociosanitary master plan) of the Health Department of the Government of Catalonia determines the guidelines for encouraging, planning, and coordinating actions in the areas of care for people with dementia, among others [9]. The most recent strategies included a new Catalan plan for dementias, aiming to improve early diagnosis and healthcare for people with dementia and their caregivers [10].

Information regarding the epidemiology and characteristics of the population with dementia in the Catalan setting is limited [11–14]. Likewise, to our knowledge, international reports using population datasets to analyze health and social plans are also scarce. Furthermore, dementia is considered a global epidemic and should be a public healthcare priority with investments in research and healthcare plans. In this context, assessing the dynamics of the burden of dementia is important to evaluate existing plans and design improved health and social interventions [14–18]. This study aimed to perform a cross-sectional analysis of healthcare services utilization in 2019 among all elderly persons diagnosed with dementia in Catalonia, using the Catalan Health Surveillance System (CHSS) data. In addition, this eight-year (2013–2020) retrospective study also described the characteristics of the dementia population, as well as the evolution of incidence, prevalence and mortality, in order to better contextualize and interpret the results for the principal objective.

Methods

Study design, population, and data source

This was an observational, retrospective study based on data obtained from an administrative database, the Catalan Health Surveillance System (CHSS), which contains information on morbidity and healthcare-related services utilization within the Catalan Health Service (CatSalut). All patients aged ≥ 65 diagnosed with dementia in Catalonia between January 2013 and December 2020 were included. Point prevalence and incidence were used as frequency measures to analyze the evolution of dementia throughout this period. Incident cases were defined as newly diagnosed dementia individuals. Prevalent cases were defined as individuals with a previous dementia diagnosis, alive and living in Catalonia. For comorbidities, healthcare services utilization, and expenditure, a cross-sectional analysis of data from 2019 was performed using period prevalence. 2019 data was used to avoid a possible effect of the COVID-19 pandemic. CHSS provides free healthcare services in Catalonia (7.7 million in 2020). The CHSS registry collects data from numerous sources within the public system, such as hospitalization, primary care, mental and intermediate care centers, prescription drug expenditure, and visits to different types of healthcare services, and has been used in previous epidemiology, morbidity, and resources utilization studies [19, 20]. The RECORD reporting guideline for observational studies based on routinely-collected health data was applied whenever possible [21]. Patient informed consent

was not required as only pseudonymized data were extracted, precluding identification. The ethics principles of the Helsinki Declaration, the local Personal Data Protection Law (LOPD 3/2018) and the General Data Protection Regulation (EU) were observed, and the Research Ethics Committee of the University of Vic/Central University of Catalonia (UVIC-UCC) approved the study (reference number 183/2021).

Variables

Sociodemographic variables considered were age, sex, and income level, and are detailed in the Supplementary materials file. Clinical variables for dementia and comorbidities were identified through diagnostic coding according to the International Classification of Diseases, ninth revision, Clinical Modification (CDC, ICD-9-CM) [22, 23]. Dementia diagnoses were classified as AD, VD, FTD, LBD, and unspecified dementia (UD) (Table S1). The International Classification of Diseases, Ninth Revision (ICD-9) codes have been assessed for accuracy in measuring multimorbidity in administrative data with moderate-to-high accuracies and validation for most of the diagnostic codes assessed [24]. Date of dementia diagnosis and death were collected; death was established considering all patients with a recorded date of death as deceased. Along with single identifiable pathologies, the identification of patients with chronic conditions and complex needs (chronic complex patients, CCPs) and those with advanced chronic conditions (advanced chronic patients, ACPs) were also considered [20]. The comorbidity burden was classified based on the Adjusted Morbidity Groups (GMA) methodology, which considers the type of disease (acute or chronic), the number of systems affected, and complexity of each disease to stratify patients' risk according to their morbidity burden [25–27]. The criteria for stratification according to GMA risk is summarized in the Supplementary materials file.

This analysis included the following variables: healthcare services utilization and expenditure in primary care, outpatient care, day hospital, hospitalization, acute care hospitalization, emergency department, intermediate care, long-term care, nursing home and post-acute care, outpatient mental health care, psychiatric hospitalization, other healthcare services, and drug prescription per patient. These variables are described in detail in the Supplementary materials file.

Statistical methods

Categorical variables were presented as frequencies and percentages, and continuous variables as the mean and standard deviation (SD). Incidence and prevalence rates were expressed per 1000 inhabitants and mortality rates per 100 for each year of the study period. The utilization of healthcare services and associated expenditure of

patients diagnosed with dementia were compared with the population without dementia using an indirect standardization adjusted for age, sex, and income level [28]. Missing data was not expected, as all sociodemographic variables were complete and the absence of codes for outcomes was considered as absence of outcomes. Differences between dementia subtypes were analyzed using the chi-squared test for categorical variables and the Student's t-test for continuous variables. The non-parametric Mann-Whitney test was used to analyze expenditure-related variables. The threshold for statistical significance was set at a 2-sided α -value of 0.05, and all analyses were performed using the R software package (version 4.0.3.).

