Age and Ageing 2015; **44:** 642–647
doi: 10.1093/ageing/afv020
Published electronically 10 March 2015

Who has undiagnosed dementia? A cross-sectional analysis of participants of the Aging, Demographics and Memory Study

George M. Savva, Antony Arthur

School of Health Sciences, University of East Anglia, Edith Cavell Building, Norwich Research Park, Norwich NR4 7TJ, UK

Address correspondence to: G. M. Savva. Tel: (+44) 160 359 7091. Email: g.savva@uea.ac.uk

Abstract

Background: delays in diagnosing dementia may lead to suboptimal care, yet around half of those with dementia are undiagnosed. Any strategy for case finding should be informed by understanding the characteristics of the undiagnosed population. We used cross-sectional data from a population-based sample with dementia aged 71 years and older in the United States to describe the undiagnosed population and identify factors associated with non-diagnosis.
Methods: the Aging, Demographics and Memory Study (ADAMS) Wave A participants ($N = 856$) each underwent a detailed neuropsychiatric investigation. Informants were asked whether the participant had ever received a doctor's diagnosis of dementia. We used multiple logistic regression to identify factors associated with informant report of a prior dementia diagnosis among those with a study diagnosis of dementia.
Results: of those with a study diagnosis of dementia ($n = 307$), a prior diagnosis of dementia was reported by 121 informants (weighted proportion = 42%). Prior diagnosis was associated with greater clinical dementia rating (CDR), from 26% (CDR = 1) to 83% (CDR = 5). In multivariate analysis, those aged 90 years or older were less likely to be diagnosed ($P = 0.008$), but prior diagnosis was more common among married women ($P = 0.038$) and those who had spent more than 9 years in full-time education ($P = 0.043$).
Conclusions: people with dementia who are undiagnosed are older, have fewer years in education, are more likely to be unmarried, male and have less severe dementia than those with a diagnosis. Policymakers and clinicians should be mindful of the variation in diagnosis rates among subgroups of the population with dementia.

Keywords: *dementia, late diagnosis, neuropsychiatric symptoms, health services research, older people*

Introduction

Estimates of dementia prevalence compared with numbers of known cases suggest that in developed countries around half of people with dementia are not diagnosed [1–3] and so cannot access treatment and support that may help them and their caregivers. The UK National Screening Committee [4] and the US Preventive Task force [5] have concluded that there is no case to screen for dementia; nevertheless, the UK government has implemented 'active case finding' with the aim that by 2015, 66% of people with dementia will be diagnosed [6]. This is controversial, since the benefits and harms of diagnosis are not known, and the population with undiagnosed dementia are not well understood [7, 8].

Characteristics of the individual, their family and the wider environment, the knowledge and attitudes of medical professionals and the perceptions of available support may influence diagnosis [9–12]. Epidemiological studies of cohorts not selected on the basis of diagnosed cognitive impairment provide the only way in which to study the characteristics of the undiagnosed population. Several such studies have been conducted since the mid-1980s (reviewed in 9 and 13), whereby random samples of older people undergo a standardised dementia assessment followed by ascertainment of prior help seeking or clinical diagnoses. These have consistently found a substantial proportion of undiagnosed cases, and that males, the oldest old and those with less severe dementia are at risk of missed diagnosis. Here we present the largest such study to date

using a random sample from a Western population with dementia, an analysis of the Aging, Demographics and Memory Study (ADAMS), in which we compare socioeconomic and clinical characteristics of those with a prior diagnosis to those without.

Methods

Sample

ADAMS includes 856 individuals aged 71 years and older selected from the 2000 and 2002 waves of the Health and Retirement Study (HRS). HRS is a nationally representative longitudinal study of ageing in the United States which began in 1992 [14]. The HRS sample was recruited using clustered sampling of households across the United States, with an 80% response rate. Participants are interviewed every 2 years with re-interview participation rates of 92–95%. HRS was supplemented at various times using additional 'refresher' cohorts enrolled since 1992, with population representation of estimates derived from the sample maintained through the use of weights in analysis.

