The Prevalence and Subtypes of Young Onset Dementia in Central Norway: A Population-Based Study

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Abstract.
Background: Young onset dementia poses several challenges for the individual, health care, and society that are not normally relevant for late onset dementia, but is little researched.
Objective: To determine the prevalence and subtypes of young onset dementia in a defined catchment area in central Norway.
Methods: The main sources of patient identification were the databases at the Department of Neurology, University Hospital of Trondheim (St. Olav's Hospital), and Department of Psychiatry, Levanger Hospital. Both departments are the main sites for referral of young onset dementia (onset before age 65 years) in the county, covering approximately 90% of the catchment area of the study. Other sources included key persons in the communities, collaborating hospital departments examining dementia, and review of hospital records of all three hospitals in the area. Included patients met the DSM-IV criteria for dementia. The prevalence of dementias was calculated by sex and age.
Results: All patients identified with dementia and onset before 65 years on census date were included in the study ($n = 390$). Patients younger than 65 on census date were included in the calculation of prevalence, giving a result of 76.3 per 100 000 persons at risk in the age category of 30–65 years, and 163.1 per 100,000 for the category 45–64 years. Etiology was heterogeneous, but the main subtype of dementia was Alzheimer's disease.
Conclusions: Young onset dementia affects a significant number of people in central Norway. Prevalence figures are higher than previously reported from England and Japan, but are similar to a more recent study from Australia.

Keywords: Alzheimer's disease, early onset dementia, epidemiology, prevalence

INTRODUCTION

There has been extensive research on the prevalence of dementia in later stages of life, but few studies on the prevalence among younger patients, probably due to a considerably higher prevalence of dementia in the older population. Dementia is challenging in any case, but can be disastrous for patients and their families when it strikes at a young age. Young onset dementia (YOD), also known as early onset dementia, is commonly defined as dementia with onset before the age of 65 years. YOD impacts family, income, occupational and social life, and imposes an appreciable challenge to health care and dementia services [1–3]. These may be inexperienced

in addressing the special needs of this younger group of patients [4].

Prevalence studies on YOD vary in design and the results are conflicting. In recent years, only four population-based reports have been published where the design is relatively comparable: two from England, one from Japan, and one from Australia [5–8]. All studies relied on multiple case ascertainment to identify patients diagnosed with YOD. The results in the studies from England and Japan are fairly consistent, whereas the report from Australia indicates a higher prevalence.

The prevalence of YOD in Scandinavia has not been well documented to date. A population-based Swedish study from the area of Lundby actually found no patients with dementia under the age of 60 when prospectively investigating the total population between 1957 and 1972, and only one patient under the age of 65 [9]. Two other hospital-based reports from Sweden and Denmark produced diverging, though higher prevalence estimates of YOD than the Lundby-study [10, 11]. There are currently no publications on the prevalence of YOD from Norway.

Reliable epidemiological data on the occurrence of YOD are vital for medical professionals, providers of health care and policy makers. The aim of this study was to provide an estimate of the prevalence and subtypes of YOD in central Norway.

MATERIAL AND METHODS

Population base

Trøndelag is a county in central Norway with a total population of 449,769 as of July 1, 2016, representing 9.8% of the total population. Trøndelag includes both urban and rural populations. By far the largest municipality is the city of Trondheim with a population around 188,000. The populations in the remaining 48 municipalities range from 469 to 23,308 inhabitants. Trøndelag has slightly fewer immigrants than the national average (10.5% versus 16.3%), but the level of education, unemployment rate and general health do not differ significantly [12].

Health care organization

Norwegian health care is organized in a dual system of primary and secondary services. Primary health care is a municipal responsibility and consists of general practitioners (GP) and general health care services such as home nursing care, day care centers,

and nursing homes. Hospitals and other specialist facilities form the secondary level. Close communication between levels improves patient follow-up and increases transparency. There are three hospitals in Trøndelag: a University Hospital in Trondheim, and local hospitals in Levanger and Namsos. According to national guidelines, people under the age of 65 with symptoms indicating dementia should be referred to a specialist clinic for diagnostic work-up. Each municipality is urged to provide the services of a dementia team [13].

Health care in Norway is largely financed by public means, and private health care in the field of dementia is negligible outside the family environment.

Case identification

Primary sources

Primary sources were the hospital databases at the Department of Neurology, University Hospital of Trondheim, and the memory clinic of the Department of Psychiatry, Levanger Hospital. Both departments are main referral sites of YOD in their catchment area, covering over 90% of the target area. They constitute the leading research facilities in the study. All patients who received a diagnosis of dementia with onset < 65 years by the leading research facilities were included.