Data access, linkage method and patient selection

Full access was granted to CHSS and its different data sources. Person-level linkage across these data sources was performed using the *personal identification code*, which is an unequivocal code assigned to each person insured in the public healthcare system. The flow chart of patient selection is presented in Figure S1.

Results

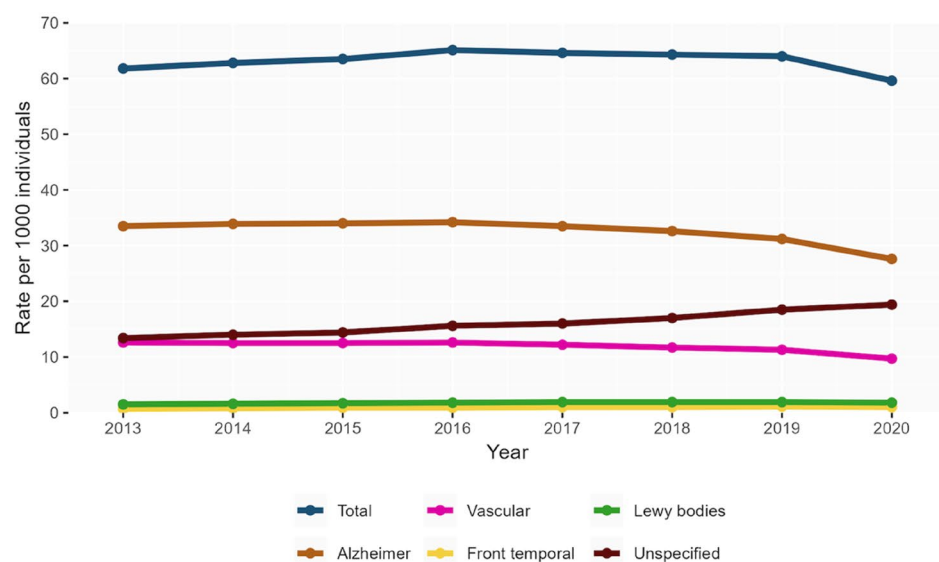
Evolution of prevalence and incidence rates of dementia diagnoses (2013–2020)

During the study period, the retrospective record included 160 553 incident dementia cases. Figure 1 shows the evolution of prevalence and incidence rates globally and for each dementia subtype from 2013 to 2020. Prevalence rates remained stable until 2019, with a slight decline in AD and VD, which became more apparent in 2020. The most prevalent type was AD, with 33.5 to 31.2 cases per 1000 inhabitants from 2013 to 2019, and a 3.6 decrease in 2020, followed by UD, which showed a slight but steady increase throughout the whole period, from 13.4 to 19.4. FTD and LBD were the least frequently diagnosed types, remaining under two cases per 1000 inhabitants. Global incidence rates declined more pronouncedly than prevalence rates, with 15.3 cases per 1000 inhabitants in 2017 to 12.4 in 2020. AD decreased from 5.9 cases per 1000 in 2017 to 3.6 in 2020, while UD showed a mild increase throughout the whole period, from 5.0 per 1000 in 2013 to 6.0 in 2020. Mean age at diagnosis was higher in women and remained stable with minimal fluctuations in the different dementia subtypes, except for FTD and LBD, which increased in 2020 (Fig. 2).

Demographic and clinical characteristics of patients with dementia (2019)

In 2019, 93 669 prevalent cases (measured using point prevalence) with some type of dementia diagnosis were identified in the Catalan public healthcare system, of which 29 104 (31.1%) were men and 64 565 (68.9%) were women. Mean age and the distribution of comorbidities

A) Prevalence



B) Incidence

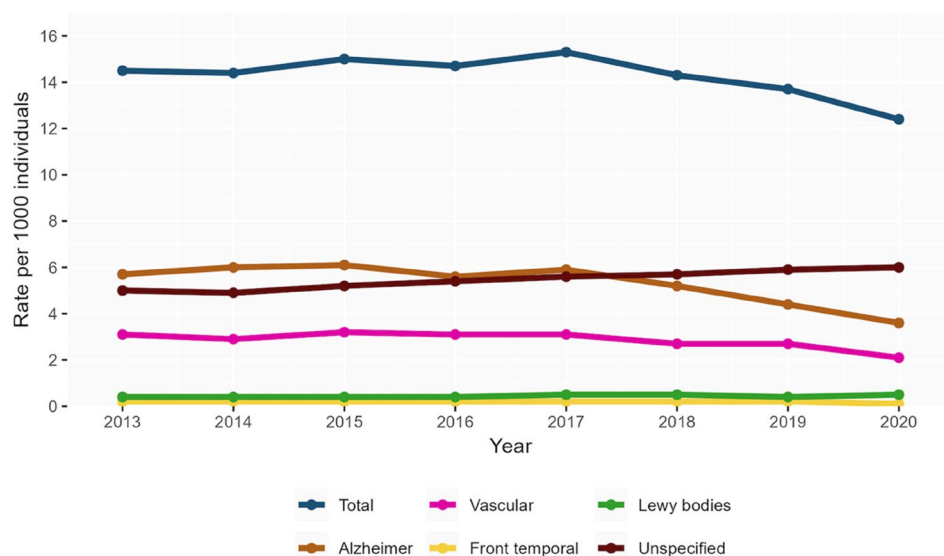


Fig. 1 Evolution of prevalence (A) and incidence (B) rates of dementia in Catalonia according to type of diagnosis (2013–2020) A)

