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Differences in diagnostic process, treatment and social Support for Alzheimer's dementia between primary and specialist care: results from the Swedish Dementia Registry

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Abstract

Background: the increasing prevalence of Alzheimer's dementia (AD) has shifted the burden of management towards primary care (PC). Our aim is to compare diagnostic process and management of AD in PC and specialist care (SC).

Design: cross-sectional study.

Subjects: a total of, 9,625 patients diagnosed with AD registered 2011–14 in SveDem, the Swedish Dementia Registry.

Methods: descriptive statistics are shown. Odds ratios are presented for test performance and treatment in PC compared to SC, adjusted for age, sex, Mini-Mental State Examination (MMSE) and number of medication.

Results: a total of, 5,734 (60%) AD patients from SC and 3,891 (40%) from PC. In both, 64% of patients were women. PC patients were older (mean age 81 vs. 76; $P < 0.001$), had lower MMSE (median 21 vs. 22; $P < 0.001$) and more likely to receive home care (31% vs. 20%; $P < 0.001$) or day care (5% vs. 3%; $P < 0.001$). Fewer diagnostic tests were performed in PC and diagnostic time was shorter. Basic testing was less likely to be complete in PC. The greatest differences were found for neuroimaging (82% in PC vs. 98% in SC) and clock tests (84% vs. 93%). These differences remained statistically significant after adjusting for MMSE and demographic characteristics. PC patients received less antipsychotic medication and more anxiolytics and hypnotics, but there were no significant differences in use of cholinesterase inhibitors between PC and SC.

Conclusion: primary and specialist AD patients differ in background characteristics, and this can influence diagnostic work-up and treatment. PC excels in restriction of antipsychotic use. Use of head CT and clock test in PC are areas for improvement in Sweden.

Keywords: older people, dementia, Alzheimer's, primary care, diagnosis, care systems

Introduction

The increasing prevalence of dementia exceeds the diagnostic capacity of specialist memory clinics and many health-care systems are shifting the burden to primary care (PC) [1–3]. This poses the question of quality of diagnosis in PC [3] and the possible inequality between patients diagnosed in PC and specialist care (SC).

The Swedish National Board of Health and Welfare emitted guidelines in 2010 stipulating the contents of a basic dementia work-up and recommending prescription of pharmacological treatment (acetylcholinesterase inhibitors—AChEI or *N*-methyl-D-aspartate—NMDA antagonists, i.e. memantine) to newly diagnosed Alzheimer's dementia (AD) patients unless contraindication exists [2]. In Sweden, there are differences between PC and SC in the proportion of diagnosis that comply with these guidelines [2]. The Swedish Dementia Registry (SveDem) is a national quality registry launched in 2007 [4]. Part of the purpose of SveDem is to evaluate the quality indicators from 2010 [4], making it a tool for instituting and evaluating public health policy. Newly diagnosed patients are entered into the registry, which covered about 75% of PC and 98% of SC in 2014 [5]. Secondary care in Sweden consists of multidisciplinary memory clinics where geriatricians, neurologists or psychiatrists may participate.

The aim of this study was to compare baseline characteristics of AD patients diagnosed in PC and SC and to determine if there are significant differences in management between these levels of care. In case of discrepancies, we aimed to determine whether these were due to background demographic differences between the patient groups.

Materials and methods

Study population

The registration process in SveDem has been previously described [4, 6, 7]. AD patients registered during 2011–14

were included in this study. Diagnoses followed ICD-10 criteria [8].

Variables and statistical analysis

The 2010 guidelines define the basic dementia work-up as a structured interview with the patient and a reliable observer, physical examination and evaluation of mental health, cognitive evaluation including clock test and Mini-Mental State Examination (MMSE), functional evaluation, structural brain imaging (computer tomography—CT recommended) and blood tests to exclude other causes of cognitive decline [2]. Demographic and social variables were examined (see Supplementary data available in *Age and Ageing* online) [9].

Descriptive statistics are provided (see Supplementary data available in *Age and Ageing* online).

Logistic regression was used to compare the demographics, work-up and treatment between PC and SC adjusting for age (tertile categories), sex, number of habitual medication (tertile categories; separate category for missing) and MMSE (tertile categories; separate category for missing). Adjusted odds ratio (OR) with 95% confidence interval (CI) are presented.

The IBM Statistical Package for Social Sciences (IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY) for Windows, version 22 was used for the analyses.

Ethical considerations

All patients were informed when diagnosed with AD about the registration in SveDem and of their right to refuse participation and withdraw their data from the registry. This study was approved by the Regional Ethical Review Board in Stockholm.

Results

A total of 9,625 patients were included; 5,734 (60%) from SC and 3,891 (40%) from PC. Demographic characteristics of the AD patients by diagnostic unit are presented in Table 1.

