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Incidence and mortality trends of people living with dementia among 7 million individuals over 10 years in Italy: A retrospective cohort study using administrative linked data

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ABSTRACT

Purpose: We aimed to estimate trends of dementia incidence and to compute and compare all-cause mortality among people living with and without dementia, in a whole regional population, from 2013 to 2023.
Methods: Our retrospective population-wide cohort study included 7,030,374 people aged 50 years and older from regional administrative data, living in Lombardy, the most populous Italian region. We computed annual age-standardised dementia incidence estimated rates and age-standardised all-cause mortality estimated rates among people living with and without dementia, both overall and stratified by age and sex.
Results: Over the last decade, age-standardised dementia incidence estimated rates have decreased by 52.8 % for women and 53.1 % for males. In contrast, age-standardised all-cause mortality estimated rates among people living with dementia grew by 14.0 % for women and 21.8 % for males. Conversely, during the pandemic, there was a higher excess in mortality estimated rates in the female population living with dementia compared to the male, up to 60 % in older groups aged 80 or older. In the male population without dementia compared to the female, the higher excess was up to 50 % in age groups of 70–74 and 75–79.
Conclusions: Our study reported a reduction in dementia incidence and increase in all-cause mortality of people living with dementia over the last decade, indicating that dementia prevalence is declining. Moreover, previously under-investigated gender disparities in mortality estimated rates emerged across different age groups during the pandemic.

Introduction

Dementia is a leading cause of death in the senior adult populations worldwide [1,2]. Due to an aging population, people living with dementia (PLWD) are estimated to be about 55 million cases, with a female-to-male prevalence ratio of 1.31, and the burden of disease is projected to increase threefold by 2050 [1,3]. Prevalence and incidence trends vary around the world. In high-income countries, PLWD incidence is decreasing in all age groups [4]. This trend is probably due to effective prevention interventions on the 14 risk factors known to date, including low level of education, hearing loss, high LDL cholesterol, depression, traumatic brain injury, physical inactivity, diabetes, smoking, hypertension, obesity, excessive alcohol consumption, infrequent social contact, air pollution and visual loss [2,4]. This is confirmed by European and North American population studies and the most updated estimates provided by the Global Burden of Disease [5–9]. Dementia incidence reduction is significant, ranging from 12 % to 35 % every decade, although some studies in the 2000s identified an upward trend [10,11].

As dementia burden threatens the sustainability of health care systems worldwide, frequent monitoring of incidence estimates is important [12]. However, few studies have been conducted since 2010 in high-income countries, reporting contradictory results about incidence trends of dementia [13]. Thus, updated data representative of entire high-income countries' populations are required. Population-based administrative data can represent a comprehensive source to fill this

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information gap. In Italy, where we estimate approximately 1 million of PLWD [14], the Italian National Health Institute developed a validated algorithm using administrative data, achieving an overall accuracy of 85.3 % in detecting dementia cases [15]. The application of this algorithm to the Data Warehouse of Lombardy [16], the most populated region of Italy with 10 million inhabitants, can provide updated epidemiological trends of dementia based on a wide population of an high-income country.

The aim of this study is to estimate rates and trends of dementia incidence in the Lombardy region and to compute and compare all-cause mortality among PLWD with the population without dementia, from 2013 to 2023.

Methods

Study design

We conducted a historical open cohort study on the whole population aged $\geq$ 50 residents in Lombardy (7,030,374 people), using data from the Lombardy healthcare system's Data WareHouse covering the 2013–2023 study period. Access to databases was provided under an agreement for research with public health purposes, in force between the University of Pavia and the Lombardy Region Welfare Directorate. This study is part of the "EPIDEM" project, led by the University of Pavia and approved by the Lombardy Welfare Directorate in 2024.