Secondary sources
Hospital based:

a. Computerized hospital records from all three hospitals were researched for potential patients with a diagnosis of dementia according to ICD-10. Patients were categorized into two groups: 1) Patients who received any diagnosis of dementia, (including G30.1 Alzheimer's disease (AD) with late onset and/or F00.1 Dementia in AD with late onset) before the age of 70, and 2) Patients who had received a diagnosis of AD with early onset (G30.0) and/or dementia in AD with early onset (F00.0). All patients and/or primary caregivers were contacted by mail and telephone in order to determine the accuracy of diagnosis, and to estimate the age at onset (AAO).

   Patients who were obviously miscoded were not included.

b. Specialized outpatient services for individuals with intellectual disabilities are located in both Trondheim and Levanger, but serve the entire catchment area, and enabled inclusion of all

patients who had received a diagnosis of YOD. These services routinely evaluate patients with Down's syndrome (trisomy 21).

c. Physicians at other departments working in close collaboration with our research group were informed about the study, and assisted with the inclusion of patients who met the criteria.

Community based

d. Dementia teams in all the 49 municipalities in the target area were personally contacted by telephone and asked to scan their municipality for candidates. In municipalities without specialized dementia teams, the heads of home nursing services were contacted. It was emphasized that all subtypes of dementia were eligible, and that patients currently older than 65 years also could meet inclusion criteria depending on the duration of symptoms.

e. If the dementia teams did not have extensive knowledge of the patients in day care centers and sheltered housing or nursing homes in their area, the facilities themselves were requested to identify potential candidates.

f. A regional center for Huntington's disease (HD) with extensive knowledge about patients throughout the entire target area with this condition provided basic information on patients with dementia.

MKA and SBS were the lead researchers in this study. Except for cases identified by SBS at the Department of Neurology in Trondheim, all the steps in case ascertainment were conducted by MKA over a period of four years between July 2014 and July 2018. Due to a lengthy investigatory process, census date was set in the middle of the inclusion period (July 1, 2016) to minimize the time between inclusion and census date. A small sample of three patients made known to us clinically were included in the days following the end of the recruitment period.

The study was approved by the Regional Committee for Medical and Health Research Ethics (REK Midt 2014/487).

Case verification

Included patients met the clinical criteria for dementia according to the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edn. and were alive and residing within the catchment area on census date [14]. Dementia on census date was systematically verified either through personal telephone interview with caregivers or hospital records, or both.

Diagnostic validation

Validated diagnostic criteria were applied for the diagnosis of various neurodegenerative diseases [15–22], vascular dementia (VaD) [23], and alcohol-related dementia [14]. Diagnostic criteria for AD, frontotemporal dementia (FTD), VaD, and alcohol-related dementia are consistent with Harvey et al. [8], Ikejima et al. [7], and Withall et al. [5]. Patients with intellectual disability and dementia (mainly Down's syndrome) were not further classified. Secondary dementias were categorized according to the underlying disease. Cases that did not meet a specific set of criteria were classed as "unspecified". Challenging cases with unclear etiology were classified following consensus meetings with specialists in neurology, geriatrics, and psychiatry.

AAO was defined as the age at appearance of the first symptom as recognized by caregiver or patient.

Consenting patients

Consenting patients who had not personally been assessed and included by the lead researchers, were consecutively evaluated through hospital records as we were made aware of them through our various sources. A telephone interview with a close caregiver was conducted by MKA if possible.

Non-consenting patients

Throughout the clinical work and investigatory process, we identified patients with YOD who were reluctant to participate in a medical research study. To limit inclusion bias, the Regional Committee for Medical and Health Research Ethics accepted our request to count these individuals, hence contributing to truer prevalence figures. Patients who did not provide formal consent are referred to as 'non-consenting patients'. All non-consenting patients were evaluated by the lead researchers. Patients older than 65 years on census date were excluded due to uncertainty of AAO. Only information on age, gender, and diagnosis was available for this group.

As patients with intellectual disability and patients with HD dementia were identified through reliable and collaborating sources, we did not seek further confirmation of these diagnoses.

