The Journal of Prevention of Alzheimer's Disease 12 (2025) 100035

Contents lists available at ScienceDirect

The Journal of Prevention of Alzheimer's Disease

journal homepage: www.elsevier.com/locate/tjpad

Review

Determinants of dementia diagnosis in U.S. primary care in the past decade: A scoping review

Chelsea G. Cox[a,*], Barbara L. Brush[a,b], Lindsay C. Kobayashi[c], J. Scott Roberts[a]

[a] Department of Health Behavior and Health Equity, University of Michigan School of Public Health, 1415 Washington Heights, Ann Arbor, MI 48109-2029, United States
[b] Department of Health Behavior and Biological Sciences, University of Michigan School of Nursing, Ann Arbor, MI, United States
[c] Department of Epidemiology, University of Michigan School of Public Health, Ann Arbor, MI, United States

ARTICLE INFO

Keywords:
Alzheimer's disease and related dementias
Mild cognitive impairment
Primary care
Detection
Diagnosis

ABSTRACT

Background: Alzheimer's disease and related dementias (ADRD) are chronically underdiagnosed in the U.S., particularly among minoritized racial and ethnic groups. Primary care providers are at the forefront of diagnosis given the increasing prevalence of cases and shortage of dementia specialists. Advances in policy, detection, and treatment in the past decade necessitate an updated review of the current state of determinants of ADRD diagnosis in U.S. primary care settings.

Methods: Following Joanna Briggs Institute guidelines, we conducted a scoping literature review on ADRD diagnosis among older adults in U.S. primary care settings. Studies published in English from January 2010 to January 2024 were retrieved from PubMed, PsycINFO, and CINAHL. We extracted primary data on study characteristics and synthesized key findings according to facilitators, barriers, and rates of diagnosis in primary care.

Results: Of 563 articles retrieved, 12 met eligibility criteria. Three studies reported rates of diagnosis, and all but one reported facilitators and/or barriers to diagnosis. ADRD remains underdiagnosed in primary care settings, especially in the earliest symptomatic stage (i.e., mild cognitive impairment). Multi-level barriers and facilitators were identified including individual beliefs about ADRD (e.g., value of early diagnosis), interpersonal relationships between patients and their family members and providers (e.g., importance of an established clinical relationship), and healthcare system limitations (e.g., insufficient resources and training).

Conclusion: Despite national policy efforts to improve timely diagnosis of ADRD, underdiagnosis remains a clinical and public health challenge. Increased attention to social and community contexts will be important for future research and intervention.

1. Background

Alzheimer's disease and related dementias (ADRD) are the sixth leading cause of death in the United States [1]. They are among the most expensive and burdensome conditions, costing the healthcare system over $350 billion annually and demanding care from 11 million unpaid caregivers [2]. More than 6.5 million Americans are currently living with ADRD, and the prevalence is projected to double by 2060 with the growing older adult population [2]. Early (or timely) diagnosis of cognitive decline due to ADRD, before progression to dementia, may help improve quality of life and care planning for patients and families. Benefits of early diagnosis include access to new treatments and clinical trials, referral to education and social support programs, and advance planning that involves the patient in financial, legal, and medical decision-making [2–4]. Diagnosis can also guide clinical decision-making, such as avoiding treatments that may worsen cognition, initiating interventions to improve or maintain cognitive function, and treating reversible causes of cognitive impairment [2].

Timely and accurate diagnosis of ADRD is a high priority of the U.S. National Alzheimer's Project Act (NAPA) (P.L. 111–375), signed into law in 2011 [5]. Research suggests less than half of people with ADRD have been formally diagnosed by a clinician, and delays in diagnosis are more common among Black, Hispanic, and Asian older adults compared to non-Hispanic White older adults [4,6,7]. Previous systematic reviews have identified multiple barriers to ADRD diagnosis at the patient, clinician, and healthcare system levels [8–13]. Studies suggest major contributors to underdiagnosis include stigma and attitudes about ADRD, challenges in patient – clinician communication, educational deficits, and system resources constraints [9]. Additionally, limited availability of dementia specialists [14] and unclear guidelines on cognitive screening and assessment [15] present challenges to ADRD diagnosis in the U.S., particularly in primary care settings.

* Corresponding author.
E-mail address: chelseak@umich.edu (C.G. Cox).

https://doi.org/10.1016/j.tjpad.2024.100035
Received 20 September 2024; Received in revised form 14 November 2024; Accepted 8 December 2024
Available online 1 January 2025

With the increasing prevalence of ADRD and shortage of specialists to diagnose and manage these conditions, experts suggest that cognitive assessment in primary care is a critical first step to early detection [16]. Establishing a cognitive baseline in primary care can assist providers in early detection of cognitive changes that merit further evaluation [16]. In alignment, the Centers for Medicare and Medicaid (CMS) require detection of cognitive impairment in beneficiaries ages 65 and older via routine brief cognitive assessment at Medicare Annual Wellness Visits (AWV). Despite policy efforts to improve timely diagnosis of ADRD in primary care, recent national surveys report that less than 20% of older adults receive regular cognitive assessments during health check-ups [17,18]. Advances in national policy and detection and treatment of ADRD over the past decade necessitate an updated review of the current state of the determinants of ADRD diagnosis in U.S. primary care settings.

1.1. Purpose

The primary goal of this scoping review is to assess the extent of the literature in the past decade addressing the question: What factors contribute to underdiagnosis of ADRD in U.S. primary care settings? Specifically, this review aims to: (1) identify rates of diagnosis of cognitive impairment or dementia due to ADRD in primary care in the past decade since recent national policy efforts to promote diagnosis (i.e., NAPA; Medicare AWV); (2) identify research studies that have examined barriers or facilitators of ADRD diagnosis in primary care settings; and (3) compare and contrast the outcomes of these studies to identify needs for future research and interventions to improve early diagnosis of ADRD. Facilitators and barriers were interpreted based on the social ecological framework, which posits that multiple levels of factors – including individual beliefs and characteristics, interpersonal relationships, institutional structures, and community environments – influence health outcomes [19].

2. Methods

This scoping review followed the Joanna Briggs Institute (JBI) guideline for scoping research and was reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines (Fig. 1) [20]. The JBI methodology provides up-to-date guidance on the conduct of scoping reviews that is aligned with the current state of knowledge and reporting standards in evidence synthesis [21].

2.1. Search strategy

A literature search of PubMed, PsycINFO, and CINAHL was conducted in February 2024 to identify studies published from January 2010 to January 2024, given the timing of implementation of NAPA and Medicare AWV. A library informationist at the University of Michigan Taubman Health Sciences Library assisted in developing comprehensive search terms for four key concepts: (1) Alzheimer's disease and related dementias, (2) detection or diagnosis, (3) determinants, and (4) primary care. Searches combined these four key concepts using the Boolean operator "AND", and terms within concepts using the Boolean operator "OR". Detailed search strategies are available in the supplementary protocol.