HRS did not include a detailed cognitive assessment, and the ADAMS sub-study was developed to study the epidemiology of dementia in the United States [15, 16]. ADAMS has been described in detail previously [15]. In short, 1,770 participants aged 70 and older were selected from HRS, stratified based on cognitive impairment, age and sex. Of the 1,770, 856 (a 56% response rate among the non-deceased) participated in sufficient assessments to receive a reliable study diagnosis of the presence or absence of dementia; 227 died before assessment, 499 refused, 59 could not be contacted and 128 could not participate for other reasons, for example illness or the unavailability of a suitable informant. We obtained ADAMS data by application to HRS [17].

The ADAMS assessments took place between 2001 and 2003; hence, the ADAMS sample represents the US population aged 71 and older during that time. Weights are applied to all prevalence estimates to correct for stratification, differential non-response and attrition.

Assessments

Participants underwent a neuropsychiatric investigation in their own home which has been described previously [15]. A knowledgeable informant was required for selection into ADAMS and described the participant's behavioural and psychiatric symptoms via the neuropsychiatric inventory (NPI). The participant completed neuropsychiatric tests, a depression measure and a standard neurological examination. Dementia diagnosis was made algorithmically based on both DSM-III-R and DSM-IV criteria, with a further consensus diagnosis made by a clinical team based on all interviews and assessments when the DSM diagnoses differed. Each participant was also assigned a clinical dementia rating (CDR) of 0.5 (mild cognitive impairment), 1 (mild dementia), 2 (moderate dementia), 3 (severe dementia), 4 (profound dementia) or 5 (terminal dementia) [18]. For our primary analysis, we defined dementia based on consensus diagnosis, although there was little disagreement between the CDR, DSM-IV, the DSM-III-R and the consensus diagnosis, with no disagreement at all among those with CDR scores of 2 or more.

NPI items were coded as present if any mention of their occurrence was made. Data from the participant's previous HRS interviews were used to ascertain race (white/non-white), asset wealth in quartiles and educational attainment coded into groups corresponding to 0–8 years, 9–11 years, 12–13 and 14+ years in full-time education.

As a part of the ADAMS medical history questionnaire, informants were asked whether the participant had ever consulted a medical professional for help for 'memory problems or thinking' and what was the final diagnosis made.

Analysis

This analysis was restricted to participants with a study diagnosis of dementia ($N = 307$). Participants with and without prior diagnosis were compared on demographic and clinical characteristics. Results were expressed both in terms of the distribution of characteristics among the diagnosed and undiagnosed and the probability of prior diagnosis across subgroups.

Logistic regression was used to estimate the correlates of prior dementia diagnosis. All statistically significant ($P < 0.05$) co-variates were simultaneously entered into a final multiple regression model.

In 27 cases, we could not determine prior diagnostic status. Complete data for multivariate analysis were available for 269 of 307 participants. Missing predictors were treated as missing at random. Sensitivity analyses considered all of the cases without known diagnosis to be diagnosed or all to be undiagnosed; used DSM-III-R, DSM-IV diagnosis and CDR score of 1 or more as alternative dementia definitions; and restricted to all those participants with informants who saw them at least several times per week over the year before the interview.

All analysis was conducted using Stata 12.1. ADAMS study procedures were approved by the Institutional Review Boards at Duke University Medical Center and the University of Michigan, and informed consent was obtained from study participants or their surrogates.

Results

Of 307 participants with dementia, 212 (69%) were female and the median age was 85 (IQR: 80–90). Sixty-six (22%) were married and lived at home, 167 (54%) were unmarried but living at home, while 74 (24%) lived in a nursing home. Informants were spouse ($N = 63$), child ($N = 148$), or other friend, relative or carer ($N = 96$). Informants were cohabiting with the participants ($N = 128$), saw the participants at least several times per week ($N = 127$) or less frequently ($N = 52$). They had known the participant for at least 10 years in 295 (95%) cases. Participants had spent a median of 10 years in education (IQR 7–12, range 0–17), and 223 (73%) were white.