Table 1
Sources of identification

Source	N (%)
Primary	*248 (63.6)*
Databases of:	
Dept. of Neurology	161 (41.3)
Dept. of Psychiatry	96 (24.6)
Both	9 (2.3)
Secondary	*142 (36.4)*
Hospital records	61 (15.6)
SOSII*	13 (3.4)
Other departments	7 (1.8)
Community research**	61 (15.6)

*Specialized outpatient services for individuals with intellectual disabilities. **12 patients were identified through the regional center for HD.

RESULTS

Patients

We identified a total of 410 individuals with YOD, of which 390 patients had dementia on census date and were included in the study. A total of 171 of these cases were between the age of 30 and 64 on census date and constituted the basis for the prevalence calculations. Sources of identification are listed in Table 1.

Diagnosis verification

Consenting patients

A total of 301 patients were consenting participants and subjected to a detailed review of hospital records. Almost two thirds of these patients received their diagnosis in leading research facilities ($n = 180$).

Clinical work-up

With the exception of one patient with alcohol-related dementia and one with AD, all consenting patients underwent some form of cognitive assessment in a specialist setting. For the isolated case of alcohol-related dementia, the diagnosis was determined on the basis of relevant hospital records, CT scan, and interview with a close family member. For the isolated case of AD, the patient had received the diagnosis from the GP, which was then confirmed in hospital records and by a close family member who described symptom progression typical of AD. All but this latter patient had some form of neuroimaging available for review. Table 2 gives an overview of the clinical work-up for consenting patients.

Non-consenting patients

A total of 89 patients were non-consenting participants. Of these, 55 patients were diagnosed by lead researchers or physicians in collaborating hospital departments. Nine patients were initially identified by hospital records in which the subtype of dementia in four of the cases was confirmed by their closest caregivers (two with AD, one with alcohol-related dementia, and one with FTD), three by collaborating physicians (one with AD, one with VaD, and one with metabolic disease), and two by the patient's GP (both alcohol-related dementia). Diagnoses of 13 patients with intellectual disability and dementia, and 12 patients with HD dementia, were confirmed by specialized regional centers for these conditions.

Descriptives

The mean age of the total population of YOD was 63.6 years (SD 8.3, range 21–81) and 58.0 years for patients who were under 65 years (SD 8.0) on census date. There was a significant difference between males and females within the total population of YOD (43.8 and 56.2%, respectively; $p = 0.02$), but not among patients younger than 65 years on census date (47.7 and 52.3%; $p = 0.52$).

Consenting patients

Mean AAO for consenting patients with YOD was 56.7 years ($n = 295$, SD 6.7, range 18–64). Mean age at diagnosis was 62.1 years ($n = 296$, SD 6.7, range 20–73). Roughly half of the consenting population (46.2%) were residing in residential care with no significant differences in gender.

Etiology

Degenerative disease accounted for the majority of cases in the sample, with AD representing more than two thirds of the degenerative dementias, and over half of all dementias. Of the 16 cases of vascular dementia, 11 were post-stroke dementias whereof 3 were caused by subarachnoid hemorrhage. Table 3 gives an overview of the distribution of diagnoses in the total sample of YOD.

Prevalence

A total of 171 patients were aged between 30 and 64 years on census date and constituted the basis for prevalence calculations. Only nine of these patients were younger than age 45 years. About 50% of the

Table 2
Medical evaluation of consenting patients

		Total n	Interview with caregiver*	Cognitive tests			Biomarkers				
				MMSE	Clock drawing test	TMT-A and/or -B	CERAD**	CSF analysis	MRI	Both CSF&MRI	DATscan
All	n	301	279	278	265	224	156	212	278	207	17
	%	100	92.7	92.4	88.0	74.4	51.8	70.4	92.4	68.8	5.6
AD	n	205	195	203	198	172	118	170	195	165	2
	%	68.1	95.1	99.0	96.6	83.9	57.6	82.9	95.1	80.5	1.0
FTD	n	26	26	24	24	19	16	21	26	21	0
	%	8.6	100.0	92.3	92.3	73.1	61.5	80.8	100.0	80.8	0.0
DLB/	n	21	18	21	19	16	13	11	18	11	13
PDD	%	7.0	85.7	100.0	90.5	76.2	61.9	52.4	85.7	52.4	61.9
VaD	n	11	10	6	3	11	1	0	7	0	0
	%	3.7	90.9	54.5	27.3	100.0	9.1	0.0	63.6	0.0	0.0

*Telephone interview performed by MKA. **CERAD Word List Test.