of cases significantly differed according to dementia subtype, although differences were generally small (Table 1). Patients with FTD and LBD were younger than those with other dementia types. Different comorbidities were highly prevalent among patients with dementia, especially arterial hypertension (81.0%) and hyperlipidemia (57.0%). Among all dementia subtypes, VD patients showed the highest prevalence for diabetes mellitus (42.9%), chronic kidney disease (40.2%), complex chronicity (44.9%), stroke (59.0%), and heart failure (35.7%) (Table 2). Comparison with the population without

dementia adjusted by sex, age, and income level showed more patients with complex chronicity (36.9%), stroke (32.2%), and atypical psychosis (7.6%) among patients with dementia. Regarding the morbidity risk, 51.0% of patients with dementia were considered at high risk, while 32.0% of people without dementia adjusted by age, sex, and income level were considered at high risk. As for the different dementia subtypes, the proportion of patients at high risk was higher in those with VD (68.0%), followed by LBD (62.0%) (Figure S2).

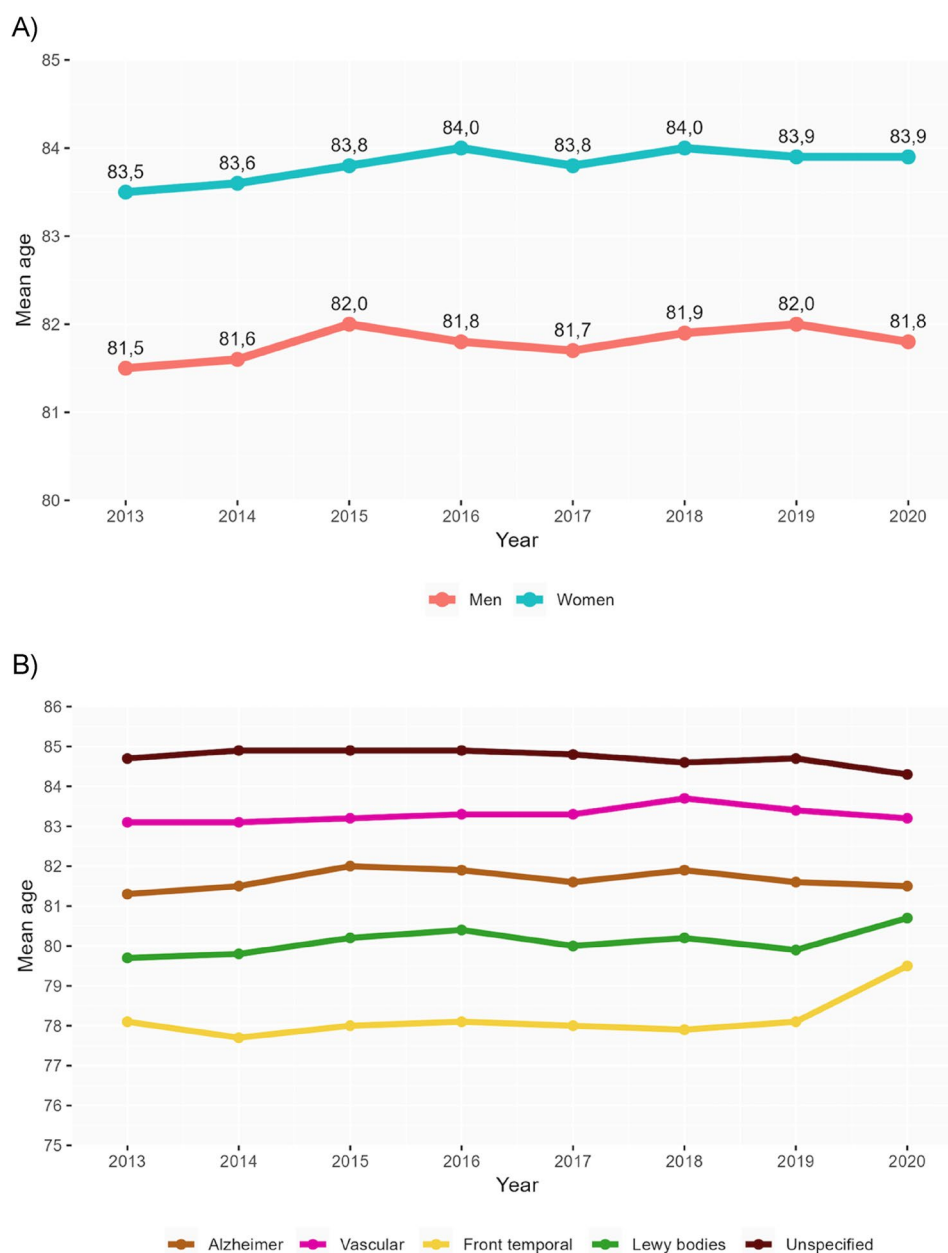


Fig. 2 Evolution of mean age of incident cases of dementia in Catalonia according to sex (A) and type of diagnosis (B) (2013–2020)