Data sources and setting

The Lombardy Region Welfare Directorate collects health records in its comprehensive healthcare system's Data WareHouse, with a star scheme model (see Supplementary Material, Fig. S1), enabling detailed longitudinal analyses at the individual level. The Population Registry includes sociodemographic information, mortality data and further records from various sources, including hospital discharge registry, drug prescriptions and outpatient services. This ensures that all citizens' interactions with the healthcare system are comprehensively captured, allowing for a full historical view of their health status and medical treatments. Each record has a unique anonymous alphanumeric ID code linked to every individual. By the matching of the ID codes between different datasets, it is possible to perform record linkage of any information flows and retrieve all data of any individual over the period 2013–2023, in compliance with the General Data Protection Regulation.

Participants

Our open cohort included all people turning the age 50 and that were resident in Lombardy over the study period. To identify PLWD cases, we used a validated algorithm (see Supplementary Material, Table S1) based on administrative data, published by the Italian National Health Institute [15]. A case of dementia was defined if having at least two different prescriptions of drugs for dementia within 12 months *OR* at least one hospital discharge with primary or secondary diagnoses of dementia *OR* if the subjects had the exemption from health-care co-payment specific for the disease *OR* if resident in LTCF with cognitive deficit reported. Thus, we selected the following four different information flows (see Supplementary Material, Fig. S2):

i) Hospital Discharges Registry;
ii) Drugs Prescriptions;
iii) Administrative Exemptions (administrative certificates for selected medical conditions that exempt from payment for health services);
iv) Long-Term Care Facilities Admissions.

After setting [joining vertically] all the records of PLWD in each database, we removed the duplicates by keeping the records with the earliest date of discharge, prescription, exemptions or admission after age 50 as the date of first diagnosis of dementia. Finally, we merged the resulting database (i.e. including PLWD cases) with the Population Registry (i.e. including sociodemographic information and mortality data), by a unique identification code (see Supplementary Material, Fig. S3).

As three administrative information flows out of four were fully retrieved since 2000, but the fourth about long-term facilities became mandatory only in 2012, our analyses were limited to the last decade (i.e. 2013–2023). However we used data retrieved from 2000 to 2012 from these three information flows, which represent the sources of more than 80 % of our data (see Supplementary Material, Fig. S4), to exclude cases diagnosed before 2013 from our incidence estimates. That approach limits the prevalent case bias in the first year of our study.

Statistical analysis

We computed annual PLWD incidence rates, overall and stratified by sex and nine quinquennial age groups (i.e. 50–54, 55–59, 60–64, 65–69, 70–74, 75–79, 80–84, 85–89, 90 +) over the period 2013–2023. Individuals were assigned to an age group based on their age at the time of dementia diagnosis. The rate numerator was computed as new incident cases per year, by summing up the new dementia diagnoses registered from the 1st of January to the 31st of December of each year, while the denominator as the total person-time, within each calendar year. The total person-time was calculated by summing up the number of days that each resident in Lombardy remained in the study cohort in each calendar year, i.e. from the 1st of January to the 31st of December or the date of death, excluding people with a previous dementia diagnosis (i.e. prevalent cases).

We computed annual mortality rates from all causes, overall and stratified by sex and age groups, in both PLWD and the population without dementia. Individuals were classified into age groups based on their age at the time of death.

For comparative purposes, we then obtained the age-standardised incidence per 10,000 person-years and mortality rates per 1,000 person-years, using the direct method based on the 2013 European standard population [17].

Results

Out of 7,030,545 individuals aged 50 years or older and living in the Lombardy region (among 10,036,258 inhabitants as of January 1, 2018), we extracted 421,697 records from "Drug prescriptions", 3,921 from "Administrative Exemptions", 178,613 from "Long-Term Care Facilities Admissions", and 286,169 from "Hospital Discharge Registry", including 8,741 records of Lombardy residents hospitalised in other Italian regions, for a total of 890,400 records registered from 2000 to 2023. The proportion of PLWD identified from different data sources is presented in Fig. S4.

After removing duplicates of same individuals within these 890,400 records, we identified 461,046 PLWD (65.1 % women; mean age at diagnosis = 82.5 $\pm$ σ 8.2 years).

Table 1 reports the number of PLWD per year, crude and age-standardised incidence estimated rates per 10,000 person-years at age 50 years or more, from 2013 to 2023. Over the last decade, age-standardised PLWD incidence estimated rates declined by 52.8 % from 85.2/10,000 in 2013–40.210,000 in 2023 among women, and by 53.1 % from 76.5/10,000 to 35.9/10,000, respectively, among men.

