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Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors

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Abstract

Dementia is a growing public health problem for which early detection may be beneficial. Currently, the diagnosis of dementia in primary care is dependent mostly on clinical suspicion based on patient symptoms or caregivers' concerns and is prone to be missed or delayed. We conducted a systematic review of the literature to ascertain the prevalence and contributing factors for missed and delayed dementia diagnoses in primary care. Prevalence of missed and delayed diagnosis was estimated by abstracting quantitative data from studies of diagnostic sensitivity among primary care providers. Possible predictors and contributory factors were determined from the text of quantitative and qualitative studies of patient-, caregiver-, provider-, and system-related barriers. Overall estimates of diagnostic sensitivity varied among studies and appeared to be in part a function of dementia severity, degree of patient impairment, dementia subtype, and frequency of patient-provider contact. Major contributory factors included problems with attitudes and patient-provider communication, educational deficits, and system resource constraints. The true prevalence of missed and delayed diagnoses of dementia is unknown but appears to be high. Until the case for dementia screening becomes more compelling, efforts to promote timely detection should focus on removing barriers to diagnosis.

INTRODUCTION

A recent epidemiological study funded by the National Institute on Aging estimated that 13.9% of American adults over age 70 have some form of dementia, most commonly due to Alzheimer's disease.¹ According to the Alzheimer's Association, the number of older adults with Alzheimer's type dementia will have increased over threefold by the year 2050.² Dementia

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has wide-ranging adverse consequences, including functional limitations, complications of co-existing medical conditions, increased health care utilization, and substantial caregiver burden.^{3–8} Thus, dementia is a significant and growing public health problem.

Early detection of dementia is consistent with the goal of high-quality health care. The Institute of Medicine defines timely care, including diagnosis, as one of its six aims for improving the quality of the health care system.⁹ Early diagnosis also offers several direct benefits to persons with dementia.¹⁰ For example, detection can prompt evaluation of the patient for reversible causes of memory loss. When the course of disease is expected to be chronic and progressive, pharmacologic intervention may slow cognitive decline.¹¹ Perhaps most importantly, early diagnosis provides time for patients and families to prepare for future care and maximizes patients' opportunities to contribute to the care planning process. Thus, a proactive approach to diagnosis and intervention may improve the well being of both persons with dementia and family members involved in their care.¹⁰

Currently, the diagnosis of dementia is initiated mostly on a clinician's suspicion based on patient symptoms or caregivers' concerns,¹² usually in a primary care setting. The diagnosis of dementia in older persons can be challenging in the primary care environment, where provider-patient interactions tend to be brief and patients often present with multiple symptoms and health conditions. Early symptoms of dementia, such as memory impairment, may not be apparent during a routine office visit unless they are directly assessed.¹³ Hence, it is not surprising that many studies reveal delayed and/or undocumented diagnosis of dementia among primary care providers.^{14–16} Although these practice-related issues are of legitimate concern, they should not be conflated with an inability to objectively differentiate normal age-related memory changes and dementia.¹⁷

Missed and delayed diagnoses in medicine have recently received increasing attention in the patient safety literature because of their potential for harm and expense.^{18–22} These events are said to occur when diagnoses are unintentionally delayed, wrong, or missed altogether.¹⁹ Missed and delayed dementia diagnosis leads to lost opportunities for treatment and increases patient and caregiver burden. The purpose of this study was to ascertain what is known about the prevalence of missed and delayed diagnosis of dementia in primary care and identify the factors contributing to problems in diagnosis. We only reviewed studies that addressed barriers to accurate and/or timely diagnosis versus those that involve screening, mostly because the benefits of routinely screening asymptomatic patients are uncertain and any early detection strategy will need to overcome these barriers to succeed.¹²

METHODS

We searched Medline and PsycINFO for original research publications related to the prevalence of or factors contributing to missed and delayed diagnosis of dementia in the primary care setting. We first searched Medline with a combination of the search headings "Diagnostic errors," "Primary health care," and "Dementia", but this combination yielded no results. Furthermore, the combination of the two search headings "Diagnostic errors" and "Dementia" failed to generate studies that were directly relevant to our aims. Because available search headings did not easily map onto the concepts we explored, we used a deliberately broad keyword search strategy and selected articles through author consensus. Thirteen search term combinations, described below, were entered into searches in each database:

1. A combination of "dementia" and "diagnosis" plus one of each of the following terms: "barrier," "attitude," "delay," "patient factors," and "caregiver factors"
2. A combination of "dementia" and "detection" plus one of each of the following terms: "barrier," "attitude," "delay," "patient factors," and "caregiver factors"

3. A combination of “dementia” plus one of each of the following: “missed diagnosis,” “delayed diagnosis,” and “diagnostic error”

Our search included studies published through June 2008. After omitting duplicate references from the two databases, the search yielded 932 initial hits. We omitted studies published in languages other than English (n = 126) and those published prior to 1980 (n = 46), leaving 760 publications for further review. The first author and two other authors independently reviewed the abstracts of these publications to determine their potential relevance to study objectives. Disagreements pertaining to study selection were discussed and resolved through consensus. This initial selection process yielded 44 articles for more detailed review. Included were studies that estimated the rate of missed, delayed, or incorrect diagnosis of dementia in primary care settings by comparing actual provider diagnoses (i.e., diagnoses disclosed to researchers or recorded in an existing medical record) against standardized reference diagnostic methods. Also included were studies that reported risk factors or contributing factors in missed or delayed diagnosis in dementia care. Studies that pertained only to undefined cognitive impairment or studies that failed to differentiate mild cognitive impairment and dementia were excluded.