Table 1 Global mean age and according to sex of prevalent and incident cases of the most important types of diagnoses for dementia in Catalonia (2019)

	Global	Alzheimer	Vascular	Frontotemporal	Lewy Bodies	Unspecified	P-value ^a
Prevalent cases (years), mean (SD)	93,669	45,681	16,578	1567	2765	27,078	
Overall	84.3 (6.78)	84.2 (6.39)	84.7 (6.64)	80.4 (6.99)	82.1 (6.33)	84.7 (7.38)	< 0.001
Men	84.3 (6.81)	84.1 (6.37)	84.8 (6.75)	80.5 (7.01)	82.0 (6.51)	84.8 (7.42)	< 0.001
Women	84.3 (6.78)	84.2 (6.40)	84.7 (6.63)	80.3 (6.90)	82.1 (6.34)	84.7 (7.38)	< 0.001
Incident cases (years), mean (SD)	19,998	6454	4000	292	597	8655	
Overall	82.4 (7.24)	81.2 (6.66)	82.7 (6.90)	77.8 (7.43)	79.4 (6.53)	83.8 (7.58)	< 0.001
Men	82.4 (7.31)	81.2 (6.62)	82.4 (7.19)	77.6 (7.76)	79.1 (6.56)	83.8 (7.63)	< 0.001
Women	82.4 (7.25)	81.1 (6.69)	82.8 (6.87)	77.8 (7.31)	79.3 (6.54)	83.7 (7.60)	< 0.001

^aAnalysis of variance

Table 2 Main comorbidities in patients diagnosed with and without dementia in Catalonia adjusted by sex, age and income level, and according to type of dementia (2019)

	Alzheimer	Vascular	Frontotemporal	Lewy Bodie	Unspecified	P-value ^a	Total Dementia	No dementia ^b	P-value ^c
Comorbidities, n (%)	53,218	20,813	1779	3357	33,046		112,213	1,369,997	
Arterial hypertension	41,376 (77.7)	18,351 (88.2)	1367 (76.8)	2693 (80.2)	27,049 (81.9)	< 0.001	90,836 (81.0)	81.3	0.021
Hyperlipidemia	29,645 (55.7)	13,286 (63.8)	1053 (59.2)	2048 (61.0)	17,920 (54.2)	< 0.001	63,952 (57.0)	50.1	< 0.001
Diabetes mellitus	16,174 (30.4)	8923 (42.9)	642 (36.1)	1174 (35.0)	11,217 (33.9)	< 0.001	38,130 (34.0)	28.1	< 0.001
Chronic kidney disease	15,721 (29.5)	8372 (40.2)	524 (29.5)	1072 (31.9)	11,542 (34.9)	< 0.001	37,231 (33.2)	32.8	0.038
Complex chronic patients	18,314 (34.4)	9347 (44.9)	596 (33.5)	1318 (39.3)	11,869 (35.9)	< 0.001	41,444 (36.9)	20.2	< 0.001
Obesity	15,539 (29.2)	7444 (35.8)	661 (37.2)	1097 (32.7)	11,189 (33.9)	< 0.001	35,930 (32.0)	33.5	< 0.001
Stroke	12,592 (23.7)	12,290 (59.0)	608 (34.2)	1054 (31.4)	9533 (28.8)	0	36,077 (32.2)	16.4	< 0.001
Neoplasia	13,104 (24.6)	6093 (29.3)	496 (27.9)	957 (28.5)	9250 (28.0)	< 0.001	29,900 (26.6)	29.0	< 0.001
Heart failure	10,367 (19.5)	7423 (35.7)	394 (22.1)	832 (24.8)	9259 (28.0)	0	28,275 (25.2)	22.3	< 0.001
Chronic obstructive pulmonary disease	8878 (16.7)	5514 (26.5)	425 (23.9)	761 (22.7)	7329 (22.2)	< 0.001	22,907 (20.4)	18.6	< 0.001
Smoking	6901 (13.0)	5283 (25.4)	517 (29.1)	794 (23.7)	5593 (16.9)	0	19,088 (17.0)	14.1	< 0.001
Ischemic heart disease	7386 (13.9)	4963 (23.8)	303 (17.0)	714 (21.3)	5721 (17.3)	< 0.001	19,087 (17.0)	16.3	< 0.001
Arthritis	5786 (10.9)	2864 (13.8)	208 (11.7)	400 (11.9)	4064 (12.3)	< 0.001	13,322 (11.9)	10.9	< 0.001
Asthma	4312 (8.10)	2064 (9.92)	158 (8.88)	317 (9.44)	3133 (9.48)	< 0.001	9984 (8.90)	8.8	0.673
Atypical psychosis	3476 (6.53)	2006 (9.64)	168 (9.44)	412 (12.3)	2464 (7.46)	< 0.001	8526 (7.60)	1.4	< 0.001
Advanced chronic patients	4373 (8.22)	2069 (9.94)	100 (5.62)	301 (8.97)	2691 (8.14)	< 0.001	9534 (8.50)	2.9	< 0.001
Major depressive disorder	2095 (3.94)	1068 (5.13)	156 (8.77)	216 (6.43)	1673 (5.06)	< 0.001	5208 (4.64)	2.0	< 0.001
Alcoholism	1099 (2.07)	1168 (5.61)	145 (8.15)	113 (3.37)	1371 (4.15)	< 0.001	3896 (3.47)	1.4	< 0.001
Schizophrenia	484 (0.91)	323 (1.55)	50 (2.81)	49 (1.46)	685 (2.07)	< 0.001	1591 (1.42)	0.4	< 0.001
Bipolar disorder	618 (1.16)	408 (1.96)	73 (4.10)	87 (2.59)	678 (2.05)	< 0.001	1864 (1.66)	0.5	< 0.001
Cirrhosis	549 (1.03)	332 (1.60)	33 (1.85)	45 (1.34)	426 (1.29)	< 0.001	1385 (1.23)	1.0	< 0.001

