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RESEARCH ARTICLE

Incidence of dementia over a period of 20 years in a Norwegian population

Bente Johnsen M.D.[1,2] | **Ieva Martinaityte PhD, MD**[1,2] | **Tom Wilsgaard Prof**[3] | **Henrik Schirmer Prof**[4,5]

[1]Department of Clinical Medicine, UiT The Arctic University of Norway, Tromsø, Norway

[2]Department of Geriatric Medicine, University Hospital of North Norway, Tromsø, Norway

[3]Department of Community Medicine, UiT The Arctic University of Norway, Tromsø, Norway

[4]Department of Cardiology, Akershus University Hospital, Lørenskog, Norway

[5]Institute of Clinical Medicine, University of Oslo, Oslo, Norway

Correspondence
Bente Johnsen, Department of Geriatric Medicine, University Hospital of North Norway, PO 100, 9038 Tromsø, Norway.
Email: bente.johnsen@unn.no

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Abstract

INTRODUCTION: In Norway, the prevalence of dementia is higher than in demographically comparable, high income countries, but reliable incidence studies are lacking. This study calculated the incidence of age-specific dementia from 2000 to 2019.

METHODS: Participants from The Tromsø Study (n = 44,214) were included. Participants with a dementia diagnosis (n = 2049 cases) were identified. Poisson regression was used to calculate age-specific yearly and 5-year incidence rates from 2000 to 2019.

RESULTS: The incidence of dementia has decreased from 2000 to 2019. The trend was highly significant for ages of 60–99 years, and was similar for both sexes.

DISCUSSION: The incidence of dementia in North Norway has decreased over the past two decades similar to that in Western countries, indicating that the total prevalence is increasing due to an aging population. This decrease of incidence could introduce a reduction in future estimation of dementia prevalence.

KEYWORDS
dementia, incidence, Norway, prevalence

1 | INTRODUCTION

Dementia is a deadly neurodegenerative disease that affects cognitive function and behavior, has a significant impact on patients and their families, and is associated with a marked socioeconomic burden. It is associated with a wide range of health and social care needs, including long-term care services. Global burden of disease[1] estimated that worldwide 57.4 million of the older adult population experience dementia, and the prevalence is indicated to triple by 2050.[1,2] In 2019, dementia was the seventh leading cause of death worldwide according to the World Health Organization,[3] however, the second leading cause of death in high-income countries (HIC). In Norway, a HIC, dementia was the third leading death cause in 2021.[4] Knowledge of the future incidence and prevalence of this severe disease is important for planning health care resources and enabling health care systems to provide the best care and treatment for people with dementia and their families. A new report by Gjøra et al., after a rigorous study in 2020 has shown a higher prevalence in Norway, compared to similar countries.[5] The authors estimated that the prevalence numbers would double by 2050, and quadruple by 2100. However, they did not account for future incidence changes. Studies in the United States have already reported a decline in prevalence between 2000 and 2012.[6] A growing body of evidence suggests that the incidence of dementia is declining in Western countries,[6–8] although the global incidence is still 10 million yearly, with increase in Asia, the Americas and Africa, according to the 2015 World Alzheimer's Report.[2] The Alzheimer

Consortium reported in 2020 a decline in the incidence of dementia by 13% per decade in Europe and North America, more so in men than in women.[8] Similar declines in incidence have been found in other Scandinavian studies,[9,10] but incidence studies in Norway over time are lacking.

Although the prevalence of dementia is increasing due to longevity of the population and aging, known risk factors for dementia are improving, including cardiovascular risk factors and higher education.[11–15] Higher education has been shown to protect against dementia,[15] but has also been argued to only delay the onset due to increased cognitive reserve capacity in those with higher education.[16] Education levels have increased in HICs in the past century, especially among women.[14] Therefore, the secular trends in the incidence of dementia in the Norwegian population are of great interest. Our aim was to explore the time trends of incidence of dementia in a large Norwegian population over two decades.

