Systematic Review

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An integrative review of system-level factors influencing dementia detection in primary care

Raymond R. Romano, III MSN, FNP (Instructor)[1], Michael A. Carter, DNSc, DNP, FNP (Professor)[2],
Alison R. Anderson, MSN, FNP (Student)[1], & Todd B. Monroe, PhD, RN (Associate Professor)[3]

ABSTRACT

Background and purpose: The incidence of Alzheimer disease (AD) is increasing in the United States, yet more than half of the people with AD are diagnosed late in the course of the disease. Most are identified outside primary care. New approaches to prevention and treatment mean that early detection of AD may improve the quality of life of those affected by the disease. Nurse practitioners (NPs) have an important role in increasing early diagnosis of AD.
The purpose of this systematic literature review is to identify health care system factors that contribute to missed or delayed diagnosis of dementia by primary care providers.

Methods: Articles were identified through a systematic electronic search of the following databases: MEDLINE, the Cochrane Central Register of Controlled Trials, CINAHL, and PsycINFO.

Conclusions and implications for practice: Results indicate considerable variation in the diagnostic accuracy of dementia by primary care providers. Missed or underdiagnosis of dementia results from organizational, provider, and patient factors. New treatments are under investigation that may slow the progression of AD much better than current therapy, emphasizing the need to improve early detection by clinicians, especially primary care NPs.

Keywords: Alzheimer disease; dementia; nurse practitioners; primary care.

Journal of the American Association of Nurse Practitioners 32 (2020) 299–305, © 2019 American Association of Nurse Practitioners

DOI# 10.1097/JXX.0000000000000230

Background

Alzheimer disease (AD) is the most common type of dementia and is estimated to affect over 5.7 million adults in the United States (Alzheimer's Association, 2018). Alzheimer disease and other forms of dementia are often not detected until advanced stages of the disease because there is currently no definitive method for diagnosing AD except through direct observation of the brain after death (Alzheimer's Association, 2018). Clinical symptoms of AD typically begin with subtle short-term memory problems or slight personality changes (Wilson, Segawa, Boyle, Anagnos, Hizel, & Bennet, 2012), making early diagnosis difficult. Epidemiological studies suggest that at least half of the people living with AD have not yet received a diagnosis (Barker et al., 2002).

The prevalence of AD is expected to triple over the next 30 years (Hebert, Weuve, Scherr, & Evans, 2013; Patterson, 2018). Estimated health care costs of AD in the United States were $277 billion for 2018 and are estimated to surpass $1.1 trillion by 2050 if there is no change in preventing or delaying AD (Alzheimer's Association, 2018). Estimates suggest that slowing disease progression by at least 5 years is estimated to reduce the overall mortality rate, financial costs, and public burden related to AD by 39% (Zissimopoulos, Crimmins, & St. Clair, 2014).

Less than half of the persons with dementia and/or their caregivers report any history of clinical cognitive evaluation (Kotagal et al., 2015). One reason for low reports of receiving a cognitive evaluation is that the United States Preventive Services Task Force does not currently recommend screening for cognitive impairment in older adults, arguing that there is insufficient evidence to support the benefit of early detection, particularly in light of ineffective treatment (Moyer, 2014). However, the lack of effective treatment may be changing because ongoing studies are testing novel drugs and nondrug therapeutic interventions that may help prevent the

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[1] *Vanderbilt University School of Nursing, Nashville, Tennessee,* [2] *Distinguished Professor Emeritus, College of Nursing, University of Tennessee Health Science Center, Nashville, Tennessee,* [3] *The Ohio State University College of Nursing, Columbus, Ohio*

Correspondence: *Michael A. Carter, DNSc, DNP, FNP, Distinguished Professor Emeritus, College of Nursing, University of Tennessee Health Science Center, 369 Belmont Acres Circle, Tumbling Shoals, AR 72581. Tel: (501) 362-0763; Cell: (501) 691-3427; Fax: (501) 362-7436; E-mail: mcarter@uthsc.edu*

Received: *27 December 2018; revised: 11 March 2019; accepted 12 March 2019*

onset or delay the progression of the disease (Cummings, Lee, Ritter, & Zhong, 2018), and current pharmacological and nonpharmacological interventions seem to be most beneficial during the earliest stages of AD (Robinson, Tang, & Taylor (2015). Thus, early recognition of AD is critical for current and future treatment effectiveness.