^aChi-squared test comparing dementia subtypes^bStandardized individuals adjusted for age, sex and income level^cChi-squared test comparing population with and without dementia

Evaluation of healthcare services utilization and associated expenditures of people with dementia (2019)

The utilization of ambulatory healthcare services was significantly higher in people with dementia compared with people without dementia adjusted by age, sex, and income level. However, non-dementia patients used day

hospitals and outpatient care more frequently (Table 3). Differences between both groups were overall small. Healthcare services utilization varied modestly but significantly according to dementia subtypes (Table 3). Patients with VD and LBD had more visits per patient and per year to the emergency room (1.4 for both) and

Table 3 Healthcare services utilization, institutionalizations and expenditure according to type of dementia diagnosis and by patients ≥ 65 diagnosed with and without dementia in Catalonia adjusted by sex, age and income level (2019)

	Alzheimer	Vascular	Frontotemporal	Lewy Bodies	Unspecified	P-value ^a	Dementia	No dementia ^b	P-value ^c
	53,218	20,813	1779	3357	33,046		112,213		
<i>Ambulatory healthcare services (visits per patient per year)</i>									
Emergency department	0.9	1.4	1.2	1.4	1.1	< 0.001	1.1	0.7	< 0.001
Mental Health	0.1	0.1	0.3	0.2	0.2	< 0.001	0.1	0.0	< 0.001
Day Hospital	0.2	0.3	0.4	0.3	0.3	< 0.001	0.2	0.3	< 0.001
Outpatient care	2.1	2.5	3.2	3.2	2.5	< 0.001	2.3	2.7	< 0.001
Primary care	13.9	17.2	16.0	16.7	16.0	< 0.001	15.2	14.2	< 0.001
Prescribed drugs	10.1	12.2	11.0	12.4	10.8	< 0.001	10.8	9.3	< 0.001
<i>Institutionalizations rate of admission per 100 patients per year</i>									
Intermediate care center	15.1	26.5	19.1	23.0	19.7	< 0.001	18.9	7.8	< 0.001
Nursing home ^d	32.0	34.2	24.2	30.4	27.3	< 0.001	30.9	7.4	< 0.001
Psychiatric center	0.2	0.8	1.7	0.3	0.6	< 0.001	0.4	0.1	< 0.001
Acute care hospital	35.3	67.7	54.4	60.0	48.9	< 0.001	46.4	33.6	< 0.001
<i>Institutionalizations days of admission per 100 patients</i>									
Post-acute care center	257.8	532.6	390.1	396.9	356.6	< 0.001	344.1	144.5	< 0.001
Long-term care centers	221.7	433.3	314.1	414.7	329.6	< 0.001	299.9	86.3	< 0.001
Nursing home	9304.7	9551.8	6934.3	8444.5	7628.4	< 0.001	8792.8	2050.1	< 0.001
Psychiatric center	3.0	18.5	42.5	11.5	16.7	< 0.001	10.7	1.3	< 0.001
Acute care hospital	192.4	449.9	343.5	361.9	299.4	< 0.001	279.2	175.2	< 0.001
<i>Institutionalizations mean days of stay</i>									
Post-acute care center	27.1	30.0	30.8	26.4	28.3	0.006	28.3	28.3	0.838
Long-term care centers	58.7	60.0	65.7	63.0	58.3	0.750	59.2	58.6	0.534
Nursing home	290.5	279.4	286.7	277.4	279.1	< 0.001	284.4	278.2	< 0.001
Psychiatric center	17.7	23.4	25.2	35.0	27.7	0.093	24.5	21.5	0.139
Acute care hospital	5.5	6.6	6.3	6.0	6.1	< 0.001	6.0	5.2	< 0.001
<i>Healthcare services expenditure mean by PPP per person (%)^e</i>									
Primary care	796 (12.5)	937 (9.8)	891 (11.0)	939 (9.9)	882 (11.9)	< 0.001	853 (11.5)	778 (15.2)	< 0.001
Prescribed drugs	1970 (30.9)	1965 (20.6)	1868 (23.0)	2682 (28.2)	1704 (22.9)	< 0.001	1910 (25.8)	1312 (25.5)	< 0.001
Hospitalization	1533 (24.0)	3005 (31.4)	2369 (29.1)	2599 (27.4)	2153 (29.9)	< 0.001	2034 (27.5)	1495 (29.1)	< 0.001
Emergency department	720 (11.3)	1164 (12.2)	891 (11.0)	1094 (11.5)	877 (11.8)	< 0.001	861 (11.6)	488 (9.5)	< 0.001
Outpatient care	298 (4.7)	393 (4.1)	502 (6.2)	474 (5.0)	376 (5.1)	< 0.001	347 (4.7)	424 (8.3)	< 0.001
Intermediate care center	865 (13.5)	1504 (15.7)	1191 (14.7)	1314 (13.8)	1046 (14.1)	< 0.001	1055 (14.3)	354 (6.9)	< 0.001