On detailed review of the selected articles we further excluded 12 that were either not original research reports (e.g., literature reviews or commentary), focused more broadly on recognition of cognitive impairment not limited to dementia, or otherwise judged to be not relevant to the study objectives. We also excluded articles that estimated the prevalence of missed diagnosis only after some type of provider intervention had taken place. We presumed that such studies would induce providers to deviate from their usual practices, inflating diagnostic accuracy and resulting in a less representative picture of typical practice. Finally, we excluded one article that defined a diagnosis of dementia on the basis of Mini-Mental Status Examination (MMSE) score in isolation, which has poor sensitivity in non-specialist settings.²³

The remaining papers represented several types of quantitative (e.g., diagnostic validation studies) and qualitative (e.g., focus group) methodologies. We manually searched the reference lists of all retrieved full-text articles and obtained an additional 9 articles for inclusion, yielding a final sample of 40 original studies. Eight studies examined the rate of missed diagnosis, and of these 7 identified predictors of detection. The other 32 studies examined risk factors for missed diagnosis but did not provide quantitative estimates of dementia detection rates.

RESULTS

Prevalence of missed diagnosis of dementia

Eight studies offered estimates of diagnostic specificity and/or sensitivity by assessing agreement between primary care providers' diagnoses and “reference” diagnoses assigned by trained raters.^{24–31} Reference diagnostic criteria varied between studies, but all involved the use of clinical interviews and previously standardized and/or validated assessment criteria. These studies assessed the proportion of patients within a geographical or practice setting who were considered to have dementia but who were not identified as such by their physicians, or whose medical records contained no such documentation. Although we used the findings of these studies to estimate the prevalence of missed dementia diagnosis, the true prevalence of missed dementia diagnosis could not be ascertained from the available literature.

The studies estimating diagnostic sensitivity and specificity are summarized in Table 1. They are methodologically heterogeneous, representing a variety of primary care patient and provider populations and multiple methods of ascertaining a provider's diagnosis. Studies also differed with respect to approaches to standardized assessment of dementia as the reference or “gold standard” means of comparison and generally used multiple assessment tools to establish a diagnosis. For example, four studies specifically cited the use of the MMSE (in addition to

other procedures) as a diagnostic tool.^{25–28} Four studies specifically cited the use of DSM diagnostic criteria^{25,27,29,31} whereas five studies specified other or additional criteria.

In 6 of 8 studies, dementia was subcategorized according to symptom severity (e.g., “mild,” “moderate,” “severe”) for sensitivity analyses. The sensitivity of providers’ diagnoses appeared to be strongly related to dementia severity. Diagnostic accuracy was poorest among patients deemed to have few or mild symptoms of dementia. For these patients, primary care providers’ diagnostic sensitivity ranged from 0.09 to 0.41. In contrast, among patients only with “severe” dementia, diagnostic sensitivity ranged from 0.60 to 1.0. Collapsed across severity categories, the overall sensitivity of providers’ diagnoses relative to standardized assessments varied widely among studies, ranging from 0.26 to 0.69. Diagnostic specificity was assessed in 2 studies and was ≥ 0.99 .^{27,31}

According to the quantitative studies we reviewed, across all dementia cases the pooled sensitivity estimate was .49 (384 true positives out of 791 cases, collapsed across severity categories). However, the reliability of this figure is highly questionable given the methodological heterogeneity among studies, and this crude estimate does not take into account nesting within studies. We continued to find considerable variability in sensitivity estimates even when we examined groups of studies with similar diagnostic methods. For example, among only those studies that used DSM criteria to determine the reference diagnosis, we found that overall estimates for primary care providers’ diagnostic sensitivity ranged from .26²⁹ to .60.³¹

Several other factors appeared to contribute to the sensitivity of providers’ diagnoses. First, four studies reported associations between the detection of dementia and the *patient’s degree of impairment or dependence on a caregiver*.^{27,28,30} Second, in two studies, the *type of dementia* was significantly associated with diagnostic sensitivity such that Alzheimer’s dementia was detected with greater sensitivity than other dementias.^{24,27} Third, two studies reported a positive relationship between accurate detection of dementia and *frequency of contact* with the demented patient.^{25,28} Fourth, presence of *depression* in the demented patient also predicted case detection.^{27,31} Finally, one study concluded that providers were more likely to detect dementia among *male patients* than female patients; the authors speculated that older males were more likely than older females to have a surviving spouse who could bring their illness to the attention of a health provider.²⁵

Factors contributing to missed diagnosis of dementia

The majority of studies we reviewed did not specify dementia detection rates but rather identified potential barriers to diagnosis or other factors associated with missed opportunities for diagnosis. We classified these contributing factors as provider-related, patient- or caregiver-related, and health care system-related.

Provider factors—Table 2 displays provider factors contributing to missed and delayed dementia diagnosis. Only one of the studies we reviewed identified *provider demographic characteristics* associated with missed dementia diagnosis.³² In this study, younger physicians tended to outperform older physicians on a test of dementia knowledge, although older physicians expressed greater confidence in their ability to diagnose dementia.

Sixteen studies specifically identified *educational needs* as a contributory factor to problematic diagnosis.^{13,32–46} These studies concluded that a lack of education about dementia care was an important concern for primary care physicians who are faced with diagnosing demented patients. Specific indicators of training needs included physicians’ lack of knowledge about what changes are “normal” in aging,^{33,35,37} perceived difficulty of detecting and/or managing

dementia,^{33–36,39,42,44,46} and the perception that specialists rather than primary care providers are more appropriate for making a diagnosis.^{37,44}

Five studies cited physicians' *concern about the consequences of misdiagnosing* dementia as a reason for missed diagnosis.^{37,38,40,41,46} Presumably, physicians were reluctant to make the diagnosis of dementia because of concerns about the potential negative impact of that diagnosis on a patient and their families; thus, they endorsed deferring a diagnosis until they were more certain.