Table 3
Primary diagnoses in the sample (n = 390)

	n	%	F/M
DEGENERATIVE DEMENTIAS	311	79.7	185/126
Alzheimer's disease	219	56.2	142/77
Huntington's disease with dementia	30	7.7	12/18
Frontotemporal dementia	30	7.7	20/10
Dementia with Lewy bodies	19	4.9	7/12
Parkinson's disease with dementia	6	1.5	1/5
Posterior cortical atrophy	5	1.3	1/4
Progressive supranuclear palsy	1	0.3	1/0
Corticobasal syndrome	1	0.3	1/0
VASCULAR DEMENTIA	16	4.1	6/10
MIXED VaD/AD	6	1.5	3/3
OTHERS	45	11.5	18/27
Alcohol-related dementia	15	3.9	6/9
Intellectual disability and dementia (mainly Down's syndrome)	13	3.3	7/6
Acquired brain injury	8	2.1	2/6
Multiple sclerosis	4	1.0	2/2
Metabolic encephalopathy	3	0.8	1/2
Normal pressure hydrocephalus	1	0.3	0/1
Encephalitis	1	0.3	0/1
UNSPECIFIED	12	3.1	7/5

patients under 65 years were aged between 60 and 64 years. Table 4 gives an overview of the prevalence according to age and gender.

AD was the most prevalent subtype of dementia among patients between 30 and 65 years of age, followed by HD dementia, alcohol-related dementia, VaD, and FTD. We did not identify any case of AD or FTD under 45 years of age. Age-specific prevalence figures for the most common diagnoses are shown in Table 5.

DISCUSSION

This is the first population-based study to investigate the prevalence of YOD in Norway, and the first of its kind in Scandinavia. The population base constitutes around 10% of the national population, and does not differ significantly from that of the rest of Norway. We identified 390 patients with YOD of whom 175 were younger than 65 on census date. This qualifies as a large cohort investigating the epidemiology of YOD [5, 6, 24].

We found an overall dementia prevalence of 76.3 per 100,000 persons at risk in the age group of 30–64 years, and 143.1 in the age group of 45–64 years. These figures are similar to those found in Australia, and considerably larger than the results from England and Japan [5, 7, 8]. For comparison, the prevalence figures of various subtypes of dementia in relevant population-based studies with similar design are shown in Table 6.

Other studies with a different approach to that used by us have demonstrated a wide range of dementia prevalence among patients younger than 65 [10,

Table 4
Age- and gender-specific prevalence figures in the study population

Population			All			Male			Female		
Age range	Male (n)	Female (n)	n	Prev*	95% CI	n	Prev*	95% CI	n	Prev*	95% CI
30–34	14 955	13 956	2	6.9	(1.0–25.0)	2	13.4	(1.6–48.3)	0	–	–
35–39	14 451	13 145	1	3.6	(1.0–20.2)	0	–	–	1	7.6	(1.0–42.4)
40–44	15 656	14 683	6	19.8	(7.3–43.0)	5	31.9	(10.4–74.5)	1	6.8	(1.0–38.0)
45–49	16 094	15 507	7	22.2	(8.9–45.6)	5	31.1	(10.1–72.5)	2	12.9	(1.6–46.6)
50–54	14 908	14 146	27	92.9	(61.3–135.2)	11	73.8	(36.8–132.0)	16	113.1	(64.7–183.6)
55–59	13 762	13 199	44	163.2	(118.6–219.0)	21	152.6	(94.5–233.2)	23	174.3	(110.5–261.4)
60–64	12 830	12 732	84	328.6	(262.2–406.7)	42	327.4	(236.0–442.2)	42	329.9	(237.8–445.6)
30–44	45 062	41 784	9	10.4	(4.7–19.7)	7	15.5	(6.2–32.0)	2	4.8	(1.0–17.3)
30–64	102 656	97 368	171	76.3	(65.3–88,6)	86	74.9	(60.0–92.6)	85	77.7	(62.1–96.0)
45–64	57 594	55 584	162	143.1	(122.0–167.0)	79	137.2	(108.6–171.0)	83	149.3	(119.0–185.1)

*Prevalence proportion calculated per 100,000 people.