RESEARCH IN CONTEXT

1. **Systematic review**: PubMed was used to review literature. Findings suggest an increase in incidence in Asia, America, and Africa. The incidence of dementia seems to be declining in Western countries, but there are great heterogeneity in samples and methods. Notably, there is a lack of longitudinal incidence studies in Norway. Dementia ranks as the third leading cause of death in Norway, and its prevalence has been found to be higher compared to similar countries.
2. **Interpretations**: In this study of a large community dwelling cohort followed for 46 years, our findings indicate a decline in the age-specific incidence of dementia over the past two decades. The trend was highly significant among individuals aged 60–99 years, and was observed in both males and females.
3. **Future directions**: The results in this large study implies a modification to the forecast of tripling prevalence of dementia over the next 30 years. The higher prevalence in Norway can likely be attributed to increased longevity, as incidence of dementia is declining

2 | METHODS

2.1 | Study design

The Tromsø Study is a community based longitudinal cohort-study. It was initiated in 1974 to investigate heart disease, but was later developed to include a broad variety of morbidities and risk factors. It has been repeated every 7–8 years and invited individuals from the municipality of Tromsø in North Norway, both previous and new participants, to respond to each survey. It has a high participation proportion of at least 65%.[17] For each survey, participants completed one or more questionnaires, underwent physical examinations, and laboratory tests.

2.2 | Study population

To calculate the incidence of dementia, participants from Tromsø1–7 were included (Figure 1). The inhabitants of Tromsø are mainly Caucasian, have access to a good, publicly funded health care system and free education, in an urban setting of approximately 77,000 inhabitants.

Endpoint data were retrieved from hospital records in the only hospital in the area, the University Hospital of North Norway, in the years 2000–2019. We identified patients who had previously participated in The Tromsø Study, and later were diagnosed with a dementia diagnosis. Using the International Statistical Classification of Diseases and Related Health Problems (ICD-10), coding Alzheimer's disease, vascular dementia, Lewy body dementia, Parkinson's dementia, and other specified and unspecified dementia diagnoses were included. The ICD codes and corresponding definitions are provided in the supplementary (table e-1).

We conducted a validation study with 150 patients, randomly chosen from each 5-year period up to the end of 2015. The records from each patient were manually reviewed to verify the diagnosis. To validate the registry from 2016 to 2019, we linked the registry to an ongoing multicenter study "The Norwegian registry of persons assessed for cognitive symptoms",[18] and we were able to validate additional 255 diagnoses from 2016 to the end of 2019. The diagnosis of dementia had high specificity (99%). The specificity of the subtype was lower (89%); therefore, we did not analyze the data set for the dementia subtypes.

2.3 | Ethics and approval

The study has been approved by the Regional Committee of Medical and Health Research Ethics in Norway (REK Sør-Øst, 2016/389) and the Data Protection Officer at University Hospital North Norway. Each participant signed a written informed consent. Consent to use the data in future research was also obtained.

2.4 | Statistical analysis

The Tromsø Study1–7 was linked to the dementia end-point registry. As we had few incident dementia cases ($n = 228$) before year 2000 and we wanted to include only new cases, we included participants who had their first dementia diagnosis registered in the hospital records from January 1, 2000. The diagnosis of dementia was dichotomized yes/no. The baseline for follow-up was the first date of participation in any Tromsø Study survey. If the first diagnosis of dementia was established