2.2. Eligibility criteria

2.2.1. Inclusion criteria

The population of focus was U.S. adults ages 65 years and older, family members or care partners of older adults with ADRD, and primary care providers who serve older adult patients. The outcomes of interest were (a) prevalence or incidence rates of ADRD diagnosis in primary care settings, or (b) factors that contribute to ADRD diagnosis in primary care settings. Studies were included if they examined at least one of these outcome categories using qualitative, quantitative, or mixed methods. Given the focus on national policies and health services, only studies conducted in U.S. regions were included. Studies had to be published in English language in peer-reviewed journals.

2.2.2. Exclusion criteria

Studies were excluded from the review if the population of focus was adults under the age of 65 years or genetically inherited causes of dementia (e.g., Huntington's disease, autosomal dominant Alzheimer's disease). Outcomes focused on diagnosis outside of primary care settings (e.g., specialty clinics, inpatient settings), evaluation of ADRD diagnostic tools (e.g., cognitive tests, biomarkers), or ADRD prevalence and incidence estimates were excluded. Since the aim of the scoping review was to examine the state of ADRD diagnosis in primary care, quality improvement and intervention studies were excluded. Additionally, systematic or scoping reviews and grey literature including reports, guidelines, and recommendations were excluded from the analysis.

2.3. Data extraction and analysis

All studies retrieved from the search were imported and managed in Covidence systematic review software (Veritas Health Innovation, Melbourne Australia, available at www.covidence.org). Covidence is a web-based collaboration software platform that streamlines the production of systematic and other literature reviews. Duplicates were removed by Covidence. A single reviewer (CGC) screened all titles/abstracts and full-text manuscripts to determine if studies met eligibility criteria and examined the reference lists of included articles for additional studies that may have been missed in the original search. A data extraction template was developed to extract information on the following study characteristics: author(s) and year published, the primary objective(s) of the study, the methodology (i.e., qualitative, quantitative, mixed) and design, the setting (i.e., U.S. region, clinic, database) the population (i.e., older adults 65+, care partners, providers), sample characteristics (i.e., average age, sex, race and ethnicity, clinical training), and main findings (i.e., facilitators, barriers, or rates of diagnosis).

Results were grouped into three broad categories related to the primary objectives of this review: (1) rates of diagnosis of ADRD in primary care; (2) facilitators of diagnosis of ADRD in primary care; and (3) barriers to diagnosis of ADRD in primary care. Results related to facilitators and barriers were further organized based on the social ecological framework [19] to help synthesize and interpret multi-level factors that may interact across patient, care partner, and provider populations to influence underdiagnosis of ADRD in primary care.

3. Results

3.1. Search results

A total of 563 articles were retrieved in the initial search and 166 duplicates were removed by Covidence (Fig. 1). After screening 397 titles and abstracts, an additional 309 articles were excluded. A full-text review was conducted on the remaining 88 articles, and 76 were excluded. The main reasons for exclusion were studies conducted in countries outside of the U.S. ($N = 44$), ineligible design or outcomes including evaluation of diagnostic tools, quality improvement, interventions, or systematic reviews ($N = 16$), ineligible population or setting including patient population under age 65 and specialty clinic settings ($N = 8$), and grey literature including reports, recommendations or guidelines ($N = 8$). A remaining 12 studies were included in this scoping review. Table 1 provides a detailed summary of the studies, organized by methodology.

3.2. Study characteristics

The 12 studies were published from 2016 to 2024. All but one study [22] reported factors that contribute to ADRD diagnosis in primary care,

Table 1
Characteristics of 12 studies that met scoping review criteria, organized by method.

Author, Year	Primary Objective(s)	Method, Design	Population, Setting	Sample Characteristics	Key Findings: Facilitators, Barriers, or Rates of Detection
Sideman et al., 2023	To describe providers' perspectives on their role in dementia diagnosis and care	Qualitative, interview	Providers; California safety net primary care clinics	*N* = 39 Providers 64% Female 41% Asian 36% White 8% Black 8% Hispanic 77% MD 15% NP 8% DO	Facilitators • Providers view themselves as first point of contact for detection and believe they're uniquely positioned to provide dementia care because of trusting relationships with patients Barriers • Providers feel they need confirmation from specialists • Most reported minimal training in dementia; concerned about additional time needed for training • Disparity between what providers wanted to do and their ability to fulfill this role due to healthcare system challenges
Nogueras et al., 2016	To learn about the experiences of adult children of elderly parents who were ultimately diagnosed with dementia	Qualitative, telephone-based interview	Care partners; U.S. rural and urban settings	*N* = 12 Care partners 83% Female All adult children	Barriers • Difficulty convincing providers to evaluate changes in parent memory/behavior • Told by providers that changes were normal part of aging, nothing to worry about • Attributed changes in parent's behavior to grief or normal function of aging • Parents' spouse/partner sometimes covered up their symptoms for many years
Blinka et al., 2023	To identify factors that delay or facilitate dementia diagnoses in racial or ethnic minoritized people living with dementia, and elicit care partner perspectives on timing and effects of diagnosis	Qualitative, semi-structured interview	Older adults and care partners; greater Maryland region	*N* = 18 Dyads *Patients*: Ave. age 83 years 72% Female *Care partners*: Ave. age 61.6 years 83% Female *N* = 1 White *N* = 11 Black *N* = 4 Asian *N* = 3 Hispanic *N* = 2 Other	Facilitators • Most care partners sought provider input, valued longstanding relationships, and found provider supportive in diagnostic process • Many care partners felt dementia screening should be routine Barriers • Lack of knowledge of dementia and normalization of "senility" • Difficulty recognizing early symptoms versus normal aging • Secrecy, stigma, respect for elders kept some families from labeling dementia • Cognitive testing not culturally sensitive • Diagnoses were family-initiated, with concerns raised by family and not by clinicians or health system

(*continued on next page*)

Table 1 (*continued*)