Table 5
Age-specific prevalence figures for the most common causes of YOD

Age range	Alzheimer's disease			Huntington's disease with dementia			Alcohol-related dementia			Vascular dementia			Frontotemporal		
	n	Prev*	95% CI	n	Prev*	95% CI	n	Prev*	95% CI	n	Prev*	95% CI	n	Prev*	95% CI
35–39										1	3.6	(1.0–20.2)			
40–44				5	16.5	(5.4–38.5)				1	3.3	(1.0–18.4)			
45–49				3	9.5	(2.0–27.5)				1	3.2	(1.0–17.6)			
50–54	6	20.7	(7.6–44.9)	4	13.8	(1.8–35.2)	2	6.9	(1.0–24.9)	1	3.4	(1.0–19.2)	1	3.4	(1.0–19.2)
55–59	15	55.6	(31.1–91.7)	3	11.1	(2.3–32.5)	2	7.4	(1.0–26.8)	3	11.1	(2.3–32.5)	7	26.0	(10.4–53.5)
60–64	53	207.3	(155.3–271.1)	5	19.6	(6.4–45.6)	7	27.4	(11.0–56.4)	4	15.6	(4.3–40.1)	4	15.6	(4.3–40.1)
30–64	74	33.0	(25.9–41.0)	21	9.4	(5.8–14.3)	11	4.9	(2.5–8.8)	11	4.9	(2.4–8.8)	12	5.4	(2.8–9.4)
45–64	74	65.4	(51.3–82.1)	15	13.3	(7.4–21.9)	11	9.7	(4.9–17.4)	9	7.1	(3.1–13.9)	12	10.6	(5.5–18.5)

*Prevalence proportion calculated per 100,000 people.

25–27]. It is commonly thought that such diverging results are due to variability of study design. Heterogeneous inclusion and diagnostic criteria, and deviating case ascertainment are well-known factors in this respect. Population-based studies are preferred to avoid selection bias, but are far more cost extensive, and often limited to small population sizes. Registry-based studies are traditionally thought to have a high level of case accuracy, and their ability to cover large areas increases the precision of the estimates. On the other hand, such studies are inevitably linked to the quality of the respective registry. The level of clinical assessment might vary and valid biomarkers are not always included. Studies based on a low level of clinical assessment favor sensitivity over specificity, and often tend to yield higher prevalence figures. This is often the case in studies where the entire study population is screened. These types of "screening-studies" also include patients that are undiagnosed and therefore unrecognized by the health care system in which the study is performed, both of which may contribute to higher prevalence. Studies based on identifying patients already diagnosed with dementia are dependent on the ability of the respective health care systems to do so, and differences in prevalence in the various studies might be a mere reflection of the health care systems in which they are operating.

The present study was performed in a well-organized and publicly-financed health care system easily accessible for patients of diverse socioeconomic background, presumably increasing the likelihood of contact with health services. The structure of small and distinct municipalities, and well-informed dementia coordinators, in turn facilitated the identification of the patients after they received their diagnosis. We consider it likely that the relatively high prevalence estimations presented in the current study are more accurate than previous reports conducted in populations with less organized health care systems.

However, all types of epidemiological studies are associated with some form of bias, with potential weaknesses and strengths depending on the approach. The main strength of this study is a relatively large sample size of high clinical accuracy, covering a geographically large area of both rural and urban

Table 6
Comparison of prevalence figures per 100,000 persons for YOD in various population-based studies

ALL DEMENTIA

Age:	Norway (Current study)	Australia [5]	Japan [7]	England [8]	England [6]
50–54	92.9	102.7	59.0	62.5	–
55–59	163.2	131.2	94.3	152.1	–
60–64	328.6	265.2	163.3	166.3	–
30–64	*76.3*	*68.2*	*51.7**	*54.0*	–
45–64	*143.1*	*132.9*	*83.3*	*98.1*	*81.0*

DEMENTIA SUBTYPES

	Norway (Current study)	Australia [5]	Japan [7]	England [8]	England [6]	Norway (Current study)	Australia [5]	Japan [7]	England [8]	England [6]
	AD					**VaD**				
Age:										
50–54	20.7	6.4	9.8	16.4	–	3.4	6.4	22.9	6.6	–
55–59	55.6	13.1	28.0	50.7	–	11.1	13.1	42.2	32.6	–
60–64	207.3	74.6	49.5	77.3	–	15.6	49.7	78.4	38.7	–
30–64	*33.0*	*9.3*	*13.4**	*17.4*	–	*4.9*	*7.7*	*10.1**	*8.7*	–
45–64	*65.4*	*19.9*	*22.3*	*35.0*	*15.1*	*7.1*	*14.9*	*38.6*	*17.9*	*8.2*
	FTD					**ARD**				
50–54	3.4	6.4	1.5	3.3	–	6.9	32.1	–	19.7	–
55–59	26.0	26.2	1.7	25.4	–	7.4	32.8	–	18.1	–
60–64	15.6	8.3	4.4	23.2	–	27.4	49.7	–	11.6	–
30–64	*5.4*	*5.4*	*1.2**	*7.5*	–	*4.9*	*16.3*	–	*6.6*	–
45–64	*10.6*	*11.6*	*2.0*	*15.4*	*15.1*	*9.7*	*33.1*	–	*13.6*	–