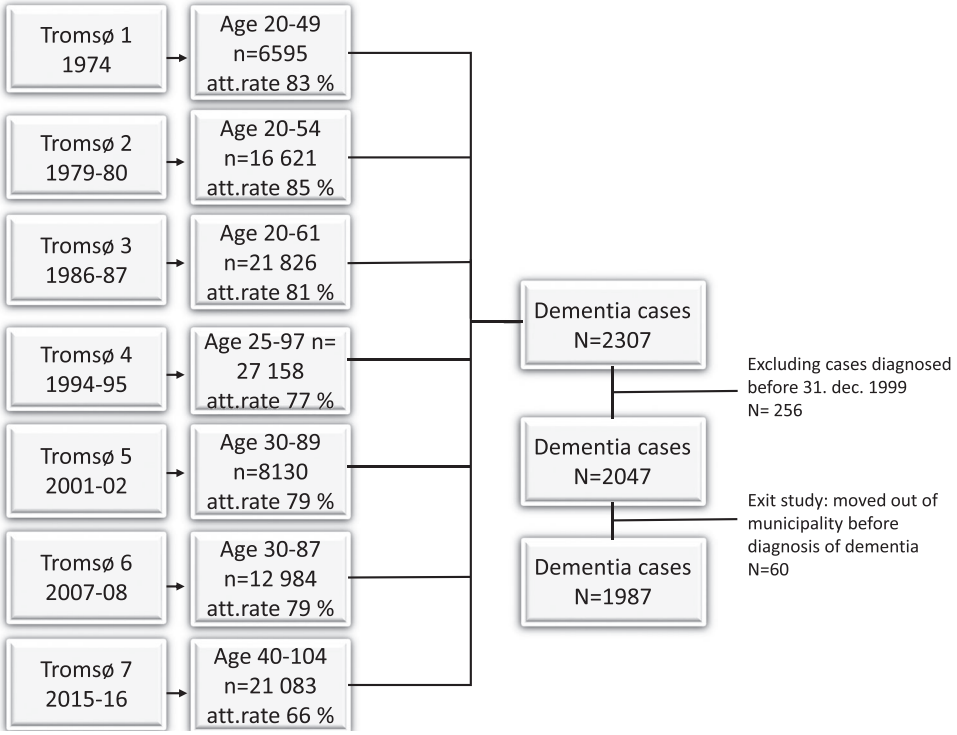

FIGURE 1 Flow chart of the participants by survey of The Tromsø Study 1–7.

before baseline, the participant was excluded. The exit date was set to the date of the first dementia diagnosis in hospital journals, the date of death, date of moving out of the municipality or the end of study; date December 31, 2019, whichever came first. The age at the start of the study was set at 1. July of the entry year minus the birthdate, divided by 365.25.

We generated a new observation for each participant for each calendar year from 2000, including age, time in years, and dementia status. We then made 10-year age groups from 50 years and older, and performed the following analysis on each age-group separately:

We used Poisson regression models to assess the association between calendar time and dementia incidence. Calendar time was modelled using fractional polynomials. The best-fitting model (out of 44 models) was determined using Akaike's information criterion. In separate Poisson models, calendar time was modelled as a categorical variable with indicator variables for each calendar year. All models were adjusted for age (Figures 2 and 3).

The incidence rate ratio was calculated by comparing the incidence in 2000 and the incidence in 2019 for each age group. To test for significant time trends, we used a likelihood ratio test that compared a model with and without calendar time.

To control for a small number of cases in annual rates within age groups, we combined calendar time into 5-year intervals and calculated incidence rates per 1000 person-years with 95% confidence intervals (CI) for each time and age group.

All analyses were performed using Stata version 17.0; StataCorp College Station, Texas, USA.

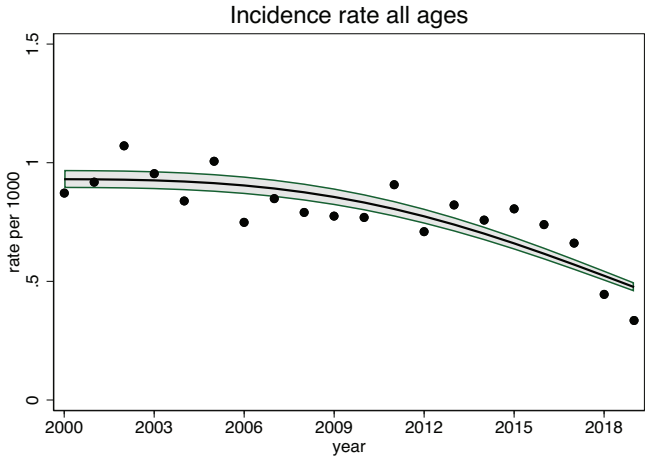

FIGURE 2 The age-adjusted annual incidence rate of dementia per 1000 person-years in participants from 50 to 99 years old. The black line indicates the mean, and the gray area shows the 95% confidence interval of the mean.

