


RESEARCH ARTICLE

Frequency of missed or delayed diagnosis in dementia is associated with neighborhood socioeconomic status

Ellen Holm^{1,2}  | Katja Kemp Jacobsen³ | Thea Bang de Lony⁴ | Maurice Lembeck⁴ | Hanne Pedersen⁵ | Charlotte Andersson⁶ | Peter Johannsen⁷ | Terese Sara Høj Jørgensen⁸ | Christian Torp-Pedersen^{9,10}

¹Department of Internal Medicine, University Hospital Zealand, Køge, Denmark

²Department of Clinical Medicine, University of Copenhagen, Copenhagen, Denmark

³Department of Technology, Faculty of Health and Technology, University College Copenhagen, Copenhagen, Denmark

⁴Geriatric Section, Department of Internal Medicine, Nykøbing Falster Hospital, Nykøbing Falster, Denmark

⁵Geriatric Section, Department of Internal Medicine in Glostrup, Amager Hvidovre Hospital, Glostrup, Denmark

⁶Department of Medicine, Section of Cardiovascular Medicine, Boston University Medical Center, Boston, Massachusetts, USA

⁷International Medical Vice President, Medical & Science, Clinical Drug Development, Novo Nordisk, Copenhagen, Denmark

⁸Section of Social Medicine, Department of Public Health, University of Copenhagen, Copenhagen, Denmark

⁹Department of Cardiology and Clinical Research, Nordsjællands Hospital, Hillerød, Denmark

¹⁰Department of Public Health, University of Copenhagen, Copenhagen, Denmark

Correspondence

Ellen Holm, MD, Department of Internal Medicine, University Hospital Zealand, Lykkebækvej 1, 4600 Køge, Denmark.
E-mail: ellh@regionsjaelland.dk

The study used national registry data, and consent from patients was therefore not necessary.

Abstract

Introduction: Underdetection of dementia in areas with low socioeconomic status (SES) may interfere with findings concerning associations between SES and dementia.

Methods: Using administrative registers we assessed the associations between age- and sex-adjusted dementia incidence and neighborhood socioeconomic status (nSES) in 94 Danish municipalities. Wealth was divided into income quartiles and other nSES variables were dichotomized into high versus low according to the median.

Results: High population density (odds ratio [OR] 1.21, 95% confidence interval [CI] 1.18–1.24), higher proportion of inhabitants in higher income quartiles (P for trend < .0001), and high educational level (OR 1.19, 95% CI 1.15–1.22) were associated with higher incidence of dementia. High proportion of residents above 65 years was associated with lower age-adjusted dementia incidence (OR 0.86, 95% CI 0.84–0.89).

Discussion: Low nSES municipalities have a lower age-adjusted incidence of dementia diagnosis. These findings corroborate prior concerns that a large number of dementia diagnoses may be missed in municipalities characterized by low SES.

KEYWORDS

Alzheimer's disease, dementia, nationwide study, neighborhood, register study, risk factor, socioeconomic status

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1 | INTRODUCTION

Several studies have demonstrated that dementia is underdiagnosed, thus there is a large number of people at risk of not being offered proper dementia care.¹ Although there are yet no pharmaceutical treatment options available to actively prevent or arrest progression of dementia due to neurodegenerative diseases such as Alzheimer's disease (AD), early diagnosis of dementia is important for a number of reasons.²⁻⁴ Among these is the relief for patients and caregivers gained from better understanding the symptoms; the possibility to make plans for the future at a time when the patient still has the cognitive capabilities needed; and being offered appropriate care pathways including, for example, medication reviews, optimal treatment for comorbidities, caregiver support, and—when needed—palliative care. Furthermore, there are several differential diagnoses that require attention and for some of these, there are options for symptomatic treatments.^{2,5}

Known risk factors for dementia include cardiovascular diseases⁶ as well as socioeconomic status (SES) including factors such as education,^{7,8} income,⁹ occupation,¹⁰⁻¹² and childhood SES.^{9,13,14} Socioeconomic factors may influence the time of diagnosis; however, the literature on this is scarce.¹⁵

The level of deprivation in a geographical area, commonly termed neighborhood socioeconomic status (nSES), is a risk factor for general health and well-being.^{16,17} However, findings concerning association between nSES and risk of dementia are inconsistent.¹⁸⁻²¹ The aim of the present study was to investigate the associations between nSES and missed or delayed diagnosis of dementia.