Sex- and age-specific PLWD incidence estimated rates in three-years periods (i.e. 2013–2015, 2017–2019, and 2021–2023), and the percentage change between the last *vs*. the first period, are reported in Table S2.

PLWD incidence estimated rates increased as age increases and declined consistently across all age groups over the study period. The smallest decreases in incidence over the study period were registered at

Table 1
Number of new cases of PLWD, crude and age-standardised (European population) incidence estimated rates (per 10,000 person-years) at age 50 + and corresponding 95 % confidence intervals (CI), by sex, from 2013 to 2023. Lombardy region (Italy).

	Women			Men		
	N. of new cases	Crude incidence rate/ 10,000(95 % CI)	Age-standardised incidence rate/10,000(95 % CI)	N. of new cases	Crude incidence rate/ 10,000(95 % CI)	Age-standardised incidence rate/10,000(95 % CI)
Calendar year						
2013	16,624	86.1 (84.8–87.4)	85.2 (83.9–86.5)	8,235	49.9 (48.9–51.0)	76.5 (74.7–78.2)
2014	14,884	75.0 (73.8–76.2)	71.8 (70.6–72.9)	7,944	46.4 (45.4–47.5)	68.5 (66.9–70.1)
2015	16,213	79.5 (78.2–80.7)	73.3 (72.2–74.5)	8,399	47.4 (46.4–48.4)	67.0 (65.5–68.5)
2016	15,140	72.3 (71.2–73.5)	64.7 (63.7–65.8)	7,970	43.5 (42.5–44.4)	59.1 (57.8–60.5)
2017	15,507	72.3 (71.2–73.4)	62.3 (61.3–63.3)	8,567	45.3 (44.3–46.2)	58.9 (57.6–60.2)
2018	15,244	69.5 (68.3–70.6)	57.5 (56.6–58.4)	8,437	43.3 (42.3–44.2)	53.8 (52.6–54.9)
2019	15,338	68.3 (67.2–69.4)	54.5 (53.6–55.4)	8,437	42.0 (41.1–42.9)	49.6 (48.6–50.7)
2020	13,401	58.5 (57.5–59.5)	44.8 (44.0–45.5)	7,658	37.2 (36.3–38.0)	41.5 (40.5–42.4)
2021	15,843	67.9 (66.9–69.0)	50.5 (49.7–51.3)	8,790	41.7 (40.9–42.6)	44.8 (43.8–45.7)
2022	16,057	67.7 (66.6–68.7)	48.2 (47.5–49.0)	9,378	43.5 (42.6–44.4)	44.5 (43.5–45.4)
2023	14,000	58.1 (57.1–59.1)	40.2 (39.5–40.9)	8,122	36.9 (36.1–37.7)	35.9 (35.1–36.7)
% difference 2023 vs. 2013		−32.5 %	−52.8 %		−26.1 %	−53.1 %

age 60–64 in women (-13.8 %), and both at age 60–64 and 65–69 in men (around −24 %). The greatest incidence falls were at age 85–89 and 90 + in women (-45 %), and at age 85–89 in men (-46.9 %). In 2023, the highest incidence estimated rates were 158.7, 293.6 and 449.6/10,000 at age 80–84, 85–89, and 90 + , respectively, in women, and 136.7, 259.4, and 375.7/10,000 in men. Over the study period, a steady reduction in incidence was observed in the most recent years in older age groups, to a greater degree especially in females, as reported in Fig. 1.

The number of annual deaths from all causes among PLWD, crude and age-standardised mortality estimated rates per 1,000 person-years at age 50 years or more, from 2013 to 2023, are reported in Table 2.

Over the last decade, age-standardised mortality estimated rates among PLWD increased by 14.0 % from 78.3/1,000 in 2013 to 89.3/1,000 in 2023 among women, and by 21.8 % from 109.5/1,000 to 133.4/1,000, respectively, among men.