Author, Year	Primary Objective(s)	Method, Design	Population, Setting	Sample Characteristics	Key Findings: Facilitators, Barriers, or Rates of Detection
Bandini et al., 2022	To understand the acceptability of screening for cognitive impairment in primary care among patients, family caregivers, and providers	Qualitative, focus group and semi-structured interview	Older adults, care partners and providers; University of Pittsburgh Medical Center and other U.S. primary care clinics	*N* = 18 Patients Ave. age 68.3 (3.2) *N* = 5 Care partners Ave. age 54 (10.4) *Patient/care partners:* 65% Female 73% White 14% Black 9% Asian *N* = 11 Providers 36% Female 64% White 27% Asian 9% Other 82% MD 18% NP	Facilitators • Most patients would be comfortable with provider asking them about memory or completing self-assessment • Patients and family felt that early detection was important in primary care, may facilitate planning for the future Barriers • Most patients reported never formally having cognitive screening by provider; variability in how they are asked about memory • Providers report not routinely screening outside of Medicare Annual Wellness Visits; absence of standardized screening methods and concern about time to administer • Providers noted issues around routine screening in absence of effective pharmacologic treatments • Providers noted difficulty screening patients limited English proficiency or low educational attainment
Perales-Puchalt et al., 2023	To explore the preferences of providers for dementia care training programs	Qualitative, interview	Providers, U.S. primary care clinics	*N* = 23 Providers 56% Female 43.5% White 43.5% Latino 9% Black 4% Asian 65% MD 30% NP 4% PA	Barriers • Providers described work burden, low awareness of resources, lack of a care plans to serve patients and their families, and social determinants of health (i.e., healthcare coverage, language, cultural proficiency) as barriers to dementia care • Providers want training/materials to promote early detection and build cultural competence, including tools for early detection and education about available tests to improve diagnosis
Abe et al., 2021	To understand the approach and challenges of primary care physicians for diagnosing dementia in Japan versus U.S. healthcare systems	Qualitative, semi-structured interview	Providers, Michigan rural and urban primary care clinics	*N* = 24 Providers 58% Female All MD	Facilitators • Provider diagnosis more likely in patients with advanced age, apparent cognitive symptoms, and access to family who can provide patient history • Established relationship with the patient to recognize when changes occur • Providers see value in ensuring safety and well-being of patients and community, gaining access to additional care resources, and family planning for future • Dementia screening requirement at Medicare Annual Wellness Visits and systematic prompting support diagnosis Barriers • Providers note challenges in diagnosing patients in early stage, younger age, living alone, lacking access to family member to discuss patient • Clinic settings without access to specialists, imaging tests • Rural areas with long distance and waiting times for appointments with specialists • Providers note no clear effect of dementia medications, limited value in specifying the type of dementia, hesitancy to label the patient given social stigma

(*continued on next page*)

Table 1 (*continued*)

Author, Year	Primary Objective(s)	Method, Design	Population, Setting	Sample Characteristics	Key Findings: Facilitators, Barriers, or Rates of Detection
Wiese et al., 2021	To examine rural stakeholder attitudes toward routine memory screening	Mixed-methods, semi-structured interview and cross-sectional surveys	Older adults, care partners, and providers; West Virginia community health centers	*N* = 22 Stakeholders Ave. age 64 (12.1) 73% Female 95% White 5% Black	Facilitators • Most stakeholders would want to know if higher risk for AD • All would want to know if they had memory problems, wanted annual memory screening, and agreed earlier diagnosis would facilitate advance care planning Barriers • Most stakeholders expressed concern that family would suffer financially if diagnosed, worried about losing health insurance • Most would not be motivated to have healthier lifestyle • Half thought doctor would not be able to provide adequate care
Aufill et al., 2019	To assess whether having a diagnosis, ratings of cognition by clinicians, or ratings of cognition by family were associated with discussion of memory during primary care visits.	Quantitative, cross-sectional design	Older adults, care partners and providers; Baltimore primary care clinics	*N* = 14 Providers *N* = 93 Dyads *Patients:*Ave. age 79.9 (7.6) 52% Female 42% Hispanic/non-White *Care partners:*Ave. age 62.3 (12.2) 75% Female	Facilitators • Each unit increase in provider-rated severity of patient cognitive impairment was associated with more memory-related discussion Barriers • Family ratings of patient cognitive impairment were not associated with memory-related discussions Rates • *N* = 43/93 (46%) were undiagnosed • *N* = 26/93 (28%) diagnosed with mild cognitive impairment • *N* = 24/93 (26%) diagnosed with dementia
Bernstein et al., 2019	To quantify perspectives and behaviors of primary care providers and neurologists with respect to evaluation and management of neurocognitive disorders	Quantitative, cross-sectional survey	Providers, U.S. database	*N* = 150 Providers 67% Primary care 33% Neurology	Facilitators • Primary care providers reported similar levels of confidence in managing care to neurologists (46–64%) • 55% of providers reported they (or staff) administer standardized cognitive screening to over half patients with cognitive concerns • Most providers ordered labs to assess for reversible causes of cognitive impairment (84%) Barriers • Few providers (21%) reported high confidence in ability to recognize when a patient has a neurocognitive disorder; fewer (13%) reported high confidence in providing a specific diagnosis • Providers reported lack of confidence and ability to implement and interpret cognitive testing and neuroimaging results; a third found cognitive tests highly useful

(*continued on next page*)

Table 1 (*continued*)

Author, Year	Primary Objective(s)	Method, Design	Population, Setting	Sample Characteristics	Key Findings: Facilitators, Barriers, or Rates of Detection
Arroyo-Miranda et al., 2023	To address primary care physicians' salient beliefs that affect their intention to diagnose ADRD early	Quantitative, cross-sectional survey	Providers, Puerto Rico College of Physicians database	*N* = 103 Providers Ave. age 50.2 (13.6) 50% Female 63% General medicine 14% Family medicine 23% Internal medicine	Facilitators • Providers' subjective norms and perceived behavioral control were positively associated with intention for early diagnosis • Number of years in practice and hours in dementia training positively associated with percentage of patients diagnosed Barriers • Few providers (14%) were comfortable making a diagnosis independently • Some providers (10%) believed referral to a specialist was a medical requirement • Most providers (85%) were unaware of support programs for patients with dementia
Perfect et al., 2023	To compare rates of newly documented mild cognitive impairment or dementia in GeriPACT and PACT settings	Quantitative, prospective matched cohort design	Older adults, U.S. Veterans Affairs Medical Centers	*N* = 470 Patients *N = 235 GeriPACT:* Ave. age 81 (6.7) *N = 235 PACT*: Ave. age 79.6 (6.9) 5% Female 85% White 12% Black 4% Other race 3% Hispanic	Facilitators • Patients with low cognitive assessment score and married/partnered were more likely to receive a diagnosis • New diagnosis rates were higher in patients who received GeriPACT compared with PACT care Barriers • Across both groups, a small percentage of patients with low cognitive scores received a diagnosis of mild cognitive impairment or dementia Rates • *N* = 26/138 (19%) of patients with low cognitive assessment score received a diagnosis during 24-month study period: 21% in GeriPACT; 17% in PACT • *N* = 18/332 (5%) of patients with higher cognitive assessment score received a diagnosis during 24-month study period: 7.4% in GeriPact; 3.6% in PACT
Liu et al., 2024	To estimate the contemporary detection rates of mild cognitive impairment in the full Medicare population for U.S. primary care clinicians/practices	Quantitative, observational study	Providers, U.S. primary care clinics	*N* = 226,756 Providers *N* = 54,597 Practices 25.5% Internal medicine 35.5% Family medicine 36% NP/PA 2.6% OBGYN 0.4% Geriatric medicine	Rates • Among Medicare beneficiaries ages 65 and older, 8% of expected cases of mild cognitive impairment were diagnosed, on average • Less than 1% of primary care clinicians and practices have diagnosis rates within the expected range for mild cognitive impairment