*Calculated. AD, Alzheimer's disease; VaD, vascular dementia; FTD, frontotemporal dementia; ARD, alcohol-related dementia.

districts, combined with case ascertainment based on multiple sources in the context of a well-organized health care system. We were able to evaluate every patient made known to us through our sources, including patients identified in the computerized search.

Nevertheless, cultural differences in the population bases and the organization of the health care system may affect which subtypes of dementia that are more likely to be diagnosed. The Norwegian health care system is largely adapted to recognize and care for dementia patients with AD, which is the dominant subtype of late onset dementia. This could explain why we found a higher prevalence of AD compared to most other reports. Our study was based on a comprehensive specialized clinical work-up for most patients, particularly for those with AD, where clinical findings have been routinely supplemented with MRI and/or cerebrospinal fluid (CSF) core biomarkers. Although clinical criteria were applied for the sake of general comparison, the vast majority of the patients diagnosed with AD also had at least one marker indicating AD-pathology. On the other hand, intellectual disability was mostly due to Down's syndrome and the subtype of their dementia was not further investigated. Although the likelihood of AD

was high, these patients were not categorized as such, and therefore represent a potential source of underestimation. Overall, we believe the number of patients with AD to be fairly accurate, though like most neurodegenerative conditions, AD is a slow, progressive disease, so accurate assessment of dementia debut will at present remain a matter of judgement on the part of the physician.

AD represents 56.9 % of the total cohort of YOD. Other cohorts have shown varying proportions of AD, but most of the studies conclude that AD is the most prevalent subtype of dementia, even among younger patients [28–30]. We identified 17 different subtypes of dementia, confirming other reports on the heterogeneity of YOD etiology [5, 31, 32]. Neurodegenerative disease counted for almost 80 % of the cases. As neurodegenerative conditions are rare before the age of 45, our findings may be a reflection of the relatively high mean age of 63.6 years [33].

Despite the advantages of a well-organized health care system, even in Norway there are formal and tacit norms for identifying and diagnosing dementia subtypes. Unfortunately, there are certain conditions where dementia occurrence was difficult to identify from patient records as dementia is not commonly used as an identifier. This was essentially

the case for most secondary dementias, and other conditions where cognitive symptoms coincide with non-cognitive symptoms, such as in VaD, alcohol-related dementia, and acquired brain injury.

With respect to alcohol-related dementia, patients with alcohol dependencies are frequently treated in other parts of our health care system, and cases with dementia might to a lesser extent be referred to dementia care units in the communities. The study from Sydney, Australia, had a particular focus on alcohol-related dementia [5]. Their findings indicate that it is a significant subtype of YOD and that the prevalence could be underestimated in many studies, as is likely the case in the present one. It also shows the need for targeted methodological measures to identify alcohol-related dementia. Additionally, due to capacity limitations, patients with potential dementia from head injuries were not investigated during the computerized search at the hospitals, though emphasized when collaborating with dementia coordinators. Departments for rehabilitation or treating substance dependencies were not contacted. Similarly, PD has traditionally been diagnosed according to motor symptoms and the cognitive deficits have largely gone unrecognized until more recently, and we identified few PD-related cases here. For these reasons we believe our figures for such conditions, though similar to figures found in several other studies, are almost certainly underestimated in the current material.

However, there will always be patients that remain undetected regardless of the techniques employed. Future estimates for the prevalence of dementia would be improved by a comprehensive approach to detect all relevant types. Despite the high number of patients with AD, we believe that this reflects only a minimum of the true prevalence. Furthermore, old diagnostic criteria which were purposely applied for the sake of comparison, serve directly to affect the outcome and artificially reduce the prevalence figures. The ability of future studies to produce an accurate frequency of AD depends on how well the diagnostic criteria will be able to detect cognitive changes during the pre-dementia phase of the condition.

Taking these considerations into account, we believe that the current study provides valuable insight into the epidemiology of YOD, generating updated and improved estimations of the prevalence and etiology on an important and particularly vulnerable subgroup of patients with dementia.

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