Eighteen studies identified *attitudes toward dementia* as a contributor to missed diagnosis. Most frequently cited among these were concern about the potential stigmatizing effects of diagnosis,^{34,35,37,40,41,47,48} doubts about the usefulness or desirability of early diagnosis,^{13,34,38,40,41,43–45} and the perception of limited treatment options.^{13,39,42,43,46,48} Other related issues included physician unwillingness to discuss cognitive function with patients or caregivers,⁴² low prioritization of cognitive problems relative to physical health problems,¹³ and the avoidance of pressure for intervention once a diagnosis has been made.³⁷ In 4 studies, physicians also expressed concern that formally giving diagnoses of dementia in every applicable case, and consequently being responsible for these patients' care, would strain the resources of their practices.^{37,38,40,41}

Five studies identified problems with *testing for dementia* as a potential factor contributing to missed diagnosis of dementia including lack of assessment tools and protocols,^{13,36} or a lack of tools perceived as helpful.^{13,37,46} Other potential barriers cited were physicians' discomfort in administering assessment instruments or procedures⁴⁵ and physicians' reluctance to seek specialty consultation or referrals for possibly demented patients.¹³

Finally, 7 studies identified *communication problems*, including perceived difficulty in disclosing or explaining the diagnosis of dementia, as barriers to accurate and timely diagnosis of dementia. Some communication problems reflected cultural issues, as in language barriers or patient perceptions of unequal treatment on the basis of ethnicity.⁴⁹ Others reflected more general patterns of ineffective communication, including poor communication skills³⁴ and providers' difficulty in discussing or explaining dementia specifically.^{36,42,44–46}

Patient and caregiver factors—Eighteen studies identified ways in which patients and their caregivers or family members might contribute to missed or delayed diagnosis of dementia (Tables 3 and 4). Three studies suggested such barriers are disproportionately represented among patients and caregivers who live in rural areas and have lower levels of education.^{50–52} Other patient characteristics associated with nondetection of dementia included patient age,^{51,53} marital status,⁵³ and dementia severity.⁵³

Patient and caregiver attitudes also affected dementia diagnosis. A commonly cited barrier was the patient's own refusal to be assessed or treated if diagnosed.^{34,45,52,54–58} Similarly, other studies found that distress about the possibility of dementia⁵⁸ and low prioritization of cognitive function concerns⁵⁹ limited patients' encounters with physicians who might diagnose their dementia. According to 9 studies, family and caregivers shared similar attitudes toward diagnosis, denying or preferring not to know the patient's condition.^{33,34,46,47,52,54–56,60}

While patient and caregiver attitudes toward dementia were identified in 13 studies as barriers to diagnosis, 9 additional studies implicated a lack of *awareness or education about dementia*. For example, the assumption that cognitive changes are normal rather than pathologic was identified as a contributing factor to missed opportunities for diagnosis.^{33,46,54–58,60} Likewise, six studies identified a lack of symptom recognition or misattribution of symptoms as a barrier.^{33,46,52,54,57,60} Finally, the perception of limited treatment options, the

belief that little or nothing can be done for patients with dementia, was also documented as an impediment to receiving a timely diagnosis.^{52,55,56,58}

As in the case of physicians, 7 studies discussed contributing factors related to *communication*. Several communication problems reflected attitudes toward the physician's role in making a diagnosis, such as relying on the physician to broach the topic of cognitive function⁵⁹ and declining to challenge the physician's authority.⁵⁶ Language barriers^{49,56,58} and other problems communicating with the physician were also identified in these studies.

Studies that included patients and their caregivers described several limitations to *access* to diagnostic care. Broadly, these included geographical and transportation-related barriers,^{52,58} lack of provider availability,^{52,55,56} and financial barriers.^{52,54,55,58} One study also identified dementia diagnosis as a perceived impediment to accessing residential care or other services.⁵² Another study cited immigrant patients' concern that seeking dementia care might lead to deportation or a change in immigration status.⁵⁸

System factors—Although none of the studies in our sample systematically evaluated the effects of policy or organizational characteristics on dementia detection, several authors documented providers' suggestions of system-related factors that contributed to difficulties in the diagnosis of dementia (Table 5).

We identified two primary system limitations from the findings of these 12 studies. The first, cited in 10 of these studies, was a *lack of resources* in several domains. For example, physicians in 7 studies reported that the brief amount of time available for a typical patient visit limited their ability to assess symptoms.^{13,34,37,42,44,45,61} Seven studies pointed to a lack of accessible services for patients with dementia,^{13,33,34,37,38,60,61} with some providers calling into question the utility of diagnosing a disease for which little community support is available. Another barrier identified was a lack of specialists available for consultation during the process of diagnosis.^{13,47,61}

A second system-related problem that emerged was *financial constraints* at the provider and health system levels. Two studies cited low financial reimbursement for dementia care as a barrier to diagnosis and management.^{34,61} Two other studies noted that health payers restrict access to dementia care, complicating the process of diagnosis. Several providers in Boise et al.'s focus group study¹³ described managed care-imposed restrictions on the accessibility of diagnostic tests, and physicians in a multinational study of European providers cited government-imposed restrictions on dementia care.⁴⁶ A majority of physicians in the latter study agreed that their governments invested too little in resources for persons with dementia, a sentiment echoed in two other surveys of health providers.^{33,60}

DISCUSSION

Current evidence does not support routine dementia screening, and hence early diagnosis of dementia based on symptoms and caregiver concerns is critical to identify reversible etiologies, delay progression, and potentially reduce patient and caregiver burden. We reviewed the literature to determine the prevalence and contributory factors of missed or delayed dementia diagnoses in the primary care setting. Although no studies definitively determined the prevalence of missed or delayed dementia diagnoses, estimates of diagnostic sensitivity suggest that the number of dementia diagnoses that are missed or delayed is substantial. Limitations of *system resources* – and particularly time constraints for routine office visits – hinder detection and discussion of early symptoms of dementia. Other barriers included attitudes, communication problems, and knowledge deficits among patients, providers, and caregivers.

The timeliness and accuracy of dementia diagnosis are increasingly relevant in light of the rapidly aging U.S. population. For instance, life expectancy continues to rise, and very old adults (age 85 and older) make up the fastest-growing segment of the population in the U.S. and other nations.⁶² As the incidence of dementia increases substantially with age, perhaps exponentially,⁶³ we anticipate that the consequences of missed and delayed diagnosis in dementia will pose a greater public health burden over time. Given the current emphasis on improving health care quality, we believe our findings are very timely.