2 | METHODS

2.1 | Population and data sources

We used two cohorts for this study. Cohort I consists of all Danish residents above the age of 65 between January 1, 2016 and December 31, 2018. Dementia cases in cohort I were identified through administrative databases. Cohort II consists of individuals diagnosed with dementia in a specialized dementia clinic. It is mandatory for these clinics to report data to the national Danish Quality Database for Dementia (DANDEM). DANDEM includes information on diagnostic work-up, dementia diagnosis, degree of dementia (light, moderate, or severe), and medical treatment, and began collecting data January 1, 2016.²² Cohort II includes persons > 65 diagnosed with dementia and registered in DANDEM between January 1, 2016 and February 28, 2020. Thus, dementia cases included in cohort II and diagnosed between January 1, 2016 and December 31, 2018 are also included in cohort I. The cohorts are shown in Figure 1.

Every person residing in Denmark is registered with a unique personal identification number in the Danish Civil Registration System (CRS), which makes it possible to link several national databases.²³ Dementia diagnosis was retrieved from the Patient Register, containing diagnoses registered according to the International Statistical Classification of Diseases and Related Health Problems, 10th revision

(ICD-10) for all hospital contacts.²⁴ Date of birth, household size, and place of residence were retrieved from the Danish CRS,²⁵ educational level from the population education register,²⁶ levels of income and transfer payments from the income statistics registry,²⁷ and use of anti-dementia medicine from the National Prescription Registry.²⁸

2.2 | Dementia diagnosis, dementia severity, and nSES

In cohort I, individuals with a diagnosis of dementia (ICD-10: F00.0–F03.9; G30.0–G30.9; G31.8; G31.9) or who had redeemed a prescription of any anti-dementia drug (Anatomical Therapeutic Chemical code N06D) were identified as dementia cases.

We defined date of dementia onset as the date of the first dementia diagnosis registered or the date of the first prescription filled, whichever came first. The validity of dementia diagnoses in Danish hospital registers has been shown to be high, although not in younger individuals and we therefore included only individuals aged 65 or above.²⁹ Severity of dementia (light, moderate, or severe) was included in the analyses only for patients diagnosed in one of the dementia clinics reporting to DANDEM (cohort II). We used severity of dementia at time of diagnosis as a proxy for delayed diagnosis.

We used the municipalities to define geographical neighborhood unit. There are 98 municipalities in Denmark. The indicators used to characterize nSES were population density, proportion of residents aged 65 or above, income levels of inhabitants aged 25 and above, level of education, and proportion of individuals aged 25 and above who had received welfare support for at least 6 weeks during the period January 1, 2016 until December 31, 2018. Income was divided into quartiles and education into below or above bachelor degree level. All nSES indicators were dichotomized into low or high according to the median of all municipalities. We used differences in dementia incidences in the municipalities as an indicator of missed dementia diagnoses.

2.3 | Statistical methods

Individuals in cohort I were followed from January 1, 2016 or at age 65, and until diagnosis of dementia, death, emigration, or December 31, 2018, whatever came first. We assessed the associations between nSES and incidence of dementia in an age- and sex-adjusted Poisson regression model estimating rate ratios of dementia in municipalities with high versus low classified SES variables. Incidence rate ratios in the municipalities were calculated with the municipality Odense (municipality ID 461) as the reference area. This reference municipality was chosen based on a combination of a high incidence of dementia and a large population. Municipalities with <50 cases were excluded from the analysis leaving 94 municipalities for analysis. The 95% confidence intervals (CIs) were calculated under the assumption that the observed number of cases followed a Poisson distribution.