3 | RESULTS

3.1 | Characteristics of participants

A total of 44,214 participants were included in The Tromsø Study from 1974 to 2016. The baseline characteristics of the population are presented in Table 1. Of these, 2047 (58% women) developed dementia after 31 December 1999. The mean age for dementia diagnosis

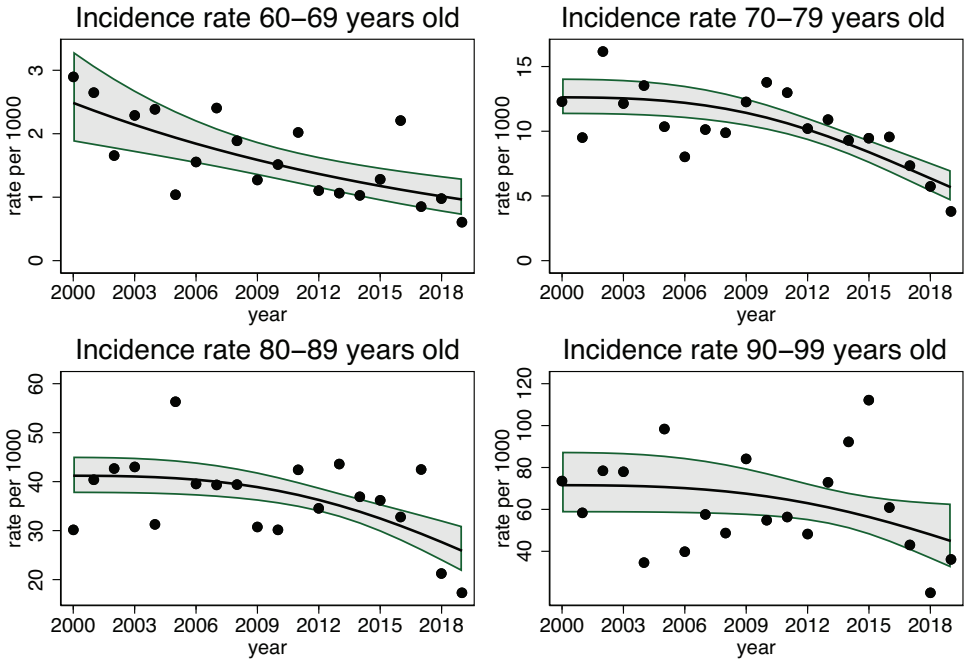

FIGURE 3 Age-adjusted annual incidence rate per 1000 person-years by age groups. The black line indicates the mean, and the gray area shows the 95% confidence interval of the mean.

was 81.5 (95% CI, 81.0–82.0) for women and 78.8 (95% CI, 78.3–79.3) for men. Person-years from year 2000 to the end of 2019 were 495,035. There were fewer men than women who developed dementia (874 men, 1205 women). Those who developed dementia, reported to be more inactive, had lower education level, had more hypercholesterolemia, and hypertension. They also reported more depression and anxiety (Hopkins symptom check list).

3.2 | Incidence

During a 20-year period, we found that incidence decreased in the entire sample aged 60–99 years, with no significant interaction between sex and time. The decrease was significant in each 10-year age group. For participants 50–59 years of age, there was no significant change in the incidence of dementia (Table 2).

4 | DISCUSSION

In this study of a large community-based cohort followed for 46 years, we found that age-specific incidence of dementia in 5-year time groups had decreased by up to 61% over the past two decades. The trend was significant in participants aged 60–99 years, and was similar for both sexes. This could introduce a modification to the forecast of a tripling prevalence over the next 30 years in both Norway and other comparable populations.[2,5]

To our knowledge, we are the first to report on the incidence of dementia over time in Norway. Our findings are similar to a study from the neighboring country Denmark, which used a registry of the entire national population,[10] over a similar time period (1996–2015). However, the study found an increase peaking in 2010, followed by a 2% annual decrease to 2015, along with a continuous increase in prevalence in all age groups, without birth cohort effects. They also found that the prevalence increased most among the older age groups, supporting the hypothesis that higher longevity is a partly cause of the increasing prevalence. A decrease first after 2010 was not seen in our study, suggesting a different development in Danish and Norwegian populations in regards to risk factor improvement.