Age-standardised mortality estimated rates in people without dementia declined by 10.5 % in women (from 12.4 to 11.1/1,000) and by 17.6 % in men (from 20.5 to 16.9/1,000), as shown in Table 3.

Increasing mortality trends over the study period were reported in both sexes among PLWD, while decreasing mortality trends were reported among people without dementia, as presented in Fig. 2, except for 2020.

In fact, during the first year of the COVID-19 pandemic, both PLWD and people without dementia registered a high increase of mortality. However, we observed different patterns in age-specific mortality estimated rates excess across sexes among PLWD, as compared to people without dementia (see Fig. S5).

A greater excess in mortality estimated rates in 2020 *vs.* 2019 was observed among the male population without dementia, up to 50 % in younger age groups of 70–74 and 75–79, and in the female population living with dementia, up to 60 % in older groups aged 80 or over.

Discussion

Our region-wide cohort study suggests that incidence of PLWD is decreasing over the last decade. During the same period, all-cause mortality trends among PLWD are rising, but not among people without dementia.

Our temporal analysis indicates a decline in age-standardised dementia incidence in both males and females in Lombardy over the last decade. The most up-to-date data indicate a PLWD age-standardised incidence of 40.2/10,000 in women and 35.9/10,000 in men. This contrasts with the most recent study of *Chen et al* from a high-income country over two decades [13] which reported an increase in dementia incidence since 2008. In that study, data were collected using computer-assisted personal interviews and self-completion questionnaires, but participants were not clinically screened for dementia, so they self-reported dementia diagnosis. Similar increasing trends resulted from a study of *Avan et al*, using Global Burden of Disease (GBD) 2019 data, showing an increasing rates of dementia incidence in Italy from 2010 to 2019 (101 vs 103.7 per 100,000 person-years) [5]. However,

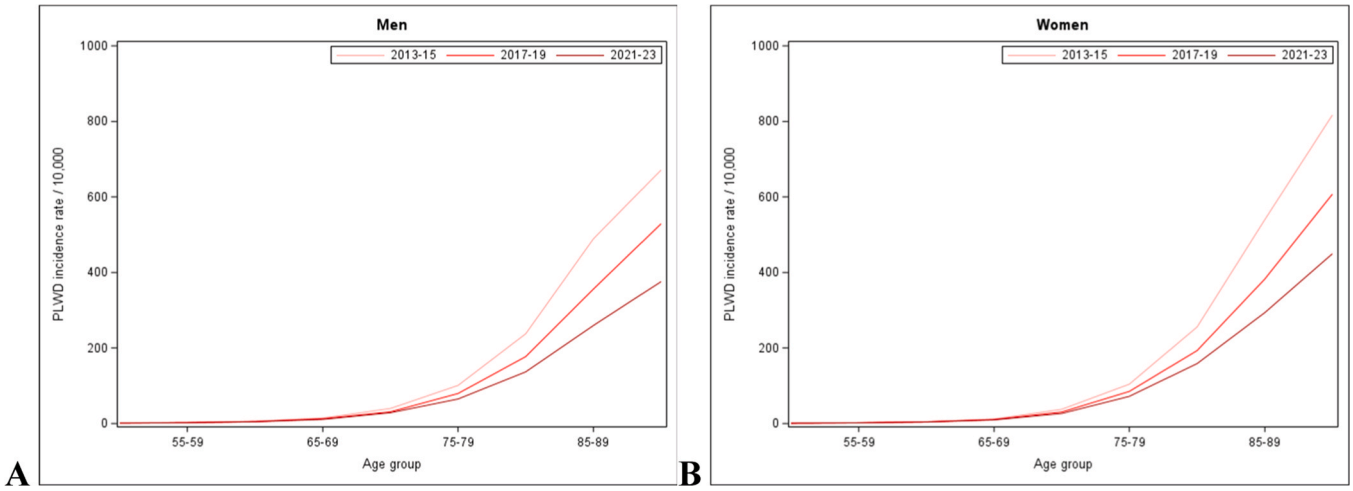

Fig. 1. PLWD incidence rate by age in (A) men and (B) women in 2013–2015, 2017–2019, 2021–2023 in Lombardy, Italy.