There are other reasons that nurse practitioners (NPs) and other primary care providers may not screen for AD. One reason contributing to limited screening for AD results from health care system factors minimizing the need for this service. For example, health care system models may constrain NPs' practice behavior by failing to recognize how important early diagnosis is to individuals with AD and their families. Andersen behavioral model of health service utilization suggests that environmental characteristics influence behavior (Andersen, 2008; Andersen, Harada, Chiu, & Makinodan, 1995). This model proposes the importance of understanding the relationships between environmental characteristics and screening behaviors by NPs caring for people with AD and their families. Future studies focused on improving screening behaviors must consider these environmental characteristics when designing, implementing, and evaluating the behavior change intervention.

An older survey of 741 caregivers of people with AD found that 74% of families first approached their primary care provider with concerns about the memory of their loved one (Wilkinson, Stave, Keohane, & Vincenzino, 2004). However, in the same study, the authors found that in 70% of the cases, the diagnosis of AD was made by someone other than their primary care provider (Wilkinson et al., 2004). To our knowledge, this is the most recent study to address this phenomenon.

Objective

The overall goal of this literature review was to better understand why NPs may not routinely screen patients for AD. The specific objective was to identify factors in primary care practices reported in the literature that influence missed or delayed diagnosis of cognitive impairment. Understanding these factors will assist NPs in providing optimal care to patients with AD and their caregivers. Early detection of cognitive changes is necessary to trigger further evaluation leading to a formal diagnosis. This is not only critical to diagnosing dementia but also for uncovering reversible causes of cognitive decline such as normal pressure hydrocephalus, thyroid disease, vitamin deficiency, or depression.

Methods

Studies were searched electronically through MEDLINE (Ovid interface, 1948 onward), the Cochrane Central Register of Controlled Trials (Wiley interface, current issue), CINAHL, and PsycINFO. The search strategy aimed to find peer-reviewed articles that identified organizational, provider, or patient characteristics of the primary care setting that influenced screening in AD. A combination of three terms, "dementia" and "diagnosis" and "primary care," were used, and four purposefully selected search terms—"barrier," "attitude," "organizational factors," and "missed diagnosis"—were used in each electronic search. All potential English language articles were exported directly to EndNote.

Articles were considered for inclusion if they met the following criteria: 1. They were empirical studies; 2. They identified factors for missed or delayed diagnosis; 3. They included a comparison of diagnostic accuracy by primary care providers; or 4. They identified organizational characteristics related to diagnosis of AD. Articles were excluded for the following criteria: 1. They were not published in English; 2. They were reviews or commentaries; or 3. Full articles could not be obtained.

First, all duplicates were removed. Next, articles that were not topically related based on the title and subsequent reading of the abstract were excluded. Third, articles that met the above exclusion criteria were removed.

A piloted data collection form was developed and revised to capture consistent information to address the research objective. The data collection form included information on the estimated prevalence of dementia in the sample; the accuracy of provider diagnosis including cognitive impairment, dementia, AD, vascular dementia, and other diagnosis; the tools used by the provider to make an estimation of cognitive impairment; and the tool used to determine accuracy in diagnosis. In addition, the form collected textual data on any factors identified that contributed to the diagnosis of AD or a related dementia. The overwhelming majority of the literature focused on "Alzheimer disease" or "dementia," and for the purposes of this article, we elected to use the term "AD" because it is the most common subtype of dementia, and there are specific diagnostic criteria for probable or possible AD.

Risk of bias in the remaining studies was assessed using design specific tools developed by the Risk Assessment Work Group of the National Heart, Lung, and Blood Institute (Risk Assessment Work Group, 2013). The ratio was calculated for each study between point values (e.g., No = 0, Yes = 1, Good = 2, Fair = 1, and Poor = 0) assigned for each item to total number of questions. Each author reviewed the scoring criteria, and a final score consensus was reached by all authors.