Informants for 145 participants reported that the participant had seen a doctor for memory problems, while 151 had not and in 11 cases this was unknown. Of the 145 who had seen a doctor, 120 had received a diagnosis of dementia, 9 had not, while in 17 cases the informant did not know. In one case, the participant was known to be using anti-cholinesterase inhibitors despite the informant reporting no diagnosis and so was coded as having a prior diagnosis for subsequent analysis. Therefore, excluding those cases in which diagnostic status was not known, a prior diagnosis of dementia had been made for 121 participants (weighted proportion 42%; 95% CI: 33–51%), while in 159 it had not. When further restricting to cases with a close informant, a diagnosis was reported in 91 of 236 cases (weighted proportion 37%; 95% CI: 28–47%).

Those older than 90 years of age were less likely to be diagnosed (weighted proportion = 27%) than younger participants ($P = 0.02$), while prior diagnosis was more substantially more common among married women (67%) than among other groups ($P = 0.001$). Those in the lowest quartile of education had a significantly lower rate of diagnosis (27%) compared with other groups ($P = 0.003$), although race and asset wealth had no effect (Table 1). More nursing home residents had a prior diagnosis (60%) than those living in their own homes (37%), with 83% of the non-diagnosed population living in their own homes.

Prior diagnosis rose from 15% among those with CDR 0.5 (corresponding to mild cognitive impairment) to 83% (CDR 5, terminal dementia) (Table 2). Almost a third (weighted proportion 31.9%) of those with undiagnosed dementia had a CDR score of 0.5, and 76% had a CDR score of 1 (mild dementia) or less. When the 49 participants with CDR of 0.5 were removed, the overall proportion diagnosed rises to 50% (95% CI: 40–60%).

Those with vascular dementia were less likely to have a prior diagnosis (30%) than those with Alzheimer's disease (47%), although this was not statistically significant.

Agitated or aggressive behaviour was present among 12% of the non-diagnosed compared with 38% of those with prior diagnosis (Table 2). Aberrant motor behaviour (28 versus 10%) and apathy (36 versus 15%) were also more commonly reported among the diagnosed compared with the undiagnosed.

Multivariate analysis

The effects of age, dementia severity, education, gender and marital status were retained in multivariate analysis controlling for other clinical and demographic characteristics (Table 3). Aberrant motor behaviour (OR = 3.1; 95% CI = 1.1–8.4) also retained an independent association with diagnosis, but no other symptoms were independently associated with prior diagnosis in multivariate analysis. The effect of nursing home residence was also no longer statistically significant.

Sensitivity analysis

Using DSM-III-R or DSM-IV criteria results in lower estimates (39 and 36%), owing to a larger number of people

Table 1. The distribution of demographic and socioeconomic factors among people with dementia aged 71 years and older with and without a prior diagnosis of dementia, the weighted diagnosis rate among those with dementia and univariate odds ratio for the effect of each characteristic on the odds of diagnosis

Factor	Number (%) among undiagnosed, $N = 159$	Number (%) among diagnosed, $N = 121$	Weighted % with prior diagnosis	Univariate odds ratio	95% Confidence interval
Age					
71–74	29 (23.9)	29 (20.2)	38.3	1	ref
75–79	33 (29.0)	36 (29.8)	43.1	1.1	0.54–2.2
80–89	40 (24.8)	33 (38.6)	53.4	0.8	0.41–1.6
90+	57 (22.2)	23 (11.4)	27.4	0.4	0.20–0.82
Single male	36 (23.7)	13 (12.4)	27.8	1	ref
Married male	25 (13.4)	14 (11.1)	37.9	1.55	0.62–3.86
Single female	88 (56.9)	69 (58.1)	43.0	2.17	1.07–4.41
Married female	10 (6.0)	25 (18.4)	69.4	6.9	2.63–18.3
Lives in own home	134 (82.6)	82 (64.9)	36.6	1	ref
Nursing home resident	25 (17.4)	39 (35.1)	59.8	2.55	1.4–4.5
White	113 (82.0)	94 (77.5)	41.1	1	ref
Non-white	46 (18.0)	27 (22.5)	48.0	0.71	0.4–1.2
Lowest asset wealth quartile	61 (27.6)	35 (35.1)	48.4	1	ref
2nd	40 (35.7)	28 (19.9)	29.1	1.22	0.65–2.31
3rd	35 (23.1)	34 (27.9)	47.1	1.69	0.90–3.2
Highest asset wealth quartile	23(13.6)	24 (17.1)	48.0	1.81	0.90–3.69
Education					
<9 years	77 (42.3)	34 (20.9)	26.7	1	ref
9–11 years	28 (13.7)	23 (19.5)	51.1	1.86	0.94–3.68
12–13 years	32 (25.1)	44 (37.6)	52.4	3.11	1.69–5.72
>13 years	22 (18.8)	20 (21.9)	46.1	2.06	0.99–4.26