Table 3 (continued)

	Alzheimer	Vascular	Frontotemporal	Lewy Bodies	Unspecified	P-value ^a	Dementia	No dementia ^b	P-value ^c
Other health-care services	200 (3.1)	590 (6.2)	414 (5.1)	392 (4.1)	397 (5.3)	< 0.001	338 (4.6)	279 (5.5)	< 0.001
Global expenditure	6385 (100.0)	9559 (100.0)	8129 (100.0)	9499 (100.0)	7440 (100.0)	< 0.001	7404 (100.0)	5139 (100.0)	< 0.001

PPP purchasing power parity

^aAnalysis of variance comparing dementia subtypes^bStandardized individuals adjusted for age sex and income level^cAnalysis of variance comparing population with and without dementia^dPatients in nursing homes during 2019 regardless of the year of admission^eCalculated over the total healthcare costs for each group

primary care (17.2 and 16.7, respectively), more prescribed drugs (12.2 and 12.4, respectively), and higher admission rates per 100 patients per year in acute care hospitals (67.7 and 60.0, respectively) than those with other dementia subtypes. However, admission rates in psychiatric centers (1.7) were higher for FTD (i.e., eight times those observed in AD [0.2]) (Table 3).

Days of admission per 100 patients were especially high in nursing homes compared with other institutions for AD and VD patients (9304.7 and 9551.8, respectively). VD patients had more admission days in acute care (449.9), post-acute care (532.6), and long-term care (433.3) than other dementia subtypes, followed by LDB. Admission rates and days of admission were higher among patients with dementia than those without dementia in all types of services. Among the dementia subtypes, differences in mean days of stay were small but statistically significant for acute and post-acute care hospitals and nursing homes. Mean days of stay showed small but significant differences between dementia and non-dementia patients for nursing homes and acute care hospitals. Global healthcare-related expenditure by purchasing power parity (PPP) was higher among VD and LBD patients (€3343 and €3322, respectively), mainly at the expense of prescribed drugs, hospitalization, and intermediate care center admissions (Table 3). Expenditure was higher among people with dementia in all types of services utilization, except for outpatient care, resulting in higher total healthcare costs for people with dementia, with the expenditure attributable to dementia of €792 per person per year, which represents an increase of 44.1% of total healthcare costs.

Regarding drugs prescribed in 2019, antidepressants were the most frequently administered (59.3–61.5% of AD and UD patients, and 65.6–68.0% of VD, FTD, and LBD patients), followed by antipsychotics (50.9–60.2% of AD, VD, FTD, and UD patients, and 68.9% of LBD patients), and anticholinesterase drugs (> 50.0% of AD and LBD patients) (Table S2). During 2013–2020, antidepressants and benzodiazepine derivatives showed a general decline in all dementia subtypes, whereas the use of

antipsychotics slightly increased in AD and VD patients. Memantine and anticholinesterase drugs remained stable for all dementias, while anticholinesterase drugs showed a minimal increase in the last three years for UD (Figure S3).

Evolution and evaluation of mortality in dementia patients

Mortality rates for patients with dementia showed a modest, gradual increase between 2013 and 2019 for all dementia subtypes, except for UD, which was stable between 2013 and 2017 and declined in 2018 and 2019 (Fig. 3). However, in 2020, mortality rates showed a steep increase. Changes in mortality rates adjusted by sex, age, and income level and stratified in the different age groups showed a similar trend in men and women, with overall lower rates in women than in men. In the population without dementia, mortality rates increased with age, especially in people > 84 years, whereas patients with dementia > 84 years showed lower mortality rates than those aged 75–84 years (Figure S4). Changes in mortality rates according to GMA risk level followed a similar trend regardless of sex. Patients with dementia showed higher mortality rates than those without dementia across all GMA risk levels (Figure S4).