For cohort II, we assessed the associations between nSES and incidence of severe dementia in an age- and sex-adjusted Poisson

RESEARCH IN CONTEXT

1. Systematic Review: The authors reviewed the literature regarding individual and neighborhood socioeconomic status (nSES) associated with risk of dementia using a PubMed search. Few studies concerning nSES and dementia were identified.
2. Interpretation: Studying 94 Danish municipalities, we observed that low nSES was associated with low incidence of dementia indicating that there are a large number of missed dementia diagnoses in low SES municipalities. Furthermore low nSES was associated with high proportion of severe dementia cases indicating a high proportion of delayed diagnoses.
3. Future Directions: Future studies should clarify how health services may be improved to meet the needs for dementia diagnostics and care in low SES municipalities.

regression model estimating rate ratios of severe dementia in municipalities with high versus low classified nSES variables.

By merging cohort I and II, we were able to examine the proportion of cases diagnosed in a dementia clinic between January 1, 2016 and December 31, 2018. For all analyses, we used STATA/SE 15.1.

2.4 | Ethics

In Denmark, register-based studies do not require approval by an ethical committee. The study was approved by the Danish Data Protection Agency, P-2019-19.

3 | RESULTS

We identified 20,165 incident dementia cases registered in the Patient or Prescription Register between January 1, 2016 and December 31, 2018 (cohort I), see Figure 1.

Between January 1, 2016 and February 28, 2020, there were 23,647 cases classified as light, moderate, or severe dementia registered in DANDEM (cohort II). The proportion examined in the specialized dementia clinics was 74.0% (95% CI 74.0–75.0) with a range of 49.3% to 88.3%; details are shown in Table S1 in supporting information.

3.1 | nSES and dementia

Four municipalities were excluded due to low number of cases. The remaining 94 municipalities had rates of dementia per 1000 person-years varying between 3.5 (95% CI 3.0–4.2) and 10.2 (95% CI 9.0–11.5), details shown in Table S2 in supporting information. The municipality used as reference had 902 cases corresponding to 9.1 (95% CI 8.6–9.8) cases per 1000 person-years. The variation in age- and sex-adjusted rate ratios is illustrated in Figures 2 and 3.