Results

The search yielded 140 empirical studies. Of these, 133 studies were excluded because they focused on the validation of specific screening tools, the detection of other illnesses, or dementia care outside primary care. This resulted in seven articles selected to be included in the literature review: two were interventional studies, two were case comparison studies, and three were cross-sectional studies. None of these studies examined NP practices specifically, and it is likely that few, if any, NPs were included in the sample. A comparison of study characteristics is provided in **Table 1**. Most studies were rated as high quality, with the weakest study receiving a calculated score of 0.52 (range 0–2) using the bias risk tool described earlier. The major threat to internal validity was selection bias across all studies because most studies relied on non-random methods to select participants. A description of internal threats to validity is presented in **Table 2**.

The studies estimating diagnostic accuracy after intervention are summarized in **Table 3**. Two studies compared the provider's clinical judgment against a neuropsychological test battery, whereas one study compared clinical diagnosis to autopsy results. The prevalence estimated by clinicians ranged from 6% to 51%, and the accuracy of diagnosis was between 19% and 81%. Identifying factors contributing to the detection of dementia are summarized in **Table 4**. The most widely cited organizational barrier was lack of services, whereas the most widely cited provider barrier was lack of the provider's ability to accurately make the diagnosis. A frequently noted patient barrier to accurate diagnosis of dementia was the occurrence of confounding comorbidities or frailty.

Discussion

This review of research literature suggests that the clinical presentation of dementia is heterogeneous and results in variation in diagnostic accuracy. Results indicate that primary care providers have varying ability to accurately diagnose AD irrespective of education and training (Alzheimer's Association, 2018; Mok, Chow, Zheng, Mack, & Miller, 2004; Tierney et al., 2014). The study by Mok et al. (2004) suggested that diagnostic accuracy was 84% when confirmed via autopsy among a group of community based primary care providers. Similarly, Tierney et al., (2014) reported that the specificity of clinical judgment to detect AD was 86% in primary care providers. Tierney et al., (2014) concluded that many provider and patient characteristics influenced the likelihood of detecting dementia and that providers seeing a greater number of cognitively impaired individuals demonstrated better clinical judgment. The authors further noted that overall complexity of dual comorbidities heavily influenced diagnostic accuracy (Tierney et al., 2014). The ability to accurately discern cognitive impairment was not associated with routinely conducting cognitive assessments on individuals with positive family history or frequently asking about cognitive function on examination (Tierney et al., 2014).

Similarities in the results from Mok et al. (2004) and Teierney et al., (2014) suggest that organizational need, such as higher patient burden, may be a greater factor influencing accuracy in diagnosis and may be an influencing factor on practice behavior. No intervariable correlations were presented by Teireny et al., (2014), but it may be possible that NPs will increase their screening for AD as the number of patients with dementia in the practice increases.

Provider educational needs have been identified as a major factor at both the provider and the patient level to diagnosis of AD (Edwards, Voss, & Iliffe, 2015; Fortinsky, Zlateva, Delaney, & Kleppinger, 2010; Martin et al., 2015; Veneziani et al., 2016). Provider attitude toward dementia care and treatment are also major factors influencing the accurate detection and diagnosis of dementia (**Table 4**). An educational intervention developed for primary care providers showed an improvement on pretest versus

Table 1. Descriptive comparison of studies

First Author (Year)	Country	Population	N	Study Type	Theme(s)
Veneziani et al. (2016)	Italy	Provider	131	Cross-sectional survey	Knowledge of AD
Magin et al. (2016)	Australia	Patients	489	Cross-sectional survey	Attitudes toward AD
Edwards et al. (2015)5	England	Providers and care staff	28 and 62	Interventional	Educational intervention to improve patient-centered outcomes
Tierney et al. (2014)	Canada	Providers and patients	13 and 133	Case comparison	Accuracy of diagnosis
Fortinsky et al. (2010)	United States	Providers	422	Cross-sectional survey	Geographic variation to approached and barriers
Boustani et al. (2005)	United States	Patients	3,340	Quality improvement	Implementing screening protocols
Mok et al. (2004)	United States	Patients	463	Case comparison	Accuracy of diagnosis