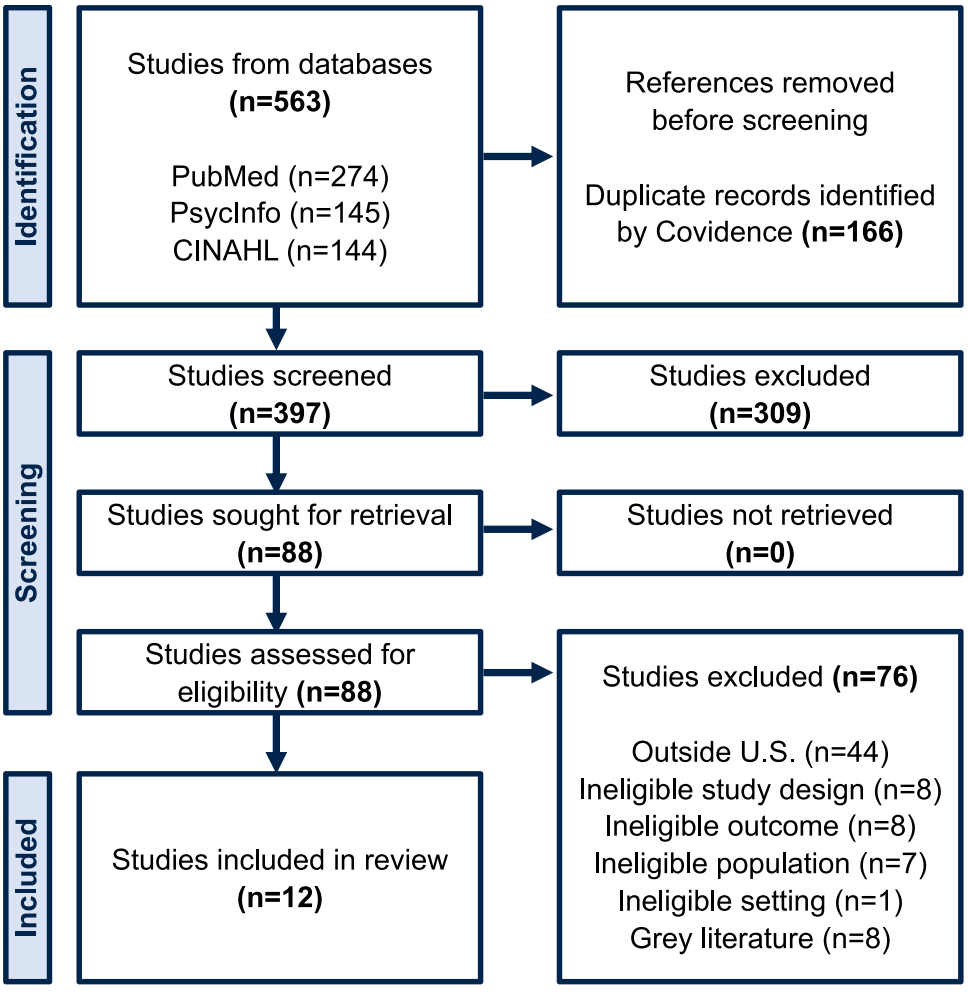

Fig. 1. PRISMA flow diagram, identification of studies via databases.

and three studies reported rates of diagnosis of mild cognitive impairment (MCI) or dementia in primary care settings [22–24]. One study used parallel mixed methods [25], six studies used qualitative methods, and five used quantitative methods. All qualitative studies used semi-structured interviews to examine perspectives of older adults with ADRD and their care partners [26,27] or primary care providers [28–31], and one study involved focus groups of older adults without ADRD and care partners of patients with ADRD [29]. Of the quantitative studies, two were cross-sectional surveys of primary care providers' perspectives [32,33], and three examined rates of diagnosis using cross-sectional analysis [22,23] or a prospective cohort design [24]. While not delineated in Table 1, four of the 12 studies applied theoretical frameworks to their analysis including the National Institute on Aging Health Disparities Framework [26], the Behavior Change Wheel [33], the Theory of Planned Behavior [32], and the Sociocultural Health Belief Model [25].

Most studies included primary care providers ($N = 8$); four recruited providers from regional clinics [23,28,31,32] and four involved national samples [22,29,30,33]. All studies of primary care providers included physicians, and four included nurse practitioners and/or physician assistants [22,29–31]. Five studies included older adults (average age range from 68 to 83 years) from regional primary care clinics [23,29], community settings [25,26], or U.S. VA Medical Centers [24]. Three of these studies included older adults living with ADRD [23,24,26], and three included older adults without cognitive impairment [24,25,29]. Five studies included care partners of people with ADRD [23,25–27,29], most of whom were female with average age ranging from 54 to 62 years.

3.3. Synthesis of study results

3.3.1. Rates of diagnosis in primary care

Three of the 12 studies reported diagnostic rates of MCI or dementia in primary care. Aufill and colleagues (2019) used a cross-sectional design to examine interactions between 93 patient/care partner dyads and their providers at Baltimore based primary care clinics. Nearly half of participants with probable cognitive impairment, identified using the Callahan six-item cognitive instrument [34], had no diagnosis in their electronic health record (46%), 28% had a diagnosis of MCI, and 26% had a diagnosis of dementia. Perfect and colleagues (2023) compared MCI and dementia diagnostic rates among 470 U.S. Veterans receiving care at geriatric-focused versus traditional primary care clinics across 57 VA medical centers. Among 138 patients with objective cognitive impairment, evaluated in two-parts using the Callahan six-item cognitive instrument and the modified Telephone Interview for Cognitive Status (mTICS) [35], 19% received a clinician diagnosis during the 24-month study period (21% in the geriatric-focused clinic; 17% in the traditional clinic). In an observational study of the full Medicare population for U.S. primary care providers ($N = 226{,}756$), Liu and colleagues (2024) estimated that, on average, 8% of expected cases of MCI were diagnosed, based on a predictive model using data from the Health and Retirement Study [36], and that fewer than 1% of providers and practices have diagnosis rates within the expected range. Taken together, the results of these studies indicate ADRD remains frequently underdiagnosed in primary care, particularly in the earliest stages (i.e., MCI) and even within clinics focused on geriatric care.