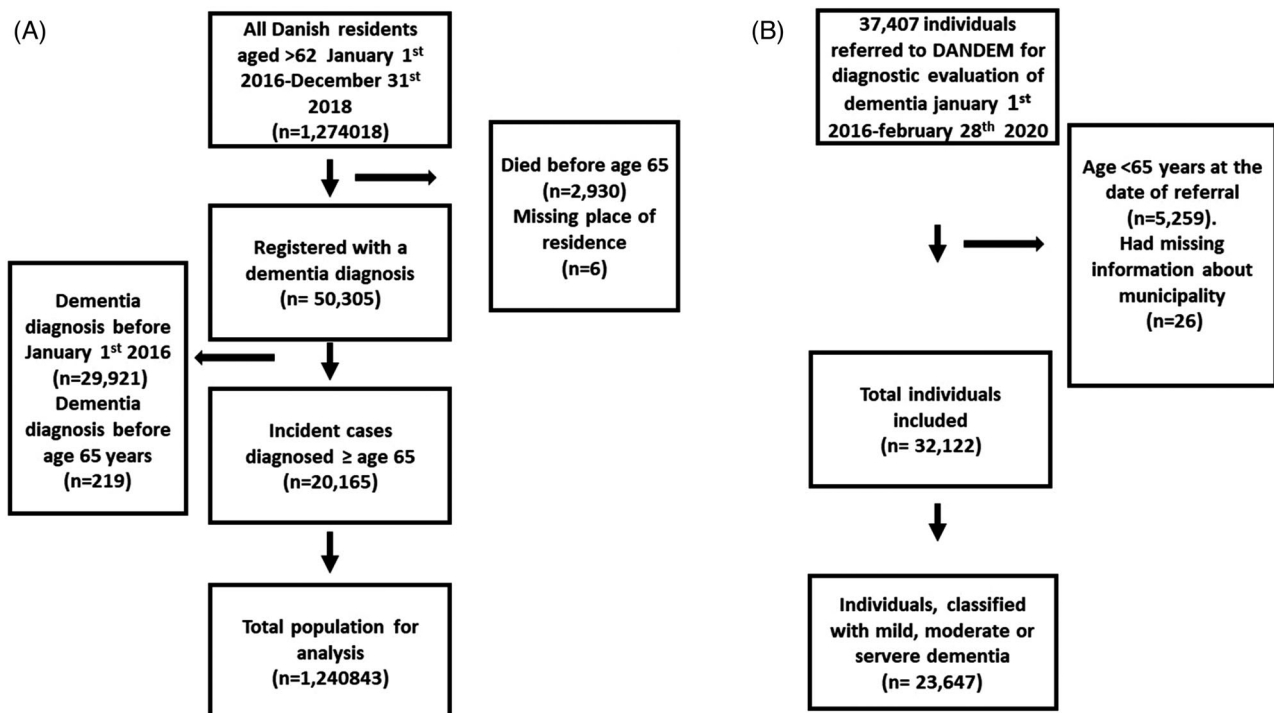


FIGURE 1 Flowchart showing the formation of cohort I (Figure 1A) and cohort II (Figure 1B). DANDEM, Danish Quality Database for Dementia