Table 2. The distribution of dementia subtype, dementia severity (CDR) and the presence of behavioural and psychological symptoms among people with dementia aged 71 and older with and without a prior diagnosis of dementia, the diagnosis rate and univariate odds ratio for the effect of each clinical characteristic on the odds of diagnosis

Factor	Number (%) among undiagnosed, $N = 159$	Number (%) among diagnosed, $N = 121$	Weighted % with prior diagnosis	Univariate odds ratio	95% Confidence interval
Dementia subtype					
Alzheimer's disease	113 (63.7)	96 (77.6)	47.3	1	Ref
Vascular dementia	29 (21.5)	16 (12.5)	30.0	0.65	0.33–1.27
Other or unknown aetiology	17 (14.7)	9 (9.9)	33.1	0.62	0.27–1.46
Dementia severity					
CDR = 0.5	40 (31.9)	9 (7.6)	14.9	1	Ref
1	69 (43.7)	26 (21.2)	26.4	1.61	0.68–3.79
2	23 (12.7)	36 (21.8)	55.9	6.96	2.84–17.0
3	20 (8.6)	35 (33.5)	74.1	7.78	3.14–19.3
4	[a]	[a]	74.6	19.3	4.5–82.0
5	[a]	[a]	83.2	3.33	0.63–17.6
Neuropsychiatric inventory[b]					
Delusions	22 (14.1)	28 (23.4)	55.5	1.8	0.99–3.40
Hallucinations	21 (13.4)	25 (16.4)	47.8	1.68	0.89–3.19
Agitation	33 (12.1)	45 (37.5)	69.9	2.23	1.31–3.80
Depression	46 (24.7)	32 (32.2)	49.4	0.86	0.51–1.47
Apathy	28 (14.5)	38 (36.1)	65.2	2.1	1.19–3.68
Elated mood	[a]	[a]	[c]	[c]	[c]
Anxiety	38 (16.4)	21 (14.7)	40.2	0.65	0.36–1.19
Disinhibition	19 (13.2)	14 (8.9)	33.9	0.93	0.45–1.95
Irritability	27 (9.4)	23 (18.6)	59.8	1.12	0.61–2.09
Aberrant behaviour	13 (10.0)	34 (28.1)	67.6	4.39	2.19–8.79

[a]Low numbers (<5 participants) in cells removed in line with ADAMS data sharing agreement.
[b]NPI variables are binary. Results for each row relate to those with each symptom, with the reference group without each symptom not shown.
[c]There were insufficient observations to estimate the proportion diagnosed among people with abnormally elated mood.

with CDR = 0.5 receiving a dementia diagnosis using the algorithmic definitions (see Supplementary data, Tables available in *Age and Ageing* online). No sensitivity analysis leads to substantively different conclusions regarding associations in multivariable analysis, with the exception that aberrant motor behaviour is not significantly linked to prior diagnosis at $P < 0.05$ when the DSM-IV criteria are applied.

Discussion

Dementia severity was strongly linked with prior diagnosis. People aged <90 years, married women and those not in the lowest quartile of educational attainment were more likely to be diagnosed, but there was no evidence of an independent effect of wealth, race or nursing home residence. While behavioural symptoms were more common among the diagnosed, most of these associations with the exception of the effect of aberrant motor behaviour were explained by other factors.