Table 2. Comparison of quality of studies

	Quality Score[a]	Threats to Internal Validity
Cross-sectional		
Veneziani et al. (2016)	0.76	History threat (other surveys), selection bias (younger females), and social desirability
Magin et al. (2016)	0.79	Selection bias (nonrandom sample selected by the receptionist)
Fortinsky et al. (2010)	0.83	Possible selection bias (39% response rate)
Case comparison		
Tierney et al. (2014)	0.80	Selection bias (nonrandom sample)
Mok et al. (2004)	0.91	Selection bias (nonrandom selection of participants) and maturation bias (better able to access autopsy)
Interventional		
Edwards et al. (2015)	0.75	Potential testing bias (pretest cues) and potential maturation bias
Boustani et al. (2005)	0.52	Instrumentation bias (false negatives not accessed, no clinical data support) and selection bias (large number did not participate)

[a] *Ratio of the total score determined using NIH study quality assessment tools and the number of items assessed. Author consensus reached in support of scoring.*

posttest measures on both knowledge and attitudes, suggesting that knowledge is necessary to improve attitudes (Edwards et al., 2015).

Although improvements were seen on overall attitude scores, providers continued to associate lack of diagnosis with lack of community support and services (Edwards et al., 2015). In a different study, the provider practice of referring patients with cognitive impairment to community support services varied by geographic location, further suggesting that organizational factors contribute to the detection and care of dementia (Fortinsky et al., 2010).

Magin et al., (2016) reported that most patients would like to be tested for dementia. However, Veneziani et at. (2016) found lack of comfort communicating with patients about dementia and disclosing dementia diagnosis to be a contributing barrier to diagnosis. Interestingly, Veneziani et al. found that the routine practice of administering cognitive screening tests did contribute to overall knowledge and attitude about dementia. In addition, results found by Teireny et al. (2014) found that routine cognitive screening does not contribute to the ability of providers to accurately discern pathological cognitive impairment.

Findings by Boustani and colleagues (2005) support that a screening protocol alone is not sufficient to improve identifying patients with AD. In a practice with a prevalence of 6% dementia, less than half (47%) of the patients with dementia were identified by a screening protocol. The researchers concluded that a more complex intervention may be warranted. This intervention should consider all levels of the health care system (Boustani et al., 2005).

Gaps in the literature

We found no study that explicitly measured data related to organizational characteristics such as staffing levels. Only one study explored self-reported organizational level factors including reimbursement, time constraint, and community resources and did not conduct an objective, independent assessment of these factors (Fortinsky et al., 2010). Review findings suggest that organizational and environmental characteristics contribute to detection and care of dementia, yet no study directly used organizational structures as the main predictive variable.

A larger gap exists in the evidence to understand the reasons behind discordant diagnosis, although education is constantly cited as the reason. Educational needs are an obvious barrier, although Veneziani et al. (2016) did not find an association between the year of graduation of the provider and attitude or knowledge. However, other studies have demonstrated this relationship (Boise, 2006; Boise, Camicioli, Morgan, Rose, & Congleton, 1999; Bradford, Kunik, Schulz, Williams, & Singh, 2009). The lack of association in the study by Veneziani et al. may be the result of selection bias and lack of generalizability, as the sample was drawn from a research network (Veneziani et al., 2016). In addition, only three studies identified in this literature search explored how electronic health record decision support systems affected dementia care and diagnostic accuracy (Chou et al., 2012; Eichler et al., 2014; Grypma, 2007).

Limitations

The future goal of this work is to inform research about how AD screening can be implemented and evaluated by primary care NPs. This review has three main limitations. The first limitation is that one researcher conducted the literature search, review of articles, and extraction of data. To minimize this limitation, the reviewer adhered to a coding sheet and revisited articles after any edits were made to the coding sheet. Also, the authors used a published quality scale and reached consensus in the evaluation of each study, helping to reduce bias in the results.