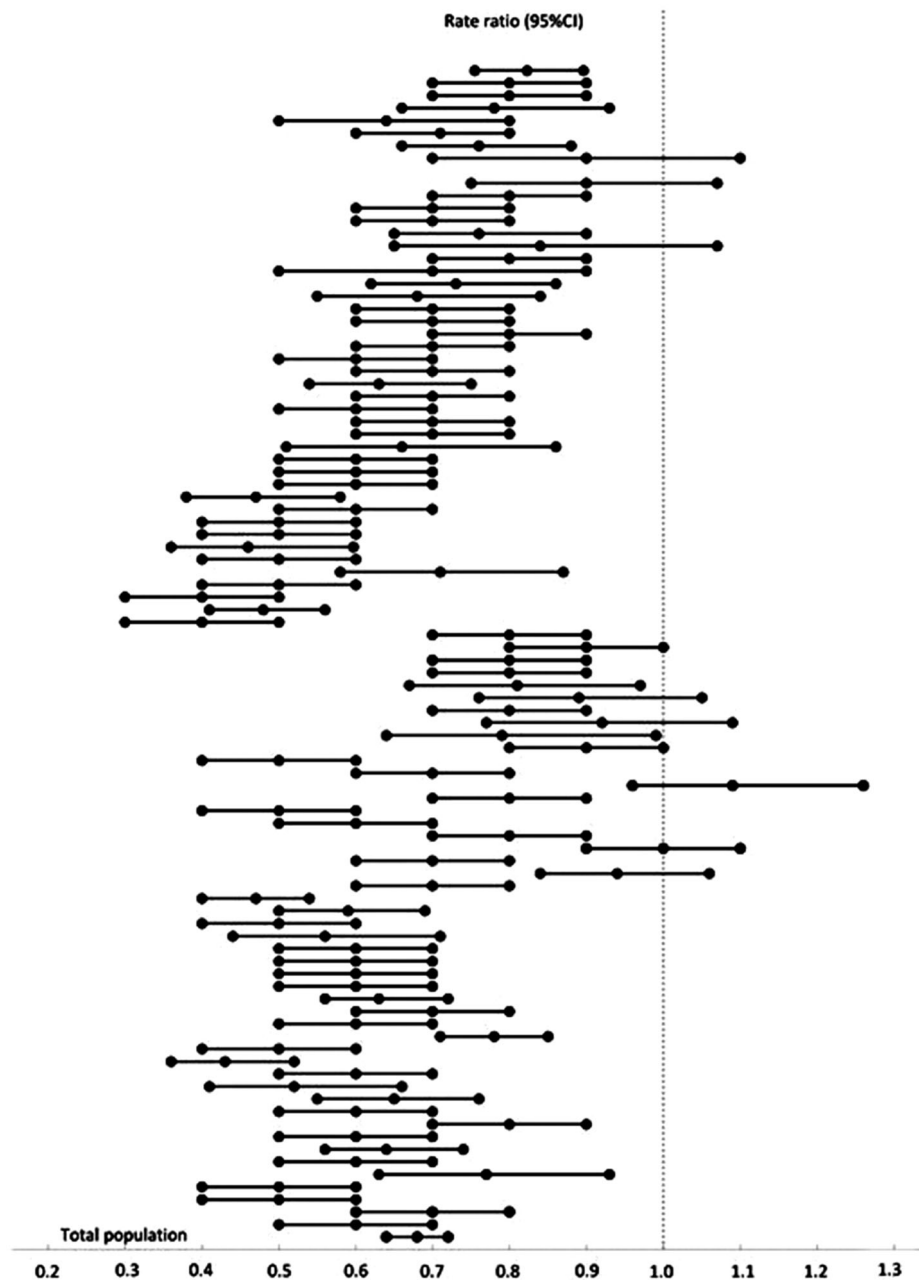


FIGURE 2 Incidence rate ratios and 95% confidence intervals (CIs) for dementia in 94 Danish municipalities

The following nSES variables were associated with high incidence of dementia in the municipalities: high population density (inhabitants per km²; odds ratio [OR] 1.21 [95% CI 1.18–1.24]), high proportion of individuals with high education (OR 1.19 [95% CI 1.15–1.22]), higher income than the median level (*P* for trend < .0001), and high proportion of individuals with welfare participation (OR 1.05 [95% CI 1.02–1.08]). High proportion of individuals above 65 years in the municipalities was associated with low age-adjusted incidence of dementia (OR 0.86 [95% CI 0.84–0.89]), see Table 1.

The following nSES variables were significantly associated with the proportion of severe dementia at time of diagnosis: high population density was associated with a lower proportion of severe dementia

(OR 0.9 [95% CI 0.84–0.98]), high proportion of inhabitants with income level within the second quartile compared to first quartile was associated with a lower proportion of severe dementia cases (OR 0.88 [95% CI 0.79–0.98]), and high proportion of residents with welfare participation was associated with a high proportion of severe dementia (OR 1.14 [95% CI 1.14–1.23]), see Table 2.

4 | DISCUSSION

The incidence in 94 municipalities varied between 3.5 (95% CI 3.0–4.2) and 10.2 (95% CI 9.0–11.5) per 1000 person-years. Given that lower

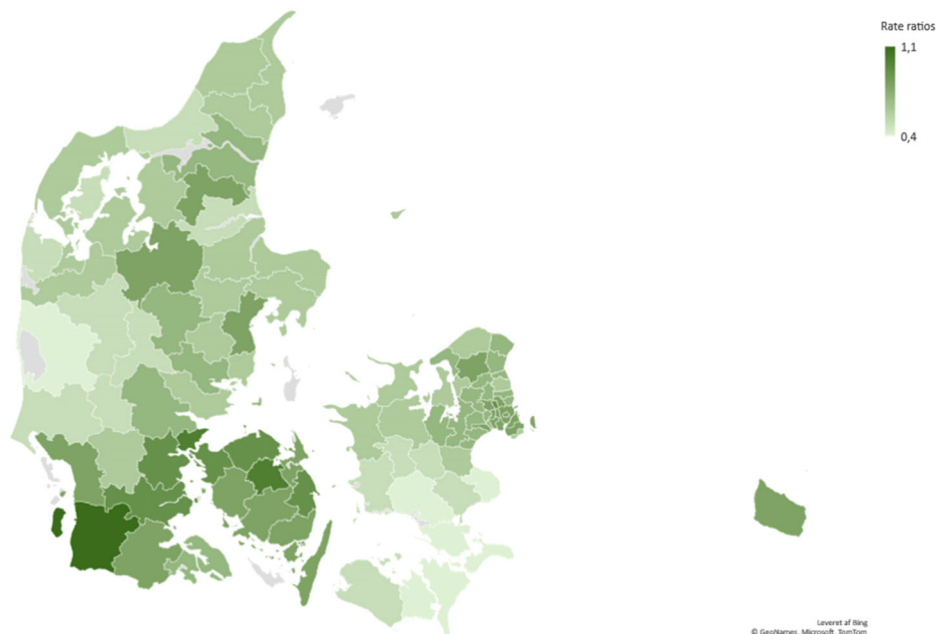


FIGURE 3 Rate ratios of incidence of dementia diagnosis mapped according to 94 Danish municipalities

TABLE 1 Dementia incidence as outcome and nSES as explanatory variables (n = 1,240,843). Reference = low (proportion below the median)