Diagnostic work-up

The time between referral and diagnosis was shorter and fewer tests were performed in PC (Table 1). Completion of MMSE and blood tests was >95% in both settings. Clock test was performed in 84% in PC (93% in SC) and brain

Table 1. Demographic and work-up characteristics of Alzheimer’s patients

	Specialist clinics (n = 5,734)	Primary care (n = 3,891)	P-value
Demographics			
Age years, mean (SD)	76.4 (8.6)	81.1 (6.6)	<0.001 ^a
Women, n (%)	3,650 (63.7%)	2,486 (63.9%)	0.829 ^b
Living at home	5,479 (95.7%)	3,555 (91.7%)	<0.001 ^b
Living alone, n (%)	2,209 (39.6%)	1,761 (49.1%)	<0.001 ^b
MMSE score, median (IQR)	22.0 (7.0)	21.0 (6.0)	<0.001 ^c
MMSE value, n (%)			
24–30	2,264 (39.5%)	1,150 (29.7%)	<0.001 ^b
20–23	1,644 (28.7%)	1,213 (31.3%)	0.007 ^b
0–19	1,649 (28.8%)	1,281 (33.0%)	<0.001 ^b
Untestable	78 (1.4%)	86 (2.2%)	0.002 ^b
Missing	93 (1.6%)	148 (3.8%)	<0.001 ^b
BMI kg/m², median (IQR)			
BMI, n (%)	24 (6.0)	25 (6.0)	<0.001 ^c
≤22	1,542 (26.9%)	595 (15.3%)	<0.001 ^b
22–25	1,386 (24.2%)	619 (15.9%)	<0.001 ^b
≥25	1,494 (26.1%)	866 (22.3%)	<0.001 ^b
Missing	1,312 (22.9%)	1,811 (46.5%)	<0.001 ^b
Total number of medications, median (IQR)			
Cardiovascular, n (%)	3.0 (5.0)	4.0 (4.0)	<0.001 ^c
Antidepressants, n (%)	2,532 (57.2%)	1,539 (59.3%)	0.093 ^b
Antidepressants, n (%)	914 (20.7%)	553 (21.3%)	0.523 ^b
Anxiolytics and/or hypnotics, n (%)	641 (14.5%)	553 (21.4%)	<0.001 ^b
Diagnostic work-up			
No. of days between referral to diagnosis, median (IQR)	104 (89)	92 (129)	<0.001 ^c
Complete basic testing	5,069 (88.4%)	2,459 (63.2%)	<0.001 ^b
MMSE performance, n (%)	5,635 (98.4%)	3,740 (96.2%)	<0.001 ^b
Clock test, n (%)	5,313 (93.4%)	3,135 (83.8%)	<0.001 ^b
Blood analysis, n (%)	5,564 (97.8%)	3,563 (95.3%)	<0.001 ^b
Brain imaging (CT and/or MRI), n (%)	5,586 (97.9%)	3,043 (81.6%)	<0.001 ^b
MRI, n (%)	1,064 (18.6%)	115 (3.0%)	<0.001 ^b
LC, n (%)	3,109 (54.2%)	168 (4.3%)	<0.001 ^b
Nuclear imaging, n (%)	632 (11.2%)	35 (1.0%)	<0.001 ^b
EEG, n (%)	684 (12.1%)	33 (0.9%)	<0.001 ^b
Assessment by occupational therapist, n (%)	2,553 (44.5%)	1,056 (27.1%)	<0.001 ^b
Assessment by physiotherapist, n (%)	218 (3.8%)	287 (7.4%)	<0.001 ^b
Neuropsychology, n (%)	1,654 (28.8%)	122 (3.1%)	<0.001 ^b
Total no. of tests, median (IQR)	5.0 (1.0)	4.0 (1.0)	<0.001 ^c
Treatment			
Cholinesterase inhibitors, n (%)	4,008 (70.2%)	2,350 (63.4%)	<0.001 ^b
NMDA antagonists, n (%)	834 (14.7%)	320 (8.8%)	<0.001 ^b
Neuroleptics, n (%)	236 (4.2%)	140 (3.8%)	0.389 ^b
Social support and care			
Day care, n (%)	162 (2.9%)	172 (4.7%)	<0.001 ^b
Home care, n (%)	1,129 (19.9%)	1,146 (30.8%)	<0.001 ^b

Abbreviations: SD, standard deviation; n, number; BMI, body mass index; MMSE, Mini-Mental State Examination (0–30); IQR, interquartile range; LC, lumbar puncture. Missing data: living at home = 40; living alone = 20; no. medication = 263; cardiovascular = 670; antidepressants = 676; neuroleptics = 682; anxiolytics and/or hypnotics = 685. Complete basic testing includes MMSE, clock test, blood analysis and brain imaging. Brain imaging: includes CT and/or magnetic resonance imaging (MRI) of the brain. Nuclear imaging includes single photon emission computer tomography (SPECT) or positron emission tomography. Missing data: clock test = 200; blood tests = 198; brain imaging = 188; MRI = 333; LC = 258; nuclear imaging = 339; EEG = 352, occupational therapist = 277; physiotherapist = 307; neuropsychology = 318; cholinesterase inhibitors = 206. NMDA antagonists = 303; neuroleptics = 363; day-care missing = 255; home care = 234.