Several other studies have shown the same decreasing incidence trends in dementia in those 60 years or older, supporting our findings. The Framingham Heart Study in the USA[7] found a 20% decrease in incidence per decade from 1977 to 2008 in participants 60 years or older without the peak seen in 2010 in the Danish population.[19] Sweden, found a 30% decrease in incidence in 1987–2004, in participants over 75 years of age.[9] Other studies compared two time points, such as the Rotterdam Study comparing dementia incidence in 1990 and 2000,[20] and found a decrease of 25% without statistical significance. A German study reported an incidence decrease between 2006 and 2009,[21] although 3 years of follow-up could be too short to conclude on a potential trend. Stronger trend findings can be found in the British studies, where a 20% decrease in incident dementia in people over 65 years of age was reported, between the two waves that occurred in 1990–1995 (CFAS I) and 2008–2013 (CFAS II).[22] Our study strengthens the findings of a decrease in age-specific incidence in western European and North American populations, where no studies have reported an increase in incidence over the past two or three decades.

We did not find any decrease in incidence for the population under the age of 60 years. Research on young-onset dementia epidemiology is scarce. A small incidence study from Norway included 89 cases under

TABLE 1 Participants from the Tromsø Study1–7; description at baseline; *p*-values, are calculated from chi-squared test, except for age calculated by t-test.

	Total	Dementia free	Dementia cases	
Variable	***N* = 44,214**	***N* = 42,167**	***N* = 2047**	***p*-Value**
Age at participation	37.8 (14.1)	36.9 (13.4)	55.5 (16.7)	<0.001
Men	50% (22,068)	50% (21,214)	42% (854)	<0.001
Follow-up time	27.0 (13.8)	27.1 (13.8)	23.9 (12.1)	<0.001
Physical activity				<0.001
Inactive	29% (12,612)	28% (11,622)	48% (990)	
Active	51% (22,402)	52% (21,609)	39% (793)	
Very active	20% (8985)	21% (8726)	13% (259)	
Education				<0.001
7–10 years primary/secondary/technical school	25% (8794)	23% (7869)	63% (925)	
High school diploma (3–4 years)	28% (9766)	28% (9411)	24% (355)	
College/university, less than 4 years	20% (6980)	20% (6892)	6% (88)	
College/university, 4 or more years	28% (9716)	28% (9615)	7% (101)	
BMI-level				<0.001
< −18.5	2% (937)	2% (915)	1% (22)	
18.5–25	62% (27,010)	62% (25,970)	51% (1040)	
25–30	28% (12,167)	27% (11,415)	37% (752)	
30–35	7% (2945)	7% (2755)	9% (190)	
35–>	2% (810)	2% (777)	2% (33)	
Hopkins symptom check list				<0.001
No symptoms	19% (3318)	19% (3256)	7% (62)	
Some symptoms	51% (9019)	50% (8475)	62% (544)	
Sub-threshold symptoms	21% (3832)	21% (3643)	21% (189)	
Significant symptoms	9% (1670)	9% (1581)	10% (89)	
Smoking				<0.001
Yes, now	40% (17,821)	41% (17,067)	37% (754)	
Yes, previously	23% (10,064)	23% (9515)	27% (549)	
Never	37% (16,187)	37% (15,455)	36% (732)	
Other risk factors and comorbidity				
Living alone	36% (15,993)	36% (15,355)	31% (638)	<0.001
Hypertension	20% (8855)	19% (7911)	46% (944)	<0.001
Hypercholesterolemia	71% (31,170)	70% (29,246)	94% (1924)	<0.001
Stroke	1% (358)	1% (307)	3% (51)	<0.001
Diabetes	1% (592)	1% (532)	3% (60)	<0.001
Heart attack	1% (507)	1% (434)	4% (73)	<0.001

the age of 64 years who reported higher incidence rates compared to previous studies from other comparable countries, but did not assess incidence over calendar time.[23] A recent large meta-analysis reported that the global incidence rate of young-onset dementia was 11 per 100,000, corresponding to 370,000 new cases annually worldwide,[24] but here also incidence over time was not reported. The incidence of young-onset dementia in 2000–2014 from our data seems to be similar to that in the meta-analysis, but appears to be increasing to 32 per 100 000 in years 2015–2019. The reason of higher rates in our population may be due to that most young people with cognitive problems in the region are evaluated in our hospital, and may reflect more precise real incidence rates.