Municipality socioeconomic factors	Cases	Rates per 1000 person-years (95% CI)	Age- and sex-adjusted rate ratios (95% CI) ^a
Population density			
Low	10,869	5.7 (5.6–5.8)	1.00
High	9296	6.9 (6.8–7.1)	1.21 (1.18–1.24)
Proportion of individuals aged 65+			
Low	9588	6.6 (6.5–6.8)	1.00
High	10,577	5.8 (5.7–5.9)	0.86 (0.84–0.89)
Proportion of individuals aged 25–64 with higher education			
Low	10,747	5.7 (5.6–5.8)	1.00
High	9418	6.8 (6.7–7.0)	1.19 (1.15–1.22)
Proportion of individuals aged 25+ with income in			
1st quartile (lowest)	6155	5.9 (5.8–6.1)	1.00
2nd quartile	4769	6.0 (5.8–6.2)	1.02 (0.98–1.06)
3rd quartile	4995	6.6 (6.4–6.8)	1.14 (1.10–1.18)
4th quartile (highest)	4246	6.4(6.2–6.6)	1.09 (1.04–1.13)
P for trend < 0.0001			
Proportion of individuals with welfare participation aged 25+ ^b			
Low	11,909	6.1 (6.0–6.2)	1.00
High	8256	6.4 (6.3–6.5)	1.05 (1.02–1.08)

^aLow education was defined as below bachelor degree level and high education as equal to or above bachelor degree level.

^bWelfare participation was defined as having received welfare support at least 6 weeks during either year 2016, 2017, or 2018.

Abbreviations: CI, confidence interval; nSES, neighborhood socioeconomic status.

TABLE 2 Dementia severity as outcome and nSES indicators as explanatory variables among individuals assessed in a dementia clinic (n = 23,647)

Municipality socioeconomic factors	Cases severe dementia (n = 2770)	Rates per 1000 person-years (95% CI)	Age- and sex-adjusted rate ratios (95% CI)
Population density			
Low	1457	42.5 (40.4–44.8)	1.00
High	1313	38.7 (36.6–40.8)	0.90 (0.84–0.98)
Proportion of individuals aged 65+			
Low	1320	39.2 (37.1–41.4)	1.00
High	1450	42.0 (39.9–44.2)	1.08 (1.00–1.17)
Proportion of individuals aged 25–64 with higher education ^a			
Low	1349	38.8 (36.8–41.0)	1.00
High	1421	42.4 (40.3–44.7)	1.08 (1.00–1.16)
Proportion of individuals aged 25+ with income in			
1st quartile (lowest)	738	41.4 (38.5–44.5)	1.00
2nd quartile	602	36.1 (33.3–39.1)	0.88 (0.79–0.98)
3rd quartile	730	39.9 (37.0–42.8)	0.98 (0.88–1.08)
4th quartile (highest)	700	45.5 (42.3–49.0)	1.10 (0.99–1.22)
			P for trend = 0.03
Proportion of individuals with welfare participation aged 25+ ^b			
Low	1596	38.2 (36.4–40.2)	1.00
High	1174	44.3 (41.8–46.9)	1.14 (1.06–1.23)

^aHigher education is defined as above or equal to bachelor degree level.

^bWelfare participation was defined as having received welfare support at least 6 weeks during either year 2016, 2017, or 2018.

Note: Age and sex-adjusted rate ratio (RR) for severe dementia versus the others. Reference = low (proportion below the median).

Abbreviations: CI, confidence interval; nSES, neighborhood socioeconomic status.

SES has previously been associated with increased risks of dementia, our data suggest a substantial underdiagnosing of dementia in the poorest communities, even within a tax-funded health-care system. The municipality used as reference (Odense) had an incidence of 9.1 per 1000 person-years (95% CI 8.5–9.7). In a previous cohort study in the municipality of Odense (the Odense Study),³⁰ the incidence among randomly drawn individuals aged 65 to 84 years was 29.5 per 1000 person-years. The main reason for the large difference in incidence between our findings and the earlier Odense Study is probably due to the fact that we identified dementia diagnoses from administrative registers while the researchers in the Odense Study performed regular cognitive assessment during the follow-up period and thereby identified all dementia cases. Thus, our findings suggest that although Odense had one of the highest incidences in our study, dementia may still be underdiagnosed.