Around three in four with undiagnosed dementia have mild dementia according to the CDR; hence, the proportion diagnosed depends on the threshold for dementia used. In England, estimates of undetected dementia are calculated by comparing prevalence estimates with cases reported by general practitioners [1, 3]. In England, the proportion with a diagnosis estimated in this way was 48.7% in 2013 (precision not reported), having increased from 37.0% in 2007/08, yet this is subject to methodological and statistical variation in prevalence estimation and case reporting, which in turn depends on the definitions of dementia used both in epidemiological and in clinical assessments [19].

Apathy, agitated or aggressive and aberrant motor behaviour were more common among the diagnosed; however, after adjusting for other factors, only aberrant motor behaviour remained significantly associated with diagnosis. Our findings are consistent with the idea that challenging behavioural symptoms prompt help seeking, although our sample size was too small to be definitive.

Most individuals with dementia who were reported to have consulted a medical professional regarding memory symptoms had received a diagnosis, suggesting that therapeutic nihilism or delay to accessing diagnostic services once help had been sought was not a major contributor to a diagnosis gap in this population.

Being married was strongly linked to prior diagnosis in this group but only among women. Among the unmarried (predominantly widowed), men and women were equally likely to be diagnosed. Perhaps in this cohort, an expectation to maintain housekeeping, caring or other roles means that cognitive deficits become more evident in married older women. Nursing home residence was not independently associated

Table 3. Multivariate regression analysis showing the independent effect of demographic and clinical factors on the odds of diagnosis among the population aged 71 and older with dementia

Factor	Multivariate odds ratio	95% Confidence interval	*P* value[b]
Age			
71–74	1	ref	0.008
75–79	1.08	0.42–2.79	
80–89	0.72	0.28–1.84	
90+	0.24**	0.09–0.64	
Education			
<9 years	1	ref	0.043
9–11 years	2.63*	1.08–6.40	
12–13 years	2.87*	1.28–6.41	
>13 years	2.34	0.88–6.17	
Single male	1	ref	0.038
Married male	0.84	0.26–2.74	
Single female	1.31	0.53–3.25	
Married female	4.59*	1.34–15.68	
Nursing home resident	1.59	0.71–3.57	0.281
CDR = 0.5	1	ref	0.0003
1	1.93	0.72–5.15	
2	10.48***	3.40–32.30	
3	7.55***	2.32–24.59	
4	12.33**	2.04–74.56	
5	3.13	0.33–30.13	
Neuropsychiatric inventory[a]			
Delusions	1.14	0.43–3.03	0.798
Hallucinations	1.01	0.39–2.61	0.985
Agitation	2.02	0.85–4.82	0.112
Depression	0.75	0.34–1.67	0.484
Apathy	2.01	0.87–4.65	0.102
Anxiety	0.52	0.21–1.29	0.157
Disinhibition	0.6	0.20–1.86	0.380
Irritability	0.51	0.18–1.48	0.216
Aberrant motor behaviour	3.07*	1.12–8.36	0.029

[a]NPI variables are binary. Results for each row relate to those with each symptom, with the reference group without each symptom not shown. Elated mood excluded because of insufficient participants.
[b]*P* value corresponds to a Wald test of the hypothesis that ORs for all factor levels compared with the reference group equal 1. *$P < 0.05$, **$P < 0.01$, ***$P < 0.001$

with prior diagnosis, although it is notable that 83% of the non-diagnosed population were resident in their own homes.

There are several possible explanations for the effects of age and dementia severity on diagnosis. People in the earliest stages of dementia might not recognise their symptoms, or they might not want a dementia diagnosis while they can manage without help. The oldest old or their carers might perceive any difficulties as a normal characteristic of ageing, or medical co-morbidity might make deficits in daily function due to poor cognition less apparent.