The secular trends of incidence are important for estimating the burden of dementia, since the prevalence of this disease increases with prolonged longevity and better health care.[25,26] Forecasts may be complicated as the modifiable risk factors for dementia also

TABLE 2 Five-year incidence rate per 1000 person-years by age group; The Tromsø Study.

Age group	50–59		60–69		70–79		80–89		90–99	
5-year group	IR/1000	95% CI	IR/1000	95% CI	IR/1000	95% CI	IR/1000	95% CI	IR/1000	95% CI
2000–2004	0.27	(0.14–0.52)	2.7	(2.1–3.6)	15.2	(13.1–17.5)	37.8	(32.8– 43.7)	63.5	(44.4–90)
2005–2009	0.26	(0.13–0.5)	1.4	(1.4–2.4)	12.0	(10.3–14.1)	41.4	(36.5–47.1)	63.9	(49.2–88)
2010–2014	0.2	(0.1–0.43)	1.2	(1.2–2.1)	12.7	(11.0–14.7)	39.4	(34.8–44.6)	66.4	(51.9–84.9)
2015–2019	0.32	(0.18–0.57)	1.1	(1.1–1.9)	7.7	(6.5–9.0)	30.1	(27.0—35.4)	52.8	(41.1-67.7)
Person years	139196		106049		58919		23531		3280	
IRR,										
2000 vs. 2019	1.0	(0.23–4.2)	0.39	(0.15–1.02)	0.45	(0.41–0.49)	0.88	(0.46–1.7)	0.63	(0.51–0.78)
Time-trend *p*-value	0.99		<0.001		<0.001		<0.001		0.04	

Abbreviations: IR, incidence rate; IRR, incidence rate ratio.

affects the estimates.[15] Though some of the risk factors, such as hypercholesterolemia,[27] hypertension, and smoking prevalence, are decreasing[13,15,28] and protective factors such as physical activity in leisure time[12,29,30] and education levels are increasing,[31] other risk factors such as the prevalence of diabetes and obesity are increasing.[29,32] However, overall improved risk factor levels in the population have already been shown to cause a decrease in incidence of stroke and myocardial infarction, and could also have contributed to the decrease in the incidence of dementia. As longevity increases due to the improvement of common risk factors for other deadly diseases, the prevalence of dementia, on the other hand, is still increasing, as Norwegian[5] and Danish studies[10] showed. However, the prognosis of the estimated future prevalence of dementia may have to be adjusted considering the decreasing incidence, as demonstrated in a study in England and Wales, where the estimated increase in prevalence was reduced by more than 50% over the next 20 years when the reduction in incidence was accounted for.[33]

4.1 | Strengths and limitations

This was a large follow-up study covering over 20 years with a large cohort and many cases, and the participation rate was high. The specificity for the diagnosis of dementia was high.

The study limitations included that the study was performed in a small geographical area with a homogenous population of mostly Caucasian people. As the endpoint registry only includes patients diagnosed or registered in hospital records or noted in death certificates, there may be unrecognized cases of dementia in the population. However, when merging with death registry, only six more cases appeared, and historically, dementia diagnosed in a hospital setting was required in the Tromsø municipality to be admitted to a nursing home. Accordingly, a majority of the dementia patients would have passed through a specialist evaluation at the hospital. Report or observation bias may also appear, as there is less focus on registering dementia diagnoses outside of geriatric / age psychiatric units.

5 | CONCLUSIONS

The incidence of dementia in Northern Norway has decreased over the past two decades for age groups 60-99, indicating that the observed increase in prevalence is due to an aging population and not an increase in the incidence of dementia. Accordingly, future prevalence estimates may have to be downscaled.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. Author disclosures are available in the supporting information.

DATA AVAILABILITY STATEMENT

Data cannot be made public as legal restrictions are set by the Tromsø Study Data and Publication Committee in order to control data. To prevent possible reverse identification, any sensitive participant information was deidentified. The data can be made available from the Tromsø Study for researchers by the Tromsø Study Data and Publication Committee. Contact information: The Tromsø Study, Department of Community Medicine, Faculty of Health Sciences, UiT The Arctic University of Norway; e-mail: tromsous@uit.no

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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