Table 2
Number of deaths from all causes, crude and age-standardised (European population) mortality estimated rates (per 1,000 person-years) at age 50 + , and corresponding 95 % confidence intervals (CI) among PLWD, from 2013 to 2023. Lombardy, Italy.

	Women			Men		
	N. of deaths	Crude mortality rate/ 1,000 (95 % CI)	Age-standardised mortality rate/1,000 (95 % CI)	N. of deaths	Crude mortality rate/ 1,000 (95 % CI)	Age-standardised mortality rate/1,000 (95 % CI)
Calendar year						
2013	12,520	177.7 (174.5–180.8)	78.3 (68.0–88.6)	6,665	225.8 (220.3–231.2)	109.5 (100.7–118.3)
2014	12,808	176.2 (173.1–179.3)	75.3 (65.9–84.8)	6,907	225.1 (219.8–230.4)	121.3 (110.4–132.2)
2015	15,283	204.2 (200.9–207.4)	87.4 (75.4–99.4)	7,877	248.6 (243.1–254.1)	131.8 (120.5–143.1)
2016	13,522	178.9 (175.9–181.9)	74.7 (64.3–85.2)	7,551	236.4 (231.1–241.7)	109.8 (100.8–118.8)
2017	14,976	194.9 (191.7–198.0)	83.9 (71.4–96.4)	7,903	241.1 (235.8–246.4)	115.0 (105.0–125.1)
2018	14,777	191.4 (188.3–194.4)	77.6 (68.8–86.5)	8,004	240.6 (235.3–245.9)	120.5 (110.6–130.4)
2019	15,047	193.8 (190.7–196.9)	91.5 (78.6–104.4)	8,265	246.2 (240.9–251.5)	120.0 (110.0–130.1)
2020	21,959	302.7 (298.7–306.7)	118.5 (106.8–130.1)	11,244	357.3 (350.7–363.9)	178.6 (165.2–192.1)
2021	13,985	198.6 (195.3–201.9)	81.7 (71.5–92.0)	7,917	258.0 (252.4–263.7)	126.6 (115.0–138.2)
2022	16,015	224.1 (220.6–227.5)	96.6 (86.5–106.6)	9,044	286.4 (280.5–292.3)	134.7 (123.6–145.7)
2023	14,610	208.2 (204.9–211.6)	89.3 (77.2–101.4)	7,907	253.2 (247.6–258.8)	133.4 (120.3–146.4)
% difference 2020 vs. 2019		+ 56.2 %	+ 29.5 %		+ 45.1 %	+ 48.8 %
% difference 2023 vs. 2013		+ 17.2 %	+ 14.0 %		+ 12.1 %	+ 21.8 %

Table 3
Number of deaths from all causes, crude and age-standardised (European population) mortality estimated rates (per 1,000 person-years) at age 50 + and corresponding 95 % confidence intervals (CI) among the population without dementia, from 2013 to 2023. Lombardy, Italy.