A 2011 review [13] identified eight studies of the diagnosis of dementia in medical records among people with dementia or severe cognitive impairment [20–27] and found an overall diagnosis rate of 38% from a mixture of small population representative and larger convenience samples. Using a similar method to the present study, prior diagnoses were reported by 36% of informants of 252 participants with dementia of the 1991 Canadian Study of Health and Ageing [28]. In agreement with the present findings, these studies consistently find that males, older people and those with less severe dementia or fewer behavioural problems are less likely to be diagnosed, while findings with respect to socioeconomic status or healthcare contacts have been equivocal.

Our analysis has limitations. Data on prior diagnosis were supplied by informants, although having a reliable informant was a requirement for entry into ADAMS, and in all but 27 cases we could ascertain whether a dementia diagnosis had been made. Second, our findings are not applicable to people who would not have had a knowledgeable informant, who may be at increased risk of missed diagnosis [29]. Third, the ADAMS sample weights were used to estimate all proportions, but this may not fully account for selection bias and it is possible that those who refuse to participate are more likely to have been those without prior diagnosis. Fourth, ADAMS is limited to those aged 71 and older, and while only a small proportion of people with dementia are 70 or younger, the pathways for diagnosis could be different in that group. Data were collected between 2001 and 2003, and diagnosis rates may have changed since that time. Finally, causal inference is difficult when using cross-sectional data, but to our knowledge, there is no data currently available with which temporal associations can be explored.

Conclusion

Epidemiological studies provide the most valid estimates of dementia diagnosis rates and their correlates. Our findings and those from previous studies consistently suggest that the oldest old, men and those living alone may be at particular risk of missed diagnosis. A large proportion of those with undiagnosed dementia are likely to have mild dementia with fewer behavioural symptoms, and the vast majority with moderate or severe dementia are diagnosed. Contemporary epidemiological data linked to medical records and follow-up to establish causation would have the potential to more directly explore the factors that influence help seeking and diagnosis among patients, caregivers and doctors, both at the level of the community and the individual.

Key points

- Dementia was not diagnosed in 58% of cases.
- Dementia severity was strongly linked to prior diagnosis.
- Most people with undiagnosed dementia lived in their own homes.

Conflicts of interest

None declared.

Funding

ADAMS is a supplement to the Health and Retirement Study (HRS), which is sponsored by the National Institute of Aging (grant number NIA U01AG009740). It was conducted jointly by Duke University and the University of Michigan. The authors received no specific funding to conduct this analysis.