Several studies suggested that symptom severity and degree of impairment are important predictors of diagnostic sensitivity. Since patients with early dementia are most likely to benefit from intervention, future efforts to improve the timeliness of dementia diagnosis should especially focus on detection of more subtle and early manifestations of disease. A study published by Cooper and colleagues⁶⁴ indirectly suggests that even small practice changes may improve diagnostic accuracy. In that study, which was excluded from our analysis due to its design, providers were told prospectively that their diagnoses would be validated, and they received “simple guidelines” to assist with detection. This yielded a diagnostic sensitivity of 0.91 in contrast to estimates of .69 or lower that we found in studies where no such intervention took place. In a current study, we are evaluating the effect of placing dementia care coordinators within the primary care setting to improve dementia diagnosis and management.^{65,66} Similar interventions that entail minimal provider burden may be useful to improve diagnosis in clinical practice.

Opportunities for Improvement

Among providers, a major barrier often noted was the *attitude* that diagnosis, particularly in the early stages of dementia, was more harmful than helpful. This attitude was linked with the tendency to diagnose only when an unavoidable problem has arisen.³⁸ Providers’ fears are likely to be overstated as research suggests most patients prefer full disclosure of a dementia diagnosis.^{67,68} Nevertheless, some providers knowingly withhold disclosure of a dementia diagnosis to avoid perceived burdens.^{69,70} Patients’ fear of or denial of cognitive problems mirrors providers’ hesitancy to proceed with diagnostic evaluation, and it is likely that patients and providers are implicit partners in avoiding discussions of cognitive function. Although one study indicated that providers have become more receptive to early detection in recent years,⁴¹ willingness to diagnose is not sufficient to adeptly address patient and/or caregiver resistance to evaluation. Multidisciplinary interventions that focus on changing attitudes among providers and patients are needed.

Several studies identified specific *communication-related* barriers to dementia diagnosis. Some, such as language barriers and providers’ difficulties in explaining the diagnosis, reflected problems in the effective exchange of information. Other communication problems appeared to reflect patients’ and providers’ differing expectations for their roles in broaching the topic of cognitive function. Both problems represent opportunities for intervention aimed at both patients’ and providers’ communication skills. The use of information technology, including electronic health records with integrated reminders for patient communication and follow-up, may also augment patient-provider communication and improve the diagnostic process.²²

Among providers, studies citing a lack of relevant training suggest that many primary care physicians perceive themselves as lacking competence in dementia care and access to valid assessment tools that are feasible to administer in the primary care environment. This concern is supported by a study of diagnostic impressions among family physicians exposed to case vignettes of patients with dementia, which revealed important training needs related to dementia subtypes and reversible etiologies.⁷¹ The need for information on normative aging and the perception of limited treatment options is evident among patients, caregivers, and

providers alike. Dissemination of information through mass educational campaigns could enhance patients' understanding and awareness of dementia and prompt them to discuss important information in subsequent visits. Similar efforts aimed at providers, such as an initiative by the UK Alzheimer's Society,⁷² could improve early diagnosis and intervention. Past interventions to enhance provider attitudes and knowledge of dementia care have had mixed success.⁷³ New strategies based on information technology (e.g., decision support tools in electronic health records) may help address knowledge deficits but have yet to be tested.

The effects of system characteristics on diagnostic accuracy received less attention than provider factors. This is striking in light of studies in other practice domains suggesting that system-level factors may be more influential to care quality than individual provider behavior.^{19,74} System-wide time pressures on routine office visits, for instance, limit providers' ability to detect and evaluate cognitive symptoms. Although resource and system limitations are likely to play a large role in missed and delayed diagnosis of dementia, their precise effects have yet to be determined. Health care financing policies may also prove to be important system-level factors in missed and delayed diagnosis of dementia.

Our review has several limitations. First, in the absence of studies that addressed the true prevalence of missed or delayed diagnosis of dementia, we estimated this prevalence by examining sensitivity rates from dementia detection studies. Although these studies may have captured cases of missed diagnosis, in retrospective record reviews it is not possible to ascertain why a diagnosis was not documented. For example, the lack of recorded diagnosis may represent a documentation error rather than a detection error, or it may represent a deliberate decision to not diagnose, a phenomenon that we did not specifically explore in our review. Even if a diagnosis is documented, it is not possible to determine retrospectively whether the diagnosis was made in a timely manner.

Variability in sensitivity estimates across studies may be partially attributable to differences among reference diagnostic assessment methods. However, it is unlikely that this is the only methodological variable that is related to differences in outcomes. Studies were heterogeneous with respect to other methodological factors that may have influenced sensitivity estimates, including diverse recruitment methods, sampling frames, and geographical characteristics. Unfortunately, the methodological heterogeneity of the studies precluded meta-analysis of quantitative data.

Current evidence does not support routine screening of patients in whom cognitive impairment is not otherwise suspected.⁷⁵ Although screening-related studies might have provided additional information about predictors of dementia detection, we did not include these studies because they address fundamentally different research questions and populations, and their results are therefore difficult to compare with those of the type we aimed to review.

Finally, our results might have been affected by publication bias. We only searched the published literature, which may have resulted in an overall underestimate or overestimate of primary care physicians' diagnostic sensitivity. Furthermore, because articles pertaining to our topic of interest were not easily located using established search headings, we relied on a keyword search strategy that may have missed some papers despite our efforts to locate relevant articles through secondary searches. Despite these limitations, the rich information we obtained from these studies illuminates several avenues for future work on the timeliness and accuracy of dementia diagnosis.

In summary, our review of the literature on missed and delayed diagnosis of dementia revealed evidence of variable and often poor diagnostic sensitivity, which was affected by several factors including disease type and severity, behavioral symptoms, and rate of contact between provider and patient. Contributing to problems with diagnosis are several interrelated provider, patient,

and caregiver factors that collectively hinder recognition of early symptoms of dementia or discourage evaluation altogether. On the positive side, many of the factors identified in this review may be amenable to intervention and, if addressed, may improve early detection. System-level factors, which have received less attention in the literature on this topic, are especially important to address in future research on dementia diagnosis.