Discussion

This observational, retrospective study, including all patients with dementia in Catalonia aged ≥ 65 years for the 2013–2020 period, showed modest fluctuations in prevalence and incidence rates of dementia. Compared to the population without this condition, people with dementia had a higher morbidity-associated risk and increased prevalence of almost all comorbidities, overall highest in patients with VD. People with dementia had increased admission rates, particularly in nursing homes and intermediate care. The number of admissions and days admitted were overall higher in people with AD and VD than in those with other dementia types. Consistently, total healthcare expenditures increased in people with dementia, with €1311.7/person/year attributable to dementia; VD was the largest contributor to increased

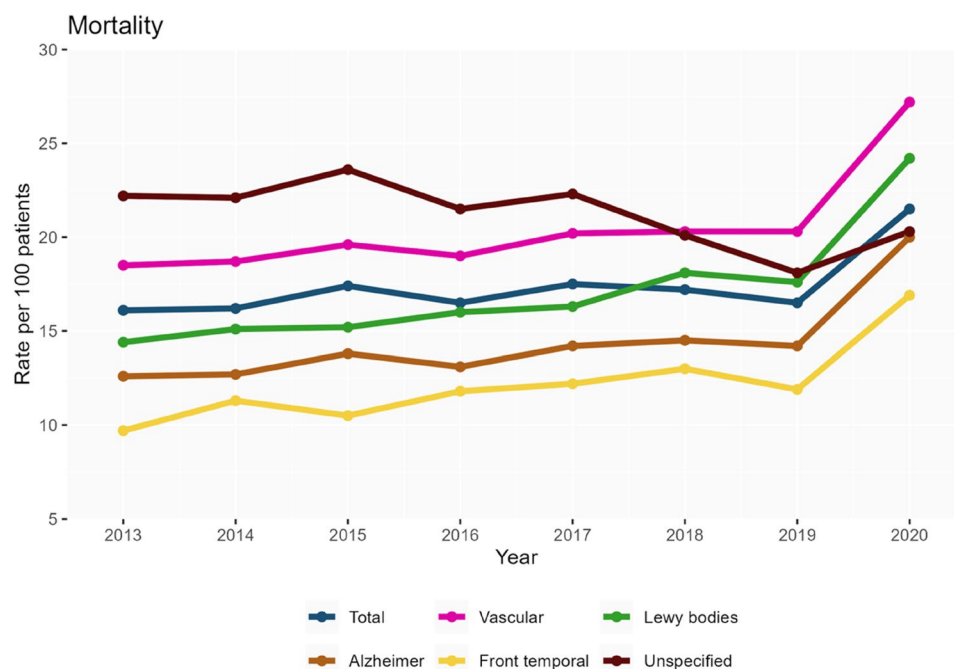


Fig. 3 Evolution of annual mortality rate (1 per 100 inhabitants) of dementia in Catalonia according to type of diagnosis (2013–2020)

expenditures. Mortality rates were higher among people with dementia than in the population without dementia adjusted by age, sex, and income level, being highest in men and women with high morbidity-associated risk in both populations.

The increased overall prevalence of dementia in Catalonia in 2013–2019 (from 61.8 to 64.0 cases/1000 inhabitants) found in this study was consistent with the increasingly older age of the Catalan population. However, incidence rates showed modest fluctuations during the study period, with a net decrease of 0.8 cases/1000 inhabitants between 2013 and 2019. Previous studies have shown substantially lower incidence rates across Europe and the US, possibly due to preventive initiatives focused on cardiovascular risk factors and the increased educational level of the population, even though this decrease was more modest in this study [29–31]. Overall, the lower dementia incidence rates lacked an impact on prevalence rates, suggesting that people diagnosed with dementia remained in the healthcare system a substantial time after diagnosis, likely due to a prolonged duration of dementia [5].

Regarding the epidemiology of the different dementia types, the substantial decrease in AD and VD incidence rates and modest increase in UD suggest that a subset of newly diagnosed dementia cases was not appropriately coded or that they remained inaccurately diagnosed. The trend towards increased UD diagnoses, with the highest incidence among all dementia subtypes in 2019, indicates that the etiology of an increasingly higher proportion of dementias remains unknown. An accurate diagnosis is

necessary to guide treatment decisions and, therefore, the criteria used to prescribe medications for UD are unclear. Furthermore, the prevalence of LBD, which is the second most common/incident dementia subtype after AD, was unexpectedly low [32]. LBD diagnosis is challenging and often associated with atypical psychosis, leading to inaccurate diagnosis as its clinical presentation overlaps that of AD or other cognitive or psychiatric disorders [33]. While the absence of these symptoms may lead to another diagnosis, after development of all symptoms, LBD and Parkinson's disease (PD) may be indistinguishable, possibly explaining, at least in part, the lower prevalence of LBD, which may be misdiagnosed as PD [34].

Results from this analysis, including all CHSS users, showed that most people with dementia were at high morbidity-associated risk (51%) and almost all had comorbidities at higher frequencies than people without dementia. Previous smaller studies had reported a high proportion of multimorbid patients among those with dementia, pointing out to increased multimorbidity in this population, even though the most frequent comorbidities differed among studies [35–38]. Nevertheless, similar to this study, hypertension, diabetes, and cardiovascular-related conditions ranked among the most common [35–38]. Of the different subtypes of dementia, the morbidity-associated risk was lowest for patients with AD and highest for patients with VD. Accordingly, people with dementia had comorbidities at higher frequencies, especially those affecting the cardiovascular system, such as arterial hypertension, hyperlipidemia, and stroke. In this regard, the higher prevalence of cardiovascular

comorbidities was not unexpected, as they are also considered risk factors for dementia.