	Women			Men		
	N. of deaths	Crude mortality rate/ 1,000 (95 % CI)	Age-standardised mortality rate/ 1,000 (95 % CI)	N. of deaths	Crude mortality rate/ 1,000 (95 % CI)	Age-standardised mortality rate/ 1,000 (95 % CI)
Calendar year						
2013	32,899	15.2 (15.1–15.4)	12.4 (12.3–12.6)	33,791	18.1 (17.9–18.3)	20.5 (20.3–20.8)
2014	32,760	14.9(14.8–15.1)	12.1 (11.9–12.2)	33,740	17.6 (17.5–17.8)	19.8 (19.5–20.0)
2015	35,968	16.2 (16.0–16.3)	12.9 (12.8–13.0)	36,309	18.6 (18.4–18.8)	20.6 (20.4–20.8)
2016	33,611	14.9 (14.8–15.1)	11.8 (11.7–11.9)	34,994	17.6 (17.4–17.7)	19.2 (19.0–19.4)
2017	35,140	15.4 (15.2–15.6)	12.0 (11.9–12.1)	35,847	17.6 (17.5–17.8)	19.1 (18.9–19.3)
2018	34,863	15.1 (15.0–15.3)	11.6 (11.5–11.8)	36,076	17.5 (17.3–17.6)	18.6 (18.4–18.8)
2019	35,138	15.1 (14.9–15.2)	11.5 (11.3–11.6)	36,375	17.3 (17.1–17.5)	18.2 (18.0–18.4)
2020	45,675	19.4 (19.2–19.6)	14.6 (14.5–14.7)	52,251	24.6 (24.3–24.8)	25.4 (25.2–25.6)
2021	38,690	16.3 (16.2–16.5)	12.3 (12.1–12.4)	41,313	19.2 (19.0–19.4)	19.7 (19.5–19.9)
2022	39,988	16.8 (16.6–16.9)	12.4 (12.2–12.5)	40,809	18.8 (18.6–19.0)	19.1 (18.9–19.2)
2023	36,323	15.1 (15.0–15.3)	11.1 (11.0–11.2)	37,329	17.0 (16.8–17.2)	16.9 (16.7–17.1)
% difference 2020 vs. 2019		+ 28.5 %	+ 27.0 %		+ 42.2 %	+ 39.6 %
% difference 2023 vs. 2013		−0.7 %	−10.5 %		−6.1 %	−17.6 %

GBD estimates of dementia incidence and prevalence are computed indirectly by cause of deaths databases [18]. As we used the same source of information for mortality, also our estimated mortality rates of PLWD reported an increasing trend. On the other hand, we accessed to other official Italian databases to compute directly incidence estimates, resulting in decreasing trends. As other authors reported on the same topic, GBD data may not fully provide a reliable dementia incidence estimate because they are based on different data sources from various time periods and case ascertainment methodologies [13]. This leads to wide 95 % uncertainty intervals, reflecting the overall uncertainty of the estimates. Several recent studies in high-income populations across Europe and North America reported declining trends [8, 9, 19, 20], aligning with our findings. These studies, as ours did, computed dementia incidence based on the dementia diagnosis, according to the International Classification of Diseases (ICD), representing a stable definition over time. Data sources provided real-world data from disease registries or primary care practices. *Hegelund et al* computed age- and sex-standardised incidence trends of dementia from 2005 to 2018 in Denmark. *Bohlken et al, Kirson et al, and Cersuolo et al* computed dementia incidence crude rates in Germany from 2015 to 2019, in US from 2007 to 2014, and in Canada from 2002 to 2013 respectively.

Our study reported the greater incidence reduction in older age groups. This trend is consistent with the prevalence reduction over the last decade of specific risk factors for dementia which impact on middle and later life of the general population. Among them, the Lancet Commission identified particulate matter air pollution, PM2.5 (fine particles with a diameter ≤2.5 μm), and PM10 (particles with a diameter ≤10 μm), smoking, hypertension and high LDL cholesterol were risk factors for dementia and cognitive impairment [2,21]. Notably, we observed over the last two decades an air pollution of PM2.5 and PM10 sharp reduction throughout Lombardy [22]. Also, smoking and cardiovascular risk reduction was reported Northern Italy over the last 10 years [23]. Similar findings highlighting the impact of lifestyle interventions against smoking and cardiovascular risk factors on dementia incidence were already reported by other studies [4, 6, 24], supporting the importance of preventive health policies for dementia.

Our study reported all-causes age-standardised mortality estimated rates among PLWD much higher than among people without dementia. These results are consistent with an updated meta-analysis, which reported a risk of all-causes mortality in PLWD 5.9 times higher, as compared to people without dementia [25]. The constant increase of all-causes mortality over the study period led to a grow in mortality estimated rates by 14.0 % among women and by 21.8 % among men. Our trends are consistent with other Italian data over a similar study