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References

1. Plassman BL, Langa KM, Fisher GG, et al. Prevalence of dementia in the United States: the Aging, Demographics, and Memory study. *Neuroepidemiology* 2007;29(1–2):125–32. [PubMed: 17975326]
2. Alzheimer's Association. Alzheimer's disease facts and figures. Alzheimer's Association Web site. 2008 [Accessed February 10, 2009]. http://www.alz.org/alzheimers_disease_facts_figures.asp Updated June 13, 2008
3. Cotter VT. The burden of dementia. *Am J Manag Care* 2007 December;13 Suppl 8:S193–S197. [PubMed: 18095782]
4. Coughlin TA, Liu K. Health care costs of older persons with cognitive impairments. *Gerontologist* 1989 April;29(2):173–82. [PubMed: 2502480]
5. Doraiswamy PM, Leon J, Cummings JL, et al. Prevalence and impact of medical comorbidity in Alzheimer's disease. *J Gerontol A Biol Sci Med Sci* 2002 March;57(3):M173–M177. [PubMed: 11867654]
6. Kunik ME, Snow AL, Molinari VA, et al. Health care utilization in dementia patients with psychiatric comorbidity. *Gerontologist* 2003 February;43(1):86–91. [PubMed: 12604749]
7. Lyketsos CG, Sheppard JM, Rabins PV. Dementia in elderly persons in a general hospital. *Am J Psychiatry* 2000 May;157(5):704–7. [PubMed: 10784461]
8. Papastavrou E, Kalokerinou A, Papacostas SS, et al. Caring for a relative with dementia: family caregiver burden. *J Adv Nurs* 2007 June;58(5):446–57. [PubMed: 17442030]
9. Institute of Medicine. *Crossing the quality chasm: A new health system for the 21st century*. Washington, D.C.: National Academies Press; 2001.
10. Moise, P.; Schwarzingler, M.; Um, M-Y. Dementia Experts' Group. *Dementia care in 9 OECD countries: a comparative analysis*. Paris: Organisation for Economic Cooperation and Development; 2004. Report No.: 13
11. Standridge JB. Pharmacotherapeutic approaches to the prevention of Alzheimer's disease. *Am J Geriatr Pharmacother* 2004 June;2(2):119–32. [PubMed: 15555488]
12. Brayne C, Fox C, Boustani M. Dementia screening in primary care: is it time? *JAMA* 2007 November 28;298(20):2409–11. [PubMed: 18042918]
13. Boise L, Camicioli R, Morgan DL, Rose JH, Congleton L. Diagnosing dementia: perspectives of primary care physicians. *Gerontologist* 1999 August;39(4):457–64. [PubMed: 10495584]
14. Callahan CM, Hendrie HC, Tierney WM. Documentation and evaluation of cognitive impairment in elderly primary care patients. *Ann Intern Med* 1995 March 15;122(6):422–9. [PubMed: 7856990]
15. Iliffe S, Haines A, Gallivan S, Booroff A, Goldenberg E, Morgan P. Assessment of elderly people in general practice. 1. Social circumstances and mental state. *Br J Gen Pract* 1991 January;41(342):9–12. [PubMed: 1805805]
16. McCormick WC, Kukull WA, van BG, Bowen JD, Teri L, Larson EB. Symptom patterns and comorbidity in the early stages of Alzheimer's disease. *J Am Geriatr Soc* 1994 May;42(5):517–21. [PubMed: 8176147]
17. Salmon DP, Bondi MW. Neuropsychological assessment of dementia. *Annual Review of Psychology* 2009;60:3.1–3.26.

18. Gandhi TK, Kachalia A, Thomas EJ, et al. Missed and delayed diagnoses in the ambulatory setting: a study of closed malpractice claims. *Ann Intern Med* 2006 October 3;145(7):488–96. [PubMed: 17015866]
19. Graber ML, Franklin N, Gordon R. Diagnostic error in internal medicine. *Arch Intern Med* 2005 July 11;165(13):1493–9. [PubMed: 16009864]
20. Schiff, G.; Kim, S.; Abrams, R., et al. Diagnosing diagnostic errors: lessons from a multi-institutional collaborative project. In: Henriksen, K.; Battles, J.; Marks, E.; Lewin, D., editors. *Advances in Patient Safety: From Research to Implementation*. Vol. 2, Concepts and Methodology. Rockville, MD: Agency for Healthcare Research and Quality; 2005. p. 255-78.
21. Singh H, Petersen LA, Thomas EJ. Understanding diagnostic errors in medicine: a lesson from aviation. *Qual Saf Health Care* 2006 June;15(3):159–64. [PubMed: 16751463]
22. Singh H, Naik AD, Rao R, Petersen LA. Reducing diagnostic errors through effective communication: harnessing the power of information technology. *J Gen Intern Med* 2008 April;23(4):489–94. [PubMed: 18373151]
23. Mitchell AJ. A meta-analysis of the accuracy of the mini-mental state examination in the detection of dementia and mild cognitive impairment. *J Psychiatr Res* 2008 June;;23.
24. Borson S, Scanlan JM, Watanabe J, Tu SP, Lessig M. Improving identification of cognitive impairment in primary care. *Int J Geriatr Psychiatry* 2006 April;21(4):349–55. [PubMed: 16534774]
25. Eefsting JA, Boersma F, Van Den BW, Van TW. Differences in prevalence of dementia based on community survey and general practitioner recognition. *Psychol Med* 1996 November;26(6):1223–30. [PubMed: 8931168]
26. Lagaay AM, van der Meij JC, Hijmans W. Validation of medical history taking as part of a population based survey in subjects aged 85 and over. *BMJ* 1992 April 25;304(6834):1091–2. [PubMed: 1586823]
27. Lopponen M, Raiha I, Isoaho R, Vahlberg T, Kivela SL. Diagnosing cognitive impairment and dementia in primary health care -- a more active approach is needed. *Age Ageing* 2003 November; 32(6):606–12. [PubMed: 14600001]
28. O'Connor DW, Pollitt PA, Hyde JB, Brook CP, Reiss BB, Roth M. Do general practitioners miss dementia in elderly patients? *BMJ* 1988 October 29;297(6656):1107–10. [PubMed: 3143447]
29. Olafsdottir M, Skoog I, Marcusson J. Detection of dementia in primary care: the Linkoping study. *Dement Geriatr Cogn Disord* 2000 July;11(4):223–9. [PubMed: 10867449]
30. Valcour VG, Masaki KH, Curb JD, Blanchette PL. The detection of dementia in the primary care setting. *Arch Intern Med* 2000 October 23;160(19):2964–8. [PubMed: 11041904]
31. Verhey FR, Jolles J, Ponds RW, et al. Diagnosing dementia: a comparison between a monodisciplinary and a multidisciplinary approach. *J Neuropsychiatry Clin Neurosci* 1993;5(1):78–85. [PubMed: 8428140]
32. Rubin SM, Glasser ML, Werckle MA. The examination of physicians' awareness of dementing disorders. *J Am Geriatr Soc* 1987 December;35(12):1051–8. [PubMed: 3680837]
33. Bond J, Stave C, Sganga A, O'Connell B, Stanley R. Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey. *International Journal of Clinical Practice* 2005;59(Suppl 146):8–14. [PubMed: 15801185]
34. Brodaty H, Howarth GC, Mant A, Kurrle SE. General practice and dementia. A national survey of Australian GPs. *Med J Aust* 1994 January 3;160(1):10–4. [PubMed: 8271977]
35. Cahill S, Clark M, Walsh C, O'Connell H, Lawlor B. Dementia in primary care: the first survey of Irish general practitioners. *Int J Geriatr Psychiatry* 2006 April;21(4):319–24. [PubMed: 16534765]
36. Downs M, Cook A, Rae C, Collins K. Caring for patients with dementia: the GP perspective. *Aging & Mental Health* 2000;4(4):301–4.
37. Iliffe S, Manthorpe J, Eden A. Sooner or later? Issues in the early diagnosis of dementia in general practice: a qualitative study. *Fam Pract* 2003 August;20(4):376–81. [PubMed: 12876106]
38. Iliffe S, Wilcock J. The identification of barriers to the recognition of, and response to, dementia in primary care using a modified focus group approach. *Dementia* 2005;4(1):73–85.
39. Kaduszkiewicz H, Wiese B, van den BH. Self-reported competence, attitude and approach of physicians towards patients with dementia in ambulatory care: results of a postal survey. *BMC Health Serv Res* 2008;8:54. [PubMed: 18321394]