Supplementary data

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

References

1. Connolly A, Gaehl E, Martin H, Morris J, Purandare N. Underdiagnosis of dementia in primary care: variations in the observed prevalence and comparisons to the expected prevalence. Aging Ment Health 2011; 15: 978–84.
2. Prince M, Bryce R, Ferri C. World Alzheimer Report 2011: the benefits of early diagnosis and intervention. London: Alzheimer's Disease International, 2011. http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf (27 August 2014, date last accessed).
3. NHS Outcomes Framework [Internet]. 2013. http://www.hscic.gov.uk/catalogue/PUB13054 (24 June 2014, date last accessed).
4. Appraisal for screening for Alzheimer's Disease [Internet]. UK National Screening Committee, 2010. http://www.screening.nhs.uk/policydb_download.php?doc=52 (1 May 2014, date last accessed).
5. Lin JS, O'Connor E, Rossom RC *et al*. Screening for Cognitive Impairment in Older Adults: An Evidence Update for the U.S. Preventive Services Task Force [Internet]. Rockville: Agency for Healthcare Research and Quality (US), 2013.
6. Department of Health. The Prime Minister's Challenge on Dementia: delivering major improvements in dementia care and research by 2015: Annual report of progress [Internet]. Department of Health, 2013 May. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200030/9535-TSO-2900951-PM_Challenge_Dementia_ACCESSIBLE.PDF (4 July 2014, date last accessed).
7. Le Couteur DG, Doust J, Creasey H, Brayne C. Political drive to screen for pre-dementia: not evidence based and ignores the harms of diagnosis. BMJ 2013; 347: f5125.
8. Fox C, Lafortune L, Boustani M, Dening T, Rait G, Brayne C. Screening for dementia--is it a no brainer? Int J Clin Pract 2013; 67: 1076–80.
9. Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. Alzheimer Dis Assoc Disord 2009; 23: 306–14.
10. Koch T, Iliffe S, EVIDEM-ED project. Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review. BMC Fam Pract 2010; 11: 52.
11. Hamilton-West KE, Milne AJ, Chenery A, Tilbrook C. Help-seeking in relation to signs of dementia: a pilot study to evaluate the utility of the common-sense model of illness representations. Psychol Health Med 2010; 15: 540–9.
12. Eustace A, Bruce I, Coen R *et al*. Behavioural disturbance triggers recognition of dementia by family informants. Int J Geriatr Psychiatry 2007; 22: 574–9.
13. Mitchell AJ, Meader N, Pentzek M. Clinical recognition of dementia and cognitive impairment in primary care: a meta-analysis of physician accuracy. Acta Psychiatr Scand 2011; 124: 165–83.
14. Juster FT, Suzman R. An overview of the Health and Retirement Study. J Hum Resour 1995; 30: S7–56.
15. Langa KM, Plassman BL, Wallace RB *et al*. The Aging, Demographics, and Memory Study: study design and methods. Neuroepidemiology 2005; 25: 181–91.
16. Plassman BL, Langa KM, Fisher GG *et al*. Prevalence of dementia in the United States: The Aging, Demographics, and Memory Study. Neuroepidemiology 2007; 29: 125–32.
17. ADAMS Supplement to the Health and Retirement Study, public use dataset. Produced and distributed by the University of Michigan with funding from the National Institute on Aging (grant number NIA U01AG009740). Ann Arbor, MI, 2007. http://hrsonline.isr.umich.edu (26 September 2014, date last accessed).
18. Morris JC. The Clinical Dementia Rating (CDR): current version and scoring rules. Neurology 1993; 43: 2412–4.
19. Erkinjuntti T, Østbye T, Steenhuis R, Hachinski V. The effect of different diagnostic criteria on the prevalence of dementia. N Engl J Med 1997; 337: 1667–74.
20. Borson S, Scanlan JM, Watanabe J, Tu S-P, Lessig M. Improving identification of cognitive impairment in primary care. Int J Geriatr Psychiatry 2006; 21: 349–55.
21. O'Connor DW, Pollitt PA, Hyde JB, Brook CP, Reiss BB, Roth M. Do general practitioners miss dementia in elderly patients? BMJ 1988; 297: 1107–10.
22. Valcour VG, Masaki KH, Curb J, Blanchette P. THe detection of dementia in the primary care setting. Arch Intern Med 2000; 160: 2964–8.
23. Wilkins CH, Wilkins KL, Meisel M, Depke M, Williams J, Edwards DF. Dementia undiagnosed in poor older adults with functional impairment. J Am Geriatr Soc 2007; 55: 1771–6.
24. Boustani M, Callahan CM, Unverzagt FW *et al*. Implementing a screening and diagnosis program for dementia in primary care. J Gen Intern Med 2005; 20: 572–7.
25. Löppönen M, Räihä I, Isoaho R, Vahlberg T, Kivelä S-L. Diagnosing cognitive impairment and dementia in primary health care—a more active approach is needed. Age Ageing 2003; 32: 606–12.
26. Olafsdóttir M, Skoog I, Marcusson J. Detection of dementia in primary care: the Linköping study. Dement Geriatr Cogn Disord 2000; 11: 223–9.
27. Boise L, Neal MB, Kaye J. Dementia assessment in primary care: results from a study in three managed care systems. J Gerontol A Biol Sci Med Sci 2004; 59: M621–6.
28. Sternberg SA, Wolfson C, Baumgarten M. Undetected dementia in community-dwelling older people: the Canadian Study of Health and Aging. J Am Geriatr Soc 2000; 48: 1430–4.
29. Rapp T. Patients' diagnosis decisions in Alzheimer's disease: the influence of family factors. Soc Sci Med 1982 2014; 118: 9–16.

Received 25 July 2014; accepted in revised form 7 January 2015