Increased multimorbidity has been associated with a higher utilization of healthcare resources in people with dementia [37, 39]. Consistently, results from our study showed that patients with dementia had increased utilization of most healthcare services, likely resulting from a combined burden of dementia and comorbidities. People with dementia had slightly increased use of ambulatory care services, except for outpatient care, which was more frequently used by patients without dementia. These findings suggest that dementia patients are referred to specialists less often and are mainly followed up in primary care. Unlike ambulatory care services, admission rates and duration of stay were markedly higher in people with dementia than in those without dementia adjusted by age, sex, and income level. In this regard, dementia has been identified as a risk factor for institutionalization in nursing homes, and a recent meta-analysis showed a 1.42 relative risk of hospitalization for people with dementia regardless of comorbidities [40, 41].

This study shows that healthcare for people with dementia was associated with significant costs (€1311.7/patient/year, 44.1% more than for people with dementia), similar to previous studies [42] (Table S3). Even though all expenditures were higher, hospitalizations in intermediate care centers were the main driver of increased expenditures, consistent with the utilization of healthcare services. In this respect, increased visits to primary care, prescribed drugs, and admission rates in acute care hospitals of VD and LBD patients may be associated with the need to control cardiovascular disease in VD patients and behavioral disorders and confusion in LBD patients. In addition to increased admission rates, VD patients had more admission days, which may be associated with cerebrovascular accidents (i.e., stroke), which are most prevalent among patients with this dementia subtype. Regarding medication, the use of antidepressants and benzodiazepines progressively decreased throughout the study period, likely due to the increased awareness of their adverse effects in older people among physicians [43, 44]. In contrast, the use of anticholinesterase drugs remained unchanged throughout the study period and was highest among AD patients followed by LBD, consistent with current recommendations [45].

The results from this study should be interpreted in the context of limitations associated with its design and the availability of retrospective data. The CHSS database used collects data in the real-world setting and, unlike databases generated prospectively, may contain inaccurate data. This may be especially relevant for dementia subtype diagnoses, which were based on ICD codes instead of on biomarker data, still missing in the CHSS database for the majority of patients. In line with this,

the elevated proportion of UD shows that dementia subtypes are not well recorded in the database, which could be biasing our results. Given that the pattern of dementia incidence has changed slightly during the study period, this could affect the estimates of healthcare service use and the cost of dementia. Furthermore, CHSS lacks information about users of private health services, and therefore, incidence and prevalence rates may have been underestimated. Nevertheless, this study intended to gather data for its application in future public healthcare plans, minimizing the impact of users of private services. Regardless of these constraints, CHSS collects data from all users of the public healthcare system of Catalonia, with a population of 7.5–7.7 million, allowing the analysis of a very large dataset without selection bias. Another limitation of this study is related to the COVID-19 pandemic in 2020, which may have biased the results. During the first wave of COVID-19, the healthcare system focused on detecting and managing COVID-19 cases, likely impacting the utilization of healthcare services. Furthermore, prevalence, incidence, and mortality rates in 2020 likely reflected the consequences of COVID-19, with a decrease in specialist referrals and an increased mortality among the elderly. Regarding its generalizability, this study used diagnostic codes of dementia based on commonly used international classifications (i.e., ICD-9-CM), enabling to generalize results to other populations and settings. However, the collection of information from primary care is uncommon in other healthcare systems, precluding data comparisons regarding the utilization of primary care resources. Furthermore, the Catalan healthcare system is universal, facilitating access to healthcare and prescription drugs and, consequently, results, at least in part, may not be generalizable to countries with non-universal healthcare systems. Nevertheless, the availability of an administrative database covering all the Catalan territory allowed to capture a large representative dataset.

Conclusions

In conclusion, between 2013 and 2019, prevalence and incidence rates of dementia in Catalonia showed modest fluctuations. Dementia patients seem to remain in the healthcare system for a long time with increased utilization of healthcare services and significant costs, despite the decreased use of antidepressants and benzodiazepines, underscoring the significant burden of dementia for the healthcare system.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12889-025-24341-4>.

Supplementary Material 1.

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Authors' contributions

EMA, ALI, EV, GPR, SS designed the study. GPR, ALI and SM performed the literature search. EV, MC, SM, EM, SS collected the data. EV and MC analysed the data. EMA, ALI, EV, GPR and SS interpreted the data. All authors read and approved the final manuscript.

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Data availability

The datasets generated and/or analyzed in this study are not publicly accessible, but are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

The ethics principles of the Helsinki Declaration, the local Personal Data Protection Law (LOPD 3/2018) and the General Data Protection Regulation (EU) were observed, and the Research Ethics Committee of the University of Vic/Central University of Catalonia (UVIC-UCC) approved the study (reference number 183/2021).

Consent for publication

No individual person's data in any form are included in this article.

Competing interests

The authors declare no competing interests.

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