40. Milne AJ, Woolford H, Mason J, Hatzidimitriadou E. Early diagnosis of dementia by GPs: an exploratory study of attitudes. *Aging & Mental Health* 2000;4(4):292–300.
41. Milne AJ, Hamilton-West K, Hatzidimitriadou E. GP attitudes to early diagnosis of dementia: evidence of improvement. *Aging Ment Health* 2005 September;9(5):449–55. [PubMed: 16024404]
42. Olafsdottir M, Foldevi M, Marcusson J. Dementia in primary care: why the low detection rate? *Scand J Prim Health Care* 2001 September;19(3):194–8. [PubMed: 11697565]
43. Renshaw J, Scurfield P, Cloke L, Orrell M. General practitioners' views on the early diagnosis of dementia. *Br J Gen Pract* 2001 January;51(462):37–8. [PubMed: 11271871]
44. Turner S, Iliffe S, Downs M, et al. General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. *Age Ageing* 2004 September;33(5):461–7. [PubMed: 15271637]
45. van HH, Vernooij-Dassen M, Bakker K, Blom M, Grol R. General practitioners on dementia: tasks, practices and obstacles. *Patient Educ Couns* 2000 February;39(2–3):219–25. [PubMed: 11040721]
46. Wilkinson D, Sganga A, Stave C, O'Connell B. Implications of the Facing Dementia SURvey for health care professionals across Europe. *Int J Clin Pract Suppl* 2005;146(27–31)
47. Teel CS. Rural practitioners' experiences in dementia diagnosis and treatment. *Aging Ment Health* 2004 September;8(5):422–9. [PubMed: 15511740]
48. Vernooij-Dassen M, Moniz-Cook E, et al. Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma. *International Journal of Geriatric Psychiatry* 2005;20(4):377–86. [PubMed: 15799080]
49. Hinton L, Franz C, Friend J. Pathways to dementia diagnosis: evidence for cross-ethnic differences. *Alzheimer Dis Assoc Disord* 2004 July;18(3):134–44. [PubMed: 15494619]
50. Incalzi R, Marra C, Gemma A, Capparella O, Carbonin P. Unrecognized dementia: sociodemographic correlates. *Aging Clin Exp Res* 1992;4(4):327–32.
51. Ross GW, Abbott RD, Petrovitch H, et al. Frequency and characteristics of silent dementia among elderly Japanese-American men. The Honolulu-Asia Aging Study. *JAMA* 1997 March 12;277(10):800–5. [PubMed: 9052709]
52. Wackerbarth S, Johnson M. The carrot and the stick: benefits and barriers in getting a diagnosis. *Alzheimer Dis Assoc Disord* 2002;16(4):213–20. [PubMed: 12468895]
53. 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 November;48(11):1430–4. [PubMed: 11083319]
54. Boise L, Morgan D, Kaye J, Camicioli R. Delays in the diagnosis of dementia: perspectives of family caregivers. *Am J Alzheimers Dis Other Dement* 1999;14(1):20–6.
55. Connell CM, Gallant MP. Spouse caregivers' attitudes toward obtaining a diagnosis of a dementing illness. *J Am Geriatr Soc* 1996 August;44(8):1003–9. [PubMed: 8708288]
56. Jones R, Chow T, Gatz M. Asian Americans and Alzheimer's disease: assimilation, culture, and beliefs. *J Aging Stud* 2006;20(1):11–25.
57. Knopman D, Donohue JA, Guterman EM. Patterns of care in the early stages of Alzheimer's disease: impediments to timely diagnosis. *J Am Geriatr Soc* 2000 March;48(3):300–4. [PubMed: 10733057]
58. Ortiz F, Fitten LJ. Barriers to healthcare access for cognitively impaired older Hispanics. *Alzheimer Dis Assoc Disord* 2000 July;14(3):141–50. [PubMed: 10994655]
59. Adelman RD, Greene MG, Friedmann E. Discussions about cognitive impairment in first medical visits: older patients' perceptions and preferences. *Am J Alzheimers Dis Other Dement* 2004 July;19(4):233–8. [PubMed: 15359561]
60. Rimmer E, Wojciechowska M, Stave C, Sganga A, O'Connell B. Implications of the Facing Dementia Survey for the general population, patients and caregivers across Europe. *Int J Clin Pract Suppl* 2005 March;(146):17–24. [PubMed: 15801187]
61. Hinton L, Franz CE, Reddy G, Flores Y, Kravitz RL, Barker JC. Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives. *J Gen Intern Med* 2007 November;22(11):1487–92. [PubMed: 17823840]
62. National Institute on Aging. A global perspective. National Institute on Aging; 2007. Why population aging matters. Report No.: 07–6134