The World Alzheimer Report from 2011 estimated that worldwide only 50% of individuals who fulfilled diagnostic criteria for dementia were diagnosed with dementia.³ A previous Danish study³¹ compared incidence of dementia based on the Danish national registers to findings from European cohort studies pooled and analyzed by the European Community Concerted Action on the epidemiology and prevention of Dementia (Eurodem)³² and estimated that overall

approximately two-thirds of patients with dementia in Denmark were actually diagnosed. However, in the older age groups the diagnostic rates were lower (61% among 80 to 89 years old and 43% among those above 90).

A high proportion of severe dementia cases in the municipalities at time of diagnosis was associated with low population density and high proportion of individuals with welfare participation. We interpret this as a sign of delayed diagnosis. Diagnostic delay might be anticipated to be associated with marital status, family relations, and social network. However, a recent study did not find this association.³³ Unfortunately, we did not have access to data on marital status in our study. Another reason for diagnostic delay may be due to the nature of a disease. The diagnosis of an acute event such as a femoral fracture or an acute myocardial infarction will probably be unrelated to social background of families and communities. However, a slow progressive disease such as AD dementia may be mistaken for normal aging and may therefore be more prone to influence from social and educational background. It may seem a paradox that municipalities with a low population density (rural areas); a high proportion of individuals above 65 years; and a high proportion of individuals with low education, low income, and high welfare participation in our study had a low age- and sex-standardized incidence of dementia.

We assume that the reason for this paradox is that patients in low SES municipalities are less likely to be diagnosed than patients in high SES municipalities. This is supported by the demonstration of an association between high proportion of severe dementia cases at time of diagnosis with low nSES indicators. This could be due to individual factors in patients and their families such as cultural and economic background;^{34–38} attitudes and resources among health-care professionals³⁹ and primary physicians;^{40,41} and/or structural factors such as number of primary physicians per 1000 inhabitants in the municipality, transportation facilities, and distance to a dementia clinic.³⁸ In a previous study, we found an inverse association between geographical distance to a dementia clinic and probability of being diagnosed with AD.⁴²

5 | STRENGTHS AND LIMITATIONS

To our knowledge, this is the first study to assess socioeconomic variables of municipalities as an indicator of missed or delayed diagnosis of dementia. The study is nationwide and thus there is no selection bias.

The variables used for SES are objective measures from validated national registers.

The study has some limitations. We used municipalities as geographical entity for neighborhood. Generally, it is recommended to use smaller units such as areas defined by census tracts or postal codes.⁴³ We chose to use larger areas to have geographical units with a reasonable number of dementia cases. This may have blunted the results. However, we would presume the associations found between neighborhood and dementia incidence to be even stronger if we had defined neighborhoods as smaller areas.

We only have administrative data when we compare dementia incidence among municipalities; that is, we do not know the true incidence of dementia. When we compare the rate ratios of dementia in the municipalities, we chose to use Odense as a sort of “gold standard.” We cannot prove that this choice is correct. However, because dementia is known to be underdiagnosed,⁴⁴ we assume that the incidence of registered cases in Odense is closer to the true incidence of dementia than registered incidences in other municipalities.

We used the proportion of cases with severe dementia at the time of diagnosis as a proxy for delay of diagnosis. There may be other reasons for more severe dementia than a delay in diagnosis, for example, specific dementia subtypes, differences in speed of progression, and marital status. However, we would assume such differences to be equally distributed in the 94 municipalities.

ACKNOWLEDGMENTS

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

CONFLICTS OF INTEREST

None of the authors have any conflicting interests related to the content of this submission.

ORCID

Ellen Holm  <https://orcid.org/0000-0002-7600-6025>

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

How to cite this article: Holm E, Jacobsen KK, de Lony TB, et al. Frequency of missed or delayed diagnosis in dementia is associated with neighborhood socioeconomic status. *Alzheimer's Dement*. 2022;8:e12271. <https://doi.org/10.1002/trc2.12271>