^aIndependent t-sample test.

^bPearson’s Chi-square.

^cP-values from binary logistic regression.

Table 2. Work-up, treatment and care in PC compared to SC

	Adjusted OR (95% CI)
Work-up	
Complete basic testing	0.23 (0.20–0.26)
MMSE performance	0.44 (0.34–0.58) ^a
Clock test	0.37 (0.32–0.43)
Blood analysis	0.57 (0.45–0.74)
Brain imaging (CT and/or MR)	0.12 (0.09–0.14)
Treatment	
Cholinesterase inhibitors	0.98 (0.89–1.08)
NMDA antagonists	0.46 (0.39–0.53)
Cardiovascular	0.87 (0.77–0.98)
Antidepressants	0.97 (0.85–1.11)
Antipsychotics	0.76 (0.60–0.96)
Anxiolytics and/or hypnotics	1.31 (1.14–1.51)
Social support and care	
Home care	1.19 (1.07–1.32)
Day care	1.33 (1.06–1.68)

OR of diagnostic procedure, treatment and social support in PC compared to SC. Diagnostic centre was considered as independent variable and diagnostic testing and treatment as outcomes. SC is reference. Results are presented as OR from logistic regression adjusted for age (entered as tertile categories), sex, number of habitual medication as proxy for comorbidity (entered as tertile categories with a separate category for missing) and MMSE (entered as tertile categories with a separate category for missing).

^aAdjusted for age, sex and number of medication, variables as described above. Treatment variables describe presence of medication category and are dichotomous.

imaging in 82% (98% in SC). Complete basic testing, including MMSE, clock test, blood analysis and brain imaging, was performed in 88% of SC patients and 63% in PC (Table 1).

After adjusting for age, sex, MMSE and number of medication, PC diagnoses were more likely to be missing basic tests (Table 2).

Treatment, social support and care

AChEI were used in 70% of patients in SC and 63% in PC (Table 1). Memantine was prescribed more in SC (15%) than in PC (9%). Use of neuroleptics was low ($\leq 5\%$) in both settings.

After adjusting, there were no differences in AChEI use, but patients in PC were less likely to receive memantine. The odds of receiving neuroleptics were 24% lower in PC while the odds of being treated with anxiolytics and/or hypnotics were 31% higher (Table 2).

Patients diagnosed at PC centres were more likely to have social support in the form of home care and day care (Table 1). These differences remained statistically significant after multivariate adjusting as is shown in Table 2.

Discussion

As the burden of AD increases, healthcare systems are diverting the responsibility of diagnosis and treatment onto PC [1, 2]. It is important to evaluate the quality of these diagnoses and to ensure that patients are receiving the right

level of care [10]. National diagnostic guidelines are one step in this direction [2], but demographic differences between patients in different settings also explain procedural differences. Previous studies from SveDem have shown that dementia work-up differs with age, with fewer and different examinations as age increases [11]. Physicians may be reticent to expand testing in fragile patients, where the benefit of diagnosing dementia may appear secondary to other concerns.

In this study from SveDem, PC patients were older, which is reasonable since patients under 65 are usually referred to SC. They had higher BMIs at the time of diagnosis, a positive prognostic factor in patients with dementia [6, 12], but they had worse cognition and more medications, reflecting more comorbidity [6]. Diagnostic time was shorter in PC, with fewer testing. Expanded examinations, such as MRI or LC, were less frequent in PC, which is appropriate, since difficult cases should be referred to SC.

The lower rate of completion of the basic examination is more concerning: one or more tests were missing in 47% of patients. Clock test and CT scan were the basic tests with the lowest completion rates in PC. The lower use of CT could be explained by the geographical isolation of some PC practices. Sweden is a large and sparsely populated country: in selected cases, sending a patient hours away for a CT scan may not be best practice. Another SveDem study found that older patients with low MMSE were less likely to obtain CT [13]. However, with 18% patients not receiving a CT, concerns arise about missing treatable causes of cognitive decline.

The lower performance of clock test in PC is also remarkable, since this test is informative, and is included in Swedish dementia diagnostic guidelines [14]. Doubts on interpretation of the results may be a factor, since several scoring systems exist [14, 15]. Encouragingly, since the launch of the national guidelines in 2010 and implementation efforts, the use of clock test in PC has increased in Sweden [5, 16].