63. Brookmeyer R, Gray S, Kawas C. Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. *Am J Public Health* 1998 September;88(9):1337–42. [PubMed: 9736873]
64. Cooper B, Bickel H, Schaufele M. The ability of general practitioners to detect dementia and cognitive impairment in their elderly patients: a study in Mannheim. *International Journal of Geriatric Psychiatry* 1992;7(8):591–8.
65. Bass DM, Clark PA, Looman WJ, McCarthy CA, Eckert S. The Cleveland Alzheimer's managed care demonstration: outcomes after 12 months of implementation. *Gerontologist* 2003 February;43(1):73–85. [PubMed: 12604748]
66. Bass, DM.; Kunik, ME.; Maslow, K. Partners in dementia care: an innovative care coordination intervention for veterans with dementia and family caregivers. Paper presented at: 60th Annual Scientific Meeting of the Gerontological Society of America; November 2007; San Francisco, CA.
67. Byszewski AM, Molnar FJ, Aminzadeh F, Eisner M, Gardezi F, Bassett R. Dementia diagnosis disclosure: a study of patient and caregiver perspectives. *Alzheimer Disease & Associated Disorders* 2007 April;-Jun;21(2):107–14. [PubMed: 17545735]
68. Erde EL, Nadal EC, Scholl TO. On truth telling and the diagnosis of Alzheimer's disease. *Journal of Family Practice* 1988 April;26(4):401–6. [PubMed: 3356973]
69. Keightley J, Mitchell A. What factors influence mental health professionals when deciding whether or not to share a diagnosis of dementia with the person? *Aging & Mental Health* 2004;8(1):13–20. [PubMed: 14690863]
70. Vassilas CA, Donaldson J. Telling the truth: what do general practitioners say to patients with dementia or terminal cancer? *Br J Gen Pract* 1998 March;48(428):1081–2. [PubMed: 9624754]
71. Maeck L, Haak S, Knoblauch A, Stoppe G. Early diagnosis of dementia in primary care : a representative eight-year follow-up study in Lower Saxony, Germany. *Int J Geriatr Psychiatry* 2007;22:23–31. [PubMed: 16955450]
72. Overcoming barriers to dementia diagnosis [editorial]. *Lancet* 2008;371(9628):1888.
73. Chodosh J, Berry E, Lee M, et al. Effect of a dementia care management intervention on primary care provider knowledge, attitudes, and perceptions of quality of care. *J Am Geriatr Soc* 2006 February; 54(2):311–7. [PubMed: 16460384]
74. McNutt RA, Abrams R, Arons DC. Patient safety efforts should focus on medical errors. *JAMA* 2002 April 17;287(15):1997–2001. [PubMed: 11960545]
75. Boustani, M.; Peterson, B.; Harris, R., et al. Systematic evidence review. Number 20. Screening for dementia. Agency for Healthcare Research and Quality; 2003. Report No.: 20
76. Glosser G, Wexler D, Balmelli M. Physicians' and families' perspectives on the medical management of dementia. *J Am Geriatr Soc* 1985 June;33(6):383–91. [PubMed: 3998347]

Table 1
Estimates of Diagnostic Accuracy for Dementia Among Primary Care Providers

Author(s), year	Patient sample	Provider sample	Description of diagnosis or detection	Reference assessment method	Accuracy of provider assessment against reference assessment
Borson et al., 2006 ²⁴	371 elderly community volunteers	199 primary care providers including 61% internists, 29% family physicians, and 5% geriatricians	Documentation of "suspected or diagnosed cognitive impairment" in the primary care medical record	Previously published research protocol including informant interview, patient observation, and structured cognitive assessment	Sensitivity in mild dementia = .41, moderate dementia = .59, severe dementia = .95
Efsthing et al., 1996 ²⁵	375 primary care patients >65 years of age	24 general practitioners	Provider judgment of "dementia" versus "cognitive impairment" or "no cognitive impairment"	Structured cognitive assessment including MMSE and assessment of DSM-III-R criteria	Sensitivity in mild dementia = .14, moderate/severe dementia = .47
Lagaay et al., 1992 ²⁶	60 community dwelling adults aged 85 and older selected at random from four medical practices	Four general practitioners	Documentation of dementia diagnosis in the medical record	Medical history and Mini-Mental State Examination performed by an internist	Sensitivity = .69
Lopponen et al., 2003 ²⁷	112 adults aged 64 and older recruited from the community and diagnosed with dementia by the research team	Not specified	Documentation of the primary care medical record	Laboratory tests, physical Examination, and semi-structured interview with caregivers present when possible; diagnosis based on DSM-IV criteria	Sensitivity = .48, specificity > .99
O'Connor et al., 1988 ²⁸	444 elderly patients who scored 23 or less on the Mini-Mental State Examination during screening for the study	Seven general practice groups	Provider judgment of "definitely demented" versus "possibly demented" or "possibly not demented"	Mini-Mental State Examination followed by CAMDEX diagnostic interview for scores ≤ 23	Sensitivity in mild dementia = .22, moderate dementia = .36, severe dementia = .67
Olafsdottir et al., 2000 ²⁹	350 patients aged 70 and older attending a primary care clinic	11 physicians in a primary care clinic	Documentation of cognitive disturbance or dementia in the medical record	Semi-structured neuropsychiatric examination and informant interview; diagnosis based on DSM-III-R criteria	Sensitivity = .26
Valcour et al., 2000 ³⁰	297 internal medicine clinic patients aged 65 and older; predominantly Asian American	6 physicians practicing within an internal medicine outpatient clinic	Provider indication of presence or absence of dementia (or unsure) based on a same-day encounter	Formal cognitive testing and informant interview; dementia diagnosed by a geriatrician according to Cummings; criteria	Overall sensitivity = .33; sensitivity in mild dementia = .09, moderate dementia = .50, severe dementia = 1.0
Verhey et al., 1993 ³¹	151 patients referred from primary care to a multidisciplinary memory clinic	"General practitioners"	Referral for suspected dementia or memory impairment	History and multidisciplinary examination using DSM-III and DSM-III-R criteria for dementia diagnosis	Sensitivity = .60; specificity = .99