3.3.2. Facilitators of diagnosis in primary care

Individual Facilitators. Nine of the 12 studies reported factors that may facilitate diagnosis of ADRD in primary care settings. At the individual level, there is often a desire to know one's risk for ADRD among older adults and family members. Qualitative studies of older adults and care partners suggest an interest in routinely (e.g., annually) being asked about memory problems to learn if they are at increased risk for ADRD [25,26,29]. Similarly, older adults, care partners, and providers communicated the importance of early detection of cognitive decline in primary care to facilitate advance care planning and access to care and resources for patients and their family members [25,28,29]. A small qualitative study of primary care providers found they view themselves as uniquely positioned to diagnose and care for patients with ADRD as the first and consistent point of contact [31].

Studies also report individual characteristics of older adults and providers that may influence whether a diagnosis is made. Patient advanced age and cognitive severity, as perceived by the provider [28], are associated with more discussion about memory functioning in clinic [23] and higher likelihood of diagnosis [24]. One study examining primary care physician characteristics found that number of years in practice and hours of ADRD training were positively associated with percentage of patients diagnosed with ADRD [32]. Additionally, physicians' perceived ability to diagnose and their normative beliefs about early detection were positively associated with an intention to make an early diagnosis of ADRD [32].

Interpersonal Facilitators. At the interpersonal level, two studies emphasized the importance of the patient, family member, and provider relationship in the early detection of ADRD. A qualitative study that focused on the diagnostic experiences of minoritized older adults with ADRD and their care partners found most families sought medical input from a primary care provider, valued their longstanding relationship, and found the provider supportive in the diagnostic process [26]. Another qualitative study of primary care physicians indicated the importance of (a) an established relationship with patients to be able to recognize when cognitive changes occur, and (b) access to family members who can provide compelling and accurate patient history [28].

Institutional Facilitators. Three studies reported on institutional level, or healthcare system, factors that may support ADRD diagnosis. In one qualitative study, primary care physicians reported that the cognitive screening requirement in Medicare AWV prompted them to look out for early signs of cognitive decline [28], and a larger survey of U.S. providers found about half (55%) administer standardized cognitive screening assessments to most patients with cognitive concerns [33]. Additionally, most primary care providers (84%) report ordering lab panels (e.g., B12, thyroid stimulating hormone) to assess for reversible causes of cognitive impairment, an important step in the diagnostic process [33]. Lastly, while Perfect and colleagues found only moderately higher diagnostic rates in geriatric-focused compared to traditional primary care clinics (Section 3.3.1), clinics specializing in collaborative care for older adults merit further exploration [37].

3.3.3. Barriers to diagnosis in primary care

Individual Barriers. All but one study (Liu et al., 2024, which focused on rates) reported barriers to ADRD diagnosis in primary care. At the individual level, most studies focused on provider barriers, but one indicated that older adults had financial concerns for themselves and their families were they to be diagnosed with ADRD [25]. Two studies reported care partners' misconceptions about memory loss, including attributing early symptoms to normal aging due to lack of knowledge of ADRD [26,27]. Similarly, providers reported older adults who are in the earliest stages of cognitive decline, younger patients, and those who live alone can be the most challenging to detect ADRD [28].

Four studies reported factors at the provider level that may inhibit ADRD diagnosis, including lack of confidence in the diagnostic process, reliance on specialists, and uncertainty of how to support patients and families post-diagnosis. In a cross-sectional survey of U.S. primary care providers, Bernstein and colleagues found few providers (20%) felt highly confident in their ability to implement and interpret cognitive testing, and less were confident in providing a specific diagnosis [33]. Similarly, qualitative studies reported that providers saw limited value in specifying the cause of dementia [28] and felt they needed confirmation from a specialist [31,32]. Additionally, providers reported no clear benefit of ADRD medications [28], and few were aware of support programs for patients and families after diagnosis [30,32].

Interpersonal Barriers. Four studies reported interpersonal barriers to ADRD diagnosis among patients, care partners, and providers. Qualitative interviews with adult child care partners found challenges with inter-family dynamics, such as patients' partners hiding symptoms from other family members for several years [27]. Other studies reported providers' reliance on family members to initiate discussions about patients' cognitive changes, including lack of access to family members as a barrier to diagnosis for providers [26,28]. On the other hand, two studies indicated that when family members reported concerns about a patient's memory, providers did not always follow up with memory-related discussions [23] or evaluations [27]. In some cases, adult children said they were told by providers that their parent's memory changes were a normal part of aging and nothing to worry about [27].

Institutional Barriers. Multiple barriers within the healthcare system were identified across five studies, including lack of time and resources, lack of standardization for ADRD diagnosis, and insufficient ADRD training for providers. Providers reported that short appointment times and higher work burden inhibit detection and diagnosis [28,30,31], including administration of cognitive screening [29]. Another concern reported was financial expense of the diagnostic workup and lack of reimbursement and funding [28,31]. Four studies cited resource constraints including lack of adequate staff [31], absence of care plans and treatments to serve patients [29,30], and limited access to specialists and diagnostic tools (e.g., neuroimaging, neuropsychological testing) [28].

One qualitative study involving interviews and focus groups with older adults ($N = 18$), care partners ($N = 5$), and providers ($N = 11$) reported challenges in standardization of cognitive assessment [29]. In alignment, most providers reported not routinely screening for cognitive decline outside of Medicare AWV, and most older adults reported never being formally screened by a provider. Additionally, patients reported variability in how they had been asked about their memory, and providers noted absence of standardized screening methods, including what tools to use, who should administer, and what types of patients to screen. For example, a survey of U.S. primary care physicians found that, among the half of physicians who routinely use standardized cognitive screening tests in their practices, 53% administered testing themselves, while 15% had a nurse and 17% had a physician assistant or other medical staff administer screening [33].

Consistent with providers' reported lack of confidence in ADRD diagnosis, providers report minimal ADRD training [31] and a need for more training and materials on topics related to early detection [30]. Qualitative interviews with providers on their training preferences also indicated a need for education on culturally competent tools to improve early detection and diagnosis [30]. This is aligned with patient and care partner reports that cognitive testing is not culturally sensitive [26] and provider reports of challenges in screening patients with limited English proficiency or low educational attainment [29].