A lower percentage of PC patients were treated with AChEI but these differences disappeared after adjusting. Memantine use was lower in PC after adjusting, perhaps reflecting lower familiarity with this medication. Patients in PC were more likely to receive anxiolytics and/or hypnotics. There is evidence that psychotropic drug use in dementia varies depending on environmental factors, independently from the severity of neuropsychiatric symptoms [17]. However, with our current data it is impossible to know which factors influenced anxiolytic use in PC.

PC performed better than SC for measures of diagnostic time and use of day care, and home care. Home-care and day-care services are provided at the local level of government in Sweden; the greater integration of PC with local services might explain this advantage. It is possible that SC underreport these aspects because they are not the ones in charge of coordinating these services.

There are large differences between healthcare systems in the independence and experience of PC physicians and

how much they are relied upon for dementia diagnosis [3, 18]. A lack of confidence and fear of ‘rushing to diagnosis’ were cited as concerns from PC physicians in a UK study, although diagnosis in PC had been initiated as a pilot trial ongoing for only a year [1]. Since dementia diagnosis is part of the primary physician's role in Sweden, it is likely that Swedish GPs are more experienced.

Barriers such as time and financial constraints, stigma or diagnostic uncertainty can hinder AD diagnosis in PC [19]. Patient barriers, such as lack of knowledge and fear of stigma, could delay help-seeking behaviours [19]. Studies on dementia diagnosis in PC have found low sensitivity but high specificity [20, 21]. Despite the central role of PC, no studies within the past decade examine dementia diagnosis in PC in Sweden [2, 21, 22]. There is ongoing effort to improve diagnosis in PC. The MMSE and clock tests have proven reliable in this setting, especially when combined, but other instruments have also been proposed [18, 23]. PC centres perform well in other variables: costs of diagnosing dementia are lower in PC [24], and follow-up of drug treatment prescribed by SCs is good [25].

There are several limitations to this study. Despite increasing coverage in SveDem is not complete. It is impossible to know if non-included patients differ from those included in SveDem, and if excluded patients were different in PC and SC. The chain of care also conditions results: most patients arriving at SC are referred from PC, although self-referrals are permitted. Quality of diagnosis is a concern, since neither PC nor SC diagnoses were independently validated. However, these diagnoses reflect normal clinical practice and regular cross-checks of patient histories are performed on a sample of SveDem patients [4]. SveDem is also missing data on functional capacity, which could not be included in this study.

Most importantly, as is evident from our data, the groups diagnosed in PC and SC are not equivalent. Despite obvious procedural differences between care settings, it is unclear which amount of testing and treatment is optimal, although the national guidelines serve as a reference [2]. The lower performance of CT and clock-testing in PC is concerning, but the recent increase in use of clock test in SveDem is a positive development [5]. Diagnostic process differs between countries and care settings [16, 26]: the national Swedish guidelines state only the minimum number of tests required for a dementia diagnosis but many patients require more, as shown by the proportion tested by a neuropsychologist (28% in SC) or occupational therapist (45% in SC, 27% in PC) (Table 1) [2].

Conclusion

In SveDem, AD patients diagnosed in PC were older, with lower MMSE scores and took more medication than SC patients. The diagnostic process in PC was faster with fewer tests performed. However, completion of the basic examination in accordance to Swedish guidelines was lower in PC, mainly due to lower proportion of patients with CT and

clock test. PC performed better in restricting the use of antipsychotics, and had better patient access to day-care and home-care services. There is a need for ongoing effort on all care levels to improve quality of AD diagnosis and reduce diagnostic delay. The use of head CT should probably increase in PC. The clock test is simple, fast, included in Swedish diagnostic guidelines [2] and should be encouraged in all settings in Sweden.

Abbreviations

AChEI, acetylcholinesterase inhibitors; AD, Alzheimer's dementia; BMI, body mass index; CI, confidence interval; CT, computer tomography; IQR, interquartile range; LP, lumbar puncture; MMSE, Mini-Mental State Examination; MRI, magnetic resonance imaging; NMDA, *N*-methyl-D-aspartate antagonists; PC, primary care; SC, secondary care; SveDem, Swedish Dementia Registry; SPECT, single photon emission computer tomography; SD, standard deviation.

Key points

- The increasing prevalence of dementia has shifted the burden of diagnosis and treatment towards PC.
- In this large national cohort, PC patients diagnosed with dementia were older, with lower MMSE.
- PC diagnoses were faster and included fewer tests.
- Head CT and clock test use should probably increase in PC.

Supplementary data

Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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Conflicts of interest

The authors report no conflicts of interest.

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