Table 2**Physician Factors Contributing to Missed and Delayed Diagnosis of Dementia**

Factor	Description	Relevant studies
Physician characteristics	Age	32*
Educational needs	Lack of knowledge of or contact with local dementia support resources	32, 36, 43, 44
	Lack of training or skills specific to dementia care	13, 33, 37, 39, 42-46
	Concern about risk of misdiagnosis	37, 38, 40, 41, 48
Attitudes toward dementia	Concern about possible burden or stigmatization of patients with diagnosis	34, 35, 37, 40, 41, 47, 48
	Concern that early diagnosis will increase demand on already limited resources	37, 38, 40, 41
	Doubts about the usefulness or desirability of early diagnosis	13, 34, 38, 41, 43-45
	Tendency to minimize or downplay patients' concerns about cognitive function	13, 49, 54, 76
	Avoidance of pressure from patients and caregivers for intervention	37
	Perception of limited treatment options	13, 42, 43, 46, 48
	Prioritize treatment of physical health problems	13
	Unwillingness to discuss cognitive problems with patients or caregivers	42
	Prioritize assessment for younger patients	13
Approach to testing process	Perception of specialist referral/consultation as unhelpful	13
	Lack of standardized validated screening protocols and/or routine implementation of screening	13, 36
	Existing assessment tools viewed as unhelpful or not feasible to implement in practice	13, 37, 46
	Embarrassment or discomfort administering assessment	45
Communication	Poor communication between physician and patients or caregivers	34
	Difficulty discussing or explaining diagnosis with patients or caregivers	36, 42, 44-46
	Language barriers	49
	Patient perception of disparities or discrimination in care	49

* Older age was associated with greater confidence in ability to make a diagnosis of dementia, whereas younger age was associated with better performance on a test of knowledge about dementia

Table 3**Patient Factors Contributing to Missed and Delayed Diagnosis of Dementia**

Factor	Description	Relevant studies
Patient characteristics	Residence in a rural area	50
	Lower level of education	51
	Age (younger ⁵³ and older ⁵¹)	51, 53
	Lower severity of dementia	53
	Marital status (unmarried)	53
Awareness/education about dementia	Assume that cognitive changes are part of normal aging	58
	Perception of limited treatment options	58
	Concern about effects of treatment	58
Attitudes	Denial of need for/refusal of assessment or treatment	34, 45, 46, 54, 58
	Fear or other negative emotional reaction to the possibility of dementia	58
	Cognitive impairment not considered a priority for discussion with physician	59
Communication	Language barrier	49, 56, 58
	Forgetting to mention cognitive symptoms	59
	Reliance on physician to bring up the topic of cognitive symptoms	59
	Unwillingness to challenge physician's authority	56
Access	Lack of transportation	58
	Concerns that seeking care might threaten immigration status or result in deportation	58
	Concern about cost of treatment or lack of health insurance	58

Table 4**Caregiver Factors Contributing to Missed and Delayed Diagnosis of Dementia.**

Factor	Description	Relevant studies
Caregiver characteristics	Younger age *	52
	Lower level of education *	52
	Residence in a rural area	52
Awareness/education about dementia	Assume that cognitive changes are part of normal aging	33: 46: 54-58
	Perception of limited treatment options	52: 55: 56
	Lack of knowledge of dementia/symptom recognition	33: 46: 52: 54: 57: 60
	Misattribution of symptoms to another condition or medication	33: 52: 60
	Uncertainty regarding appropriate choice of health provider	54
Attitudes	Denial/preference not to know the diagnosis	33: 34: 47: 48: 52: 54-56: 60
	Doubts about the value of diagnosis and treatment	52: 54: 55: 58
	Fear of negative consequences or stigmatization for the patient	33: 52: 55: 56
	Fear of confirming own risk for dementia	52
	Emotional, financial, or other burden of diagnosis on the caregiver or family	52: 54: 55: 57
	Concern about the potential involvement of social services	52
	Concern about effects of diagnosis on the patient's autonomy	52: 54
Communication	Difficulty addressing problem directly with patient	57
	Difficulty communicating with physician	54: 59
	Interpret physician silence as a sign that nothing is wrong	52: 54
Access	Perceived lack of physicians who are capable of making a diagnosis	52: 55: 56
	Concern about costs of treatment or lack of health insurance	52: 54: 55: 58
	Concern that patient might be denied access to nursing home or other service if diagnosed	52
	Geographical location farther from urban area *	52
Other	Process of diagnosis is viewed as too time consuming	55: 60

* Associated with a higher score on a questionnaire measuring total barriers to diagnostic assessment

Table 5**System-related Factors Contributing to Missed and Delayed Diagnosis of Dementia**

Factor	Description	Relevant studies
Resources	Limited time with patients	13 ¹ 34 ¹ 37 ¹ 42 ¹ 44 ¹ 45 ¹ 61
	Insufficient community services available to patients with dementia	13 ¹ 33 ¹ 34 ¹ 37 ¹ 38 ¹ 60 ¹ 61
	Lack of specialists available for consultation	13 ¹ 47 ¹ 61
Financial factors	Low financial incentives/reimbursement for dementia care	34 ¹ 61
	Limitations on diagnostic tests imposed by managed care or state health system guidelines	13 ¹ 46
	Dementia not prioritized in public health planning	33 ¹ 46 ¹ 60