Community Barriers. Community level barriers, including social and environmental factors, may contribute to underdiagnosis of ADRD, particularly among racial and ethnic minority groups in the U.S. While few studies focused on community level factors, Perales-Puchalt and colleagues (2023) reported that providers felt social determinants such as healthcare coverage, language, and culture were barriers to ADRD diagnosis and care. Providers and care partners reported that concerns about social stigma and respect for elders inhibited labeling of older adults with ADRD [26,28], which may differ across cultures [38]. One study reported rural area primary care clinics experience long distances and waiting times for appointments with specialists, which may also

be a barrier to early diagnosis of ADRD for patients who live in these communities [28].

4. Discussion

This scoping review examined the state of research on the determinants of ADRD diagnosis in U.S. primary care settings since implementation of national policy efforts to improve timely diagnosis. Recent advances in early detection and treatment of ADRD, including blood-based biomarker testing [39] and FDA-approval of the first disease-modifying drugs [40,41], necessitate understanding of current challenges faced by older adults, family members, and providers navigating ADRD diagnosis and care. The search strategy and eligibility criteria for this review aimed to capture the experiences of older adults, their family members, and primary care providers in the U.S. in the past decade, which resulted in 12 studies that used qualitative and quantitative approaches across diverse settings and geographic regions.

Consistent with previous research on diagnostic rates of ADRD [9], this review found that ADRD remains frequently underdiagnosed in U.S. primary care, including geriatric-focused clinics [23,24]. Importantly, the Medicare claims analysis by Liu and colleagues highlights the high prevalence of missed diagnoses in the earliest symptomatic stage of ADRD (i.e., MCI), a critical period for therapeutic intervention and advance care planning [22]. In October 2024, the NAPA Reauthorization Act (P.L. 118–92) was signed into law with the aim to build on the advances made since NAPA's establishment over a decade ago. In this new era of ADRD research and care, prioritization of early diagnosis in primary care will be essential to address chronic challenges of underdiagnosis. In a 2020 review, the U.S. Preventative Services Task Force (USPSTF) concluded there is insufficient evidence to recommend for or against routine cognitive screening in older adults [15]. Other experts argue routine assessment for cognitive impairment is an essential element of good clinical practice [42]. Inconsistent guidelines necessitate new screening policies to ensure all older adults and their families have access to timely diagnosis, treatment, and support for ADRD.

While underdiagnosis is prevalent across racial and ethnic groups in the U.S., numerous studies report disparities in ADRD diagnosis, including higher rates of missed and delayed diagnosis among Black, Hispanic, and Asian patients compared to non-Hispanic White patients [4,6,7]. Most studies in this review involved primarily non-Hispanic White samples or did not report race and ethnicity, and no studies examined factors contributing to ADRD diagnostic disparities in primary care settings. A recent scoping review mapping racial and ethnic disparities in ADRD healthcare similarly found very few studies examining underlying processes that may account for inequitable ADRD healthcare [43]. Given substantial evidence of disparities in ADRD diagnosis [43], future research should focus on multi-level barriers (e.g., cultural beliefs, family dynamics, healthcare access) to timely diagnosis among racial and ethnic minority groups in the U.S.

This review found factors at multiple levels of the social ecological framework that may facilitate or inhibit timely diagnosis of ADRD in primary care. At the individual level, although there seems to be a consensus among older adults, care partners, and providers that early diagnosis is valuable and cognitive screening is desirable, misconceptions of ADRD and concerns about limited resources for patients persist. In particular, evidence supports that primary care providers are operating within a system that does not align with the diagnosis and care they hope to provide their older patients with ADRD [31]. A recurring theme over the past several decades of research is insufficient resources and training for primary care providers, contributing to a lack of confidence in their ability to implement and interpret timely and accurate assessment of cognitive decline [10,12].

Practical recommendations for timely diagnosis of ADRD in primary care have been previously published [42], including a standard workflow to evaluate cognitive impairment grouped with specific assessments for differential diagnosis. Promising educational interventions aimed to address provider training deficits have been developed, such as Project ECHO (Extension for Community Healthcare Outcomes) currently implemented by the Alzheimer's Association [44,45]. The ECHO program is a tele-mentoring model that connects ADRD specialists with providers who want to improve their capacity to diagnose and care for patients with ADRD. Additionally, in an effort to address resource constraints on providers, Medicare Part B now covers Cognitive Assessment & Care Plan Services (CPT code 99483) to facilitate more detailed assessment of cognitive decline in patients who show initial signs of impairment. Research and outreach efforts are needed to increase provider awareness of these resources and to examine their utility in improving timely ADRD diagnosis in primary care.

The qualitative studies included in this review also revealed important themes at the interpersonal and community levels. Older adults, care partners, and primary care providers valued established clinical relationships to be able to discuss and recognize when cognitive changes occur. At the same time, studies found diagnoses were often initiated by family members, rather than providers, and concerns about a patient's cognitive decline were sometimes disregarded or minimized by providers. Social stigma related to memory loss and diagnostic labeling was a concern cited among older adults, family members, and providers and is consistent with previous literature reviews of the challenges of timely diagnosis of ADRD [3,46,47]. Moreover, previous studies suggest these barriers vary cross-culturally [38,48], potentially contributing to racial and ethnic disparities in ADRD diagnosis. From the studies included in this review, the extent to which underlying social and community factors (e.g., healthcare access, language barriers, discrimination, cultural stigma) contribute to underdiagnosis of ADRD in primary care is less understood and an important area for future research, particularly across different racial and ethnic groups.

4.1. Limitations

While this scoping review provides important insight into the current state of determinants of ADRD underdiagnosis in U.S. primary care, there are limitations. First, the single-reviewer approach to screening and data extraction may introduce bias, though a systematic review methodology was employed throughout the study. Many publications that focus on diagnostic challenges were likely excluded from the analysis due to this review's specific focus on studies published since 2010, primary care settings, and the U.S. Of the 12 studies that met eligibility criteria, most were qualitative with small sample sizes. Though these studies provide valuable perspectives of the older adults, care partners, and providers who were interviewed, the findings cannot be extrapolated to the general U.S. population. Most studies included in the analysis focused on primary care providers; thus, the perspectives of older adults and family members are underrepresented in this analysis. Lastly, few studies explicitly applied theoretical frameworks, limiting interpretation of how and why various factors may contribute to underdiagnosis of ADRD.

5. Conclusions

Despite national policy efforts to improve timely diagnosis of ADRD, underdiagnosis in primary care remains a significant clinical and public health challenge. Lacking a timely and accurate diagnosis limits access to treatments, clinical trials of new therapies, social support services, and advance planning for patients and families. This scoping review identified barriers to diagnosis across individual, interpersonal, institutional, and community levels, particularly from the perspective of primary care providers. More research, grounded in theory, is needed to take insight from qualitative findings and apply it to larger-scale studies of barriers to diagnosis in diverse U.S. patient and provider populations. Increased attention to social and community contexts will be important to identify needs for future public health interventions.