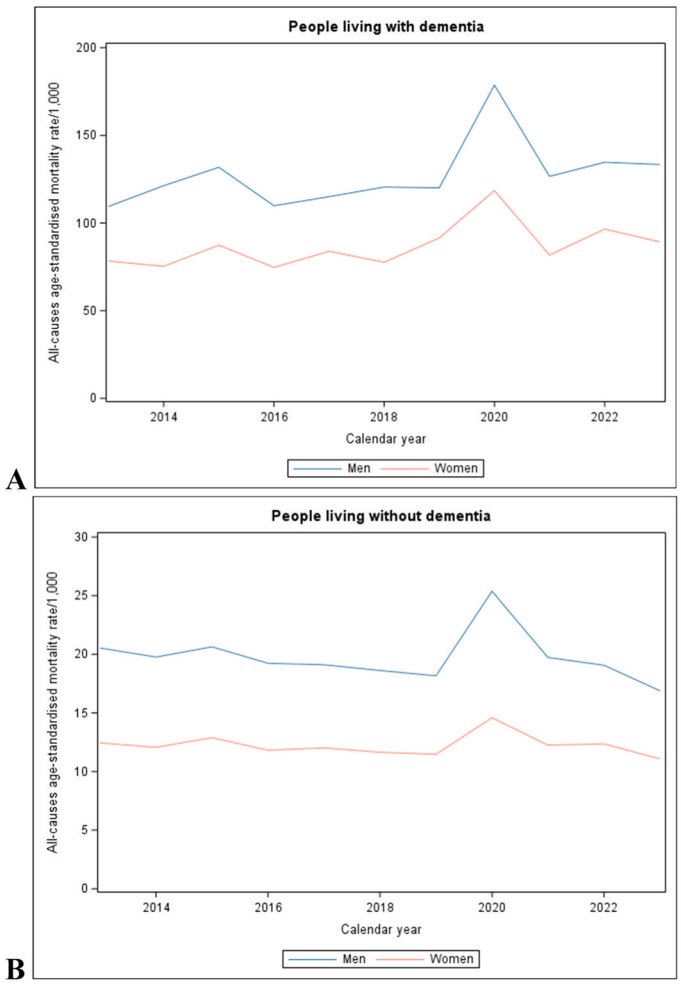

Fig. 2. Age-standardised all-causes mortality trends in PLWD (A) and in the population without dementia (B) at age 50 or over, by sex, from 2013 to 2023 in Lombardy, Italy.

period from 2012 to 2019 [26]. To our knowledge, only few other US-based studies computed and analysed all-causes PLWD mortality trends over a decade, but with discordant results [7, 27, 28]. These studies followed cross-sectional and survey-based methods. The increase in PLWD all-causes mortality has led to the formulation of a potential explanation. Indeed, the improved management and life expectancy of people with cardiovascular disease, e.g. stroke, may have led to an increase of PLWD with higher risk clinical conditions. Similar findings were highlighted in previous studies [28]. Therefore, PLWD health profile has changed over time, accumulating a greater number of cardiovascular comorbidities over their entire lives compared to previous years. Therefore, improved survival rates of acute cardiovascular disease have on the one hand increased life expectancy and on the other one increased the risk of developing dementia. This new patient population results in more frail patients with higher mortality estimated rates.

Our findings reported gender inequalities among PLWD. Males experienced a greater increase in all-cause mortality during the research period. However, women experienced a larger excess of all-cause mortality estimated rates during the COVID-19 pandemic. Prior Italian research, using the same dementia case definition and source, indicated that males had a lower susceptibility to SARS-CoV-2 infection, but nonetheless faced a higher death risk in comparison to females, regardless of age [29]. This might suggest contrasting findings compared to ours. However, a systematic review about the impact of COVID-19 on PLWD highlighted that they experienced an excess of mortality not only attributable to the infection [30]. Indeed, they experienced social isolation, decrease in mental stimuli, greater use of antipsychotics and difficulties in supplying medical cares, leading to a higher all-cause mortality. This suggests that women suffered these conditions more than men. Future studies should stratify by sex these determinants of health, which could hide potential health inequities among PLWD.