Table 3. **Comparison of accuracy of dementia diagnosis**

	Provider Method	Referenced Method	Prevalence	Accuracy
Tierney et al. (2014)	Clinical judgment	Neuropsychological test battery	30%	60.6%
Boustani et al. (2005)	Clinical judgment	6-item screener, CSI-D, CERAD battery, GDS, and semistructured interview with an informant	6%	18.5%
Mok et al. (2004)	Clinical diagnosis	Autopsy	51%	81.2%

The second limitation is the heterogeneity of diagnosis and prevalence across the articles. We did not attempt to control for this heterogeneity; therefore, interpretation of diagnostic accuracy may be skewed. Not surprisingly, most articles focus on AD or "dementia," with little attention given to diagnosing specific subtypes of dementia. However, this limitation is overcome by the overwhelming majority of dementias presenting with some form of pathologic cognitive impairment, which is a key component to accurate diagnosis. The third limitation

Table 4. **Factors identified contributing to detection and treatment of dementia**

Factors	Veneziani et al. (2016)	Magin et al. (2016)	Edwards et al. (2015)	Tierney et al. (2014)	Fortinsky et al. (2010)	Boustani et al. (2005)	Mok et al. (2004)
Organizational							
Geographical location					×		
Time					×		
Lack of services	×		×				
Lack of specialists	×						
Lack of support staff					×		
Lack of reimbursements					×		
Patient load				×	×		
Provider							
Gender	×						
Education	×		×		×		×
Attitudes			×				
Testing process	×					×	
Communication			×				
Patient							
Age		×			×		
Gender					×		
Severity/risk/comorbidities		×	×	×		×	
Awareness		×		×			
Attitudes		×					

Note: × *denotes factor contributing to diagnosis or care of dementia either identified by the provider or through statistical analyses.*

is that none of the articles reported whether NPs were included in the sample or how NP practices might be different from other providers. Multiple studies have reported that NPs and physicians have similar practice outcomes, but this may not hold for screening for AD (Stank-Hutt et al., 2013).

Conclusion

Primary care providers, and especially NPs, are the first point of contact for patients and families with concerns about memory loss. At the same time, patients presenting to health care settings with memory complaints tend to not perform well on cognitive measures (Kumar, Singh & Ekavali, 2015). As the prevalence of AD is expected to increase and new, effective treatments are developed, there is a need to develop primary care services that detect AD earlier (Hebert et al., 2013). Dementia in general is underdiagnosed, and major initiatives in the United States are aimed at improving diagnosis. For example, the National Institute on Aging in the National Institutes of Health has very useful materials on assessing cognitive impairment (National Institute on Aging, 2014), and a required part of Medicare's Annual Wellness Visit includes an assessment of cognition (Medicare, n.d.). The results of this review, however, suggest that solely implementing a screening protocol is not enough to improve identification of AD.

NPs are poised to be the frontline leaders in screening for pathologic cognitive impairment and previously mentioned known reversible causes of cognitive impairment (e.g., thyroid hormone alterations, normal pressure hydrocephalus, vitamin deficiency, severe depression, and adverse effects from some medications). Better knowledge by providers of reversible causes of cognitive decline could help address patient- and provider-level discomfort in diagnosing AD or a related dementia are not the only challenges in improving care. Importantly, findings from the current review indicate that additional interventions that improve support systems, increase services for individuals with AD and their families, and clarifying testing procedures may be a more critical step in achieving the goal of earlier diagnosis. Finally, evidence presented in this review suggests that organizational and environmental factors exist that influence provider practice, and thus, screening and diagnosis of dementia in primary care and these factors need to be explored further.

Authors' contributions: *R. R. Romano designed the project, collected data, analyzed data, drafted the initial manuscript, and revised the manuscript for final submission. M. A. Carter, A. R. Anderson, and T. B. Monroe reviewed data collection, analyzed data, and revised the manuscript for final submission.*

Competing interests: *The authors report no conflicts of interest.*

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