Funding

This project is supported by a National Institute on Aging / National Institutes of Health training award (T32AG027708) with supplemental funding from the Department of Health Behavior and Health Equity, University of Michigan School of Public Health. The sponsors had no role in the design or conduct of the study; in the collection, analysis, and interpretation of data; in the preparation of the manuscript; or in the review or approval of the manuscript. The authors declare no conflicts of interest.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

CRediT authorship contribution statement

Chelsea G. Cox: Writing – review & editing, Writing – original draft, Formal analysis, Data curation, Conceptualization. **Barbara L. Brush:** Writing – review & editing, Methodology, Conceptualization. **Lindsay C. Kobayashi:** Writing – review & editing, Resources, Methodology, Funding acquisition. **J. Scott Roberts:** Writing – review & editing, Supervision, Resources, Funding acquisition, Conceptualization.

Acknowledgments

Informationists at the University of Michigan Taubman Health Sciences Library, Kate Saylor and Kathryn Vanderboll, provided instruction on systematic review methodology as part of University of Michigan School of Nursing Course 804.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.tjpad.2024.100035.

References

[1] Ahmad FB, Cisewski JA, Anderson RN. Leading causes of death in the US, 2019-2023. JAMA 2024;332:957–8. doi:10.1001/jama.2024.15563.
[2] Alzheimer's Association2023 Alzheimer's disease facts and figures. Alzheimer's Dement 2023. doi:10.1002/alz.13016.
[3] Dubois B, Padovani A, Scheltens P, Rossi A, Dell'Agnello G. Timely diagnosis for alzheimer's disease: a literature review on benefits and challenges. J Alzheimer's Dis 2016;49:617–31. doi:10.3233/JAD-150692.
[4] Tsoy E, Kiekhofer RE, Guterman EL, Tee BL, Windon CC, Dorsman KA, et al. Assessment of racial/ethnic disparities in timeliness and comprehensiveness of dementia diagnosis in California. JAMA Neurol 2021;78:657–65. doi:10.1001/jamaneurol.2021.0399.
[5] U.S. Department of Health and Human Services. National plan to address Alzheimer's disease: 2023 update. 2024. Accessed March 18, 2024. https://aspe.hhs.gov/reports/national-plan-2023-update
[6] Davis MA, Lee KA, Harris M, Ha J, Langa KM, Bynum JPW, et al. Time to dementia diagnosis by race: a retrospective cohort study. J Am Geriatr Soc 2022;70:3250–9. doi:10.1111/jgs.18078.
[7] Lin PJ, Daly AT, Olchanski N, Cohen JT, Neumann PJ, Faul JD, et al. Dementia diagnosis disparities by race and ethnicity. Med Care 2021;59:679–86. doi:10.1097/MLR.0000000000001577.
[8] Aminzadeh F, Molnar FJ, Dalziel WB, Ayotte DA. Review of barriers and enablers to diagnosis and management of persons with dementia in primary care. Can Geriatr J 2012;15:85–94. doi:10.5770/cgj.15.42.
[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. doi:10.1097/WAD.0b013e3181a6bebc.
[10] de Levante Raphael D. The knowledge and attitudes of primary care and the barriers to early detection and diagnosis of Alzheimer's disease. Medicina 2022;58:906 (Kaunas). doi:10.3390/medicina58070906.
[11] Lang L, Clifford A, Wei L, Zhang D, Leung D, Augustine G, et al. Prevalence and determinants of undetected dementia in the community: a systematic literature review and a meta-analysis. BMJ Open 2017;7:e011146. doi:10.1136/bmjopen-2016-011146.
[12] Mansfield E, Noble N, Sanson-Fisher R, Mazza D, Bryant J. Primary care physicians' perceived barriers to optimal dementia care: a systematic review. Gerontologist 2019;59:e697–708. doi:10.1093/geront/gny067.
[13] Romano RR, Carter MA, Anderson AR, Monroe TB. An integrative review of system-level factors influencing dementia detection in primary care. J Am Assoc Nurse Pract 2020;32:299–305. doi:10.1097/JXX.0000000000000230.
[14] Rao A, Manteau-Rao M, Aggarwal NT. Dementia neurology deserts: what are they and where are they located in the U.S.? Alzheimer's Dement 2017;13:P509 –P509. doi:10.1016/j.jalz.2017.06.577.
[15] Owens DK, Davidson KW, Krist AH, Barry MJ, Cabana M, et al., US Preventive Services Task Force Screening for cognitive impairment in older adults: U.S. preventive services task force recommendation statement. JAMA 2020;323:757. doi:10.1001/jama.2020.0435.
[16] Cordell CB, Borson S, Boustani M, Chodosh J, Reuben D, Verghese J, et al. Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. Alzheimers Dement 2013;9:141–50. doi:10.1016/j.jalz.2012.09.011.
[17] Alzheimer's Association2019 alzheimer's disease facts and figures. Alzheimer's Dement 2019;15:321–87. doi:10.1016/j.jalz.2019.01.010.
[18] Jacobson M, Thunell J, Zissimopoulos J. Cognitive assessment at medicare's annual wellness visit in fee-for-service and medicare advantage plans. Health Aff 2020;39:1935–42. doi:10.1377/hlthaff.2019.01795.
[19] Sallis JF, Owen N, Fisher EB. Ecological models of health behavior. health behavior and health education: theory, research, and practice. San Francisco, CA: Jossey-Bass; 2008. p. 465–86.
[20] Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med 2018;169:467–73. doi:10.7326/M18-0850.
[21] Peters MDJ, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, et al. Updated methodological guidance for the conduct of scoping reviews. JBI Evid Synth 2020;18:2119. doi:10.11124/JBIES-20-00167.
[22] Liu Y, Jun H, Becker A, Wallick C, Mattke S. Detection rates of mild cognitive impairment in primary care for the united states medicare population. J Prev Alzheimers Dis 2024;11:7–12. doi:10.14283/jpad.2023.131.
[23] Aufill J, Amjad H, Roter DL, Wolff JL. Discussion of memory during primary care visits of older adults with cognitive impairment and accompanying family. Int J Geriatr Psychiatry 2019;34:1605–12. doi:10.1002/gps.5172.
[24] Perfect CR, Lindquist J, Smith VA, Stanwyck C, Seidenfeld J, Van Houtven CH, et al. Are geriatrics-focused primary care clinics better at diagnosing dementia than traditional clinics? A matched cohort study. J Gen Intern Med 2023;38:2710–17. doi:10.1007/s11606-023-08136-0.
[25] Wiese LK, Williams I, Williams CL, Galvin JE. Discerning rural Appalachian stakeholder attitudes toward memory screening. Aging Ment Health 2021;25:797–806. doi:10.1080/13607863.2020.1725739.
[26] Blinka MD, Gundavarpu S, Baker D, Thorpe RJ Jr, Gallo JJ, Samus QM, et al. At least we finally found out what it was": dementia diagnosis in minoritized populations. J Am Geriatr Soc 2023;71:1952–62. doi:10.1111/jgs.18329.
[27] Nogueras DJ, Postma J, Son C. Why didn't I know? Perspectives from adult children of elderly parents with dementia. J Am Assoc Nurse Pract 2016;28:668–74. doi:10.1002/2327-6924.12382.
[28] Abe M, Tsunawaki S, Dejonckheere M, Cigolle CT, Phillips K, Rubinstein EB, et al. Practices and perspectives of primary care physicians in Japan and the United States about diagnosing dementia: a qualitative study. BMC Geriatr 2021;21:540. doi:10.1186/s12877-021-02457-7.
[29] Bandini JI, Schulson LB, Ahluwalia SC, Harrison J, Chen EK, Lai JS, et al. Patient, family caregiver, and provider perceptions on self-assessment screening for cognitive impairment in primary care: findings from a qualitative study. Gerontol Geriatr Med 2022;8:23337214221131403. doi:10.1177/23337214221131403.
[30] Perales-Puchalt J, Strube K, Townley R, Niedens M, Arreaza H, Zaudke J, et al. Primary care provider preferences on dementia training: a qualitative study. J Alzheimers Dis 2023;92:1067–75. doi:10.3233/JAD-221014.
[31] Sideman AB, Ma M, Hernandez de Jesus A, Alagappan C, Razon N, Dohan D, et al. Primary care pracitioner perspectives on the role of primary care in dementia diagnosis and care. JAMA Netw Open 2023;6:e2336030. doi:10.1001/jamanetworkopen.2023.36030.
[32] Arroyo-Miranda ML, Rosario-Hernández E, Valcárcel L, Soto-Torres B, Irizarry-Ramos J. Diagnostic hesitancy of primary care physicians in Puerto Rico toward alzheimer's disease and related dementias: opportunities for transformation. P R Health Sci J 2023;42:212–18.
[33] Bernstein A, Rogers KM, Possin KL, Steele NZR, Ritchie CS, Kramer JH, et al. Dementia assessment and management in primary care settings: a survey of current provider practices in the United States. BMC Health Serv Res 2019;19:919. doi:10.1186/s12913-019-4603-2.
[34] Callahan CM, Unverzagt FW, Hui SL, Perkins AJ, Hendrie HC. Six-item screener to identify cognitive impairment among potential subjects for clinical research. Med Care 2002;40:771–81. doi:10.1097/00005650-200209000-00007.
[35] Salazar R, Velez CE, Royall DR. Telephone screening for mild cognitive impairment in hispanics using the Alzheimer's questionnaire. Exp Aging Res 2014;40:129–39. doi:10.1080/0361073X.2014.882189.
[36] Langa KM, Larson EB, Crimmins EM, Faul JD, Levine DA, Kabeto MU, et al. A comparison of the prevalence of dementia in the United States in 2000 and 2012. JAMA Intern Med 2017;177:51–8. doi:10.1001/jamainternmed.2016.6807.
[37] Heintz H, Monette P, Epstein-Lubow G, Smith L, Rowlett S, Forester BP. Emerging collaborative care models for dementia care in the primary care setting: a narrative review. Am J Geriatr Psychiatry 2020;28:320–30. doi:10.1016/j.jagp.2019.07.015.