The current study has both strengths and limitations. Among the strengths, first, we conducted a region-wide analysis using individual data, thus covering all health records of Lombardy's inhabitants and including all their accesses to the regional health services over 20 years. The long time period and extensive geographical coverage allowed us to perform a comprehensive analysis of an entire population within the most populous Italian region. Second, the current study investigated a huge sample size in the literature from a 10 million population over a decade. To our knowledge, this represents the largest cohort study on dementia incidence and mortality in the literature. Third, PLWD cases are identified by the use of a validated algorithm [15]. Our algorithm identified PLWD from the combination of hospital discharge records, drug prescriptions, administrative exemptions and long-term care admissions. Therefore, the design of the system prioritized the detection of confirmed cases rather than identifying early symptoms or cases that have not been officially diagnosed. The algorithm, validated by the Italian National Health Institute, was designed to analyse Italian administrative data [15]. This algorithm was already employed in several studies [15, 31–33]. The algorithm demonstrated a sensitivity of 74.5 %, a specificity of 96.0 %, and an overall accuracy of 85.3 % in detecting dementia cases [15]. Thus, the algorithm gave more consistency and reproducibility to the study. In addition, the study is based on good quality health administrative data, which is now used for both descriptive and analytical objectives [16]. Indeed, several studies were performed using Lombardy's Data WareHouse [33–36]. At last, to our knowledge, this is the most updated study among high-income countries, analysing the incidence and all-causes mortality and using real-world data. This study covered a period from the beginning of the 2010s till the end of 2023 and is the unique comprehensive analysis that encompasses both the pre-pandemic, pandemic and post-pandemic periods. The prompt availability of information derived from administrative databases enables the monitoring of dementia epidemiolocal trends in the region and timely planning actions.

Among the limitations, first, administrative databases do not allow for a full description of patients' clinical characteristics. As a result, this study did not stratify health outcomes of PLWD between different types of dementia, such as vascular dementia, Alzheimer's dementia and Lewy body dementia. In addition, besides sex and age, there is a lack of information on some relevant subgroups of population (e.g. place of living, socioeconomic status), which can show different incidence and mortality rates. Furthermore, administrative data rely on proper reporting by the physicians involved. This can lead to under-coding phenomenon, failing to identify PLWD cases. The validated algorithm also reported lower accuracy in detecting dementia among younger or less educated people. This may lead to providing varying degrees of underestimation among age classes and social groups. Finally, the dementia cases are identified based on criteria that may delay the identification of the first diagnosis and miss those with a shorter duration of the disease, losing the exact number of new cases in each calendar year. To limit this bias, we identified also PLWD from 2000 to 2012 according to the validated algorithm, and subsequently subtracted any cases from 2013 onwards that could be considered prevalent prior to this period. This approach ensures a more accurate estimation of incident cases after 2013 by excluding those that may have been prevalent earlier.

This study has several implications for public health. The decrease in incidence and increase in mortality suggest that the prevalence percentage of dementia decreased over the last decade. However, the absolute numbers of PLWD may continue to rise due to the population aging. Compared to estimates and forecasts, our data provide more reliable information for policymakers and suggest establishing region or national-wide monitoring tools to compute prevalence, incidence and

mortality for dementia.

Given that public health policies related to dementia risk factors may have acted positively on reducing incidence of dementia over the last decade, especially on older adults, it is necessary to continue to analyse that correlation and maximize efforts on prevention of the 14 risk factors reported by the Lancet Commission on Dementia.

Conclusions

Our findings revealed both a decrease in dementia incidence and an increase in mortality among PLWD. We also identified gender disparities that had previously been under-investigated. There is an urgent need to evaluate both the impact of social determinants of health and the access-to-care of this population. Indeed, risk factors for dementia and their population attributable fractions may also synergistically affect people, based on their gender, ethnicity, or socioeconomic status, and outline vulnerable groups at higher risk of dementia. Future findings may support public health to break potential vicious cycle and prevent health inequities.

CRediT authorship contribution statement

Blandi Lorenzo: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Odone Anna:** Writing – review & editing, Writing – original draft, Validation, Supervision, Methodology, Conceptualization. **Brand Helmut:** Writing – review & editing, Visualization, Validation, Supervision, Conceptualization. **Clemens Timo:** Writing – review & editing, Validation, Supervision, Conceptualization. **Bertuccio Paola:** Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Methodology, Formal analysis, Data curation, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.annepidem.2025.03.007.

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