[38] Sayegh P, Knight BG. Cross-cultural differences in dementia: the Sociocultural Health Belief Model. Int Psychogeriatr 2013;25:517–30. doi:10.1017/S104161021200213X.
[39] Hansson O, Edelmayer RM, Boxer AL, Carrillo MC, Mielke MM, Rabinovici GD, et al. The Alzheimer's Association appropriate use recommendations for blood biomarkers in Alzheimer's disease. Alzheimer's Dement 2022;18:2669–86. doi:10.1002/alz.12756.
[40] Cummings J, Apostolova L, Rabinovici GD, Atri A, Aisen P, Greenberg S, et al. Lecanemab: appropriate use recommendations. J Prev Alzheimers Dis 2023. doi:10.14283/jpad.2023.30.
[41] Sims JR, Zimmer JA, Evans CD, Lu M, Ardayfio P, Sparks J, et al. Donanemab in early symptomatic alzheimer disease: the TRAILBLAZER-ALZ 2 randomized clinical trial. JAMA 2023;330:512–27. doi:10.1001/jama.2023.13239.
[42] Liss JL, Seleri Assunção S, Cummings J, Atri A, Geldmacher DS, Candela SF, et al. Practical recommendations for timely, accurate diagnosis of symptomatic Alzheimer's disease (MCI and dementia) in primary care: a review and synthesis. J Intern Med 2021;290:310–34. doi:10.1111/joim.13244.
[43] Hinton L, Tran D, Peak K, Meyer OL, Quiñones AR. Mapping racial and ethnic healthcare disparities for persons living with dementia: a scoping review. Alzheimer's Dement 2023 n/a. doi:10.1002/alz.13612.
[44] Lindauer A, Wild K, Natonson A, Mattek N, Wolf M, Steeves-Reece A, et al. Dementia 360 ECHO: using technology to facilitate diagnosis and treatment. Gerontol Geriatr Educ 2022;43:202–8. doi:10.1080/02701960.2020.1835658.
[45] Rhoads K, Isenberg N, Schrier A. UW Project ECHO-Dementia: implementation of a virtual clinic and telementoring program to improve dementia diagnosis and treatment in rural and under-resourced primary care settings. Alzheimers Dement 2021(17):e051217 Suppl 8. doi:10.1002/alz.051217.
[46] Lee S, Kim D, Lee H. Examine race/ethnicity disparities in perception, intention, and screening of dementia in a community setting: scoping review. Int J Environ Res Public Health 2022;19:8865. doi:10.3390/ijerph19148865.
[47] Bunn F, Goodman C, Sworn K, Rait G, Brayne C, Robinson L, et al. Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. PLoS Med 2012;9:e1001331. doi:10.1371/journal.pmed.1001331.
[48] Alzheimer's Association2021 Alzheimer's disease facts and figures. Alzheimer's Dement 2021;17:327–406. doi:10.1002/alz.12328.