

WHITE PAPER

Diagnostic Excellence in Dementia Care

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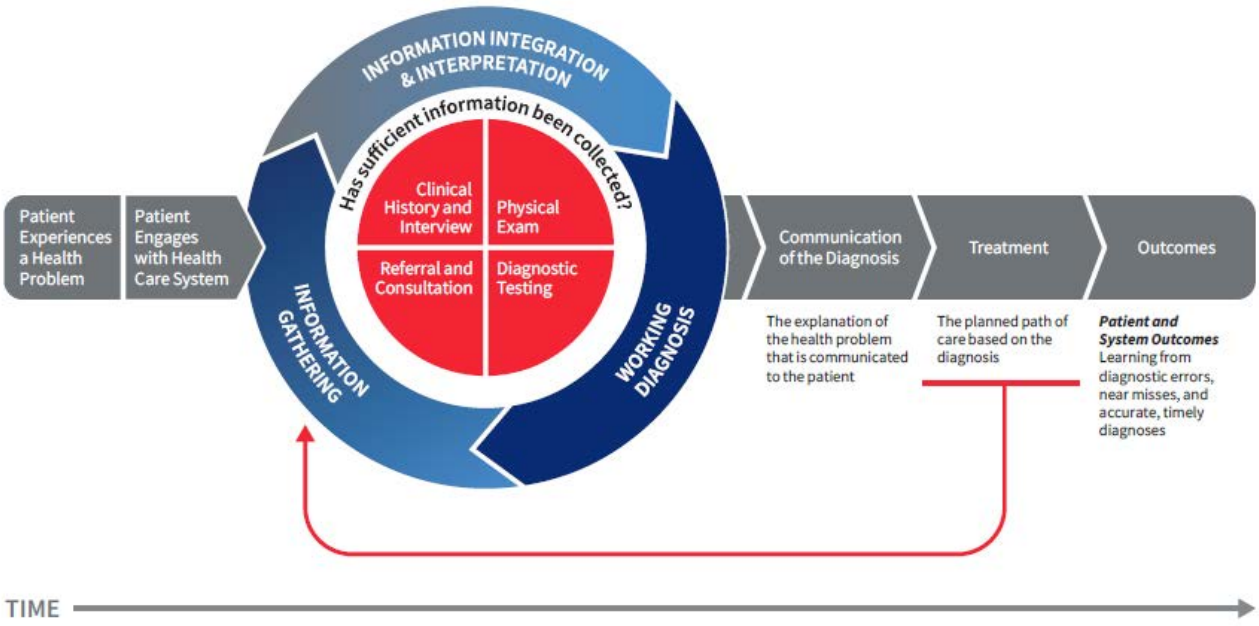
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Diagnostic Excellence in Dementia Care

Diagnostic Errors among Older Adults

Many hold the misconception that diagnosis is a single event that happens at a single point of time by a single healthcare provider. However, diagnosis is a multifaceted process that occurs within a complex system and that involves many people, meaning diagnosis may happen over multiple periods, in multiple settings, and with multiple providers. Equally important, diagnostic excellence relies on patient, family, and caregiver participation. When a patient seeks medical care, an iterative process begins during which the patient's medical care team (e.g., primary care provider, specialists) collaborate to guide patients through the diagnostic process, as illustrated in Figure 1. The Diagnostic Process.

Figure 1. The Diagnostic Process



Reprinted with permission. Balogh EP, Miller BT, Ball JR, Committee on Diagnostic Error in Health Care; Board on Health Care Services; Institute of Medicine; Improving Diagnosis in Health Care. Washington (DC): National Academies Press (US); December 29, 2015.

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Both system and human error may occur at each step of this process, and the risk of error increases with the complexity of a patient's medical profile, regardless of the patient's age. However, diagnostic errors often occur more frequently among older adults—those aged 65 and older—than younger age groups in part due to the increased likelihood of multiple comorbidities that occurs as a natural part of the aging process.(1) Because of this increased vulnerability, diagnostic errors among older adults may also result in more patient harm than those of younger age groups.

An estimated 2.59 million diagnostic errors occur annually in the United States among patients with dangerous diseases, with nearly 800,000 resulting in serious harm or death.(2) Among older adults, prevalent conditions that may be misdiagnosed include(1):

- Chronic obstructive pulmonary disease
- **Dementia and related disorders**
- Parkinson's disease
- Heart failure
- Stroke/transient ischemic attack
- Acute myocardial infarction
- Diabetes

Barriers to Timely, Accurate Dementia Diagnosis

Despite the consensus on clinical and neuropathological diagnostic criteria for dementia disorders—such as those from the American Academy of Neurology, the National Institute on Aging and Alzheimer Association, and the American College of Surgeons—there are no methods with 100% accuracy. Therefore, diagnostic errors and delays may occur, potentially culminating in over- or under-diagnosis of dementia, misdiagnosis of the wrong dementia, or misdiagnosis of a nondementia-related illness or condition. One study of nearly 1,000 patients diagnosed with Alzheimer's disease via autopsy and neuropathology confirmation found that approximately 12% of cases received a false-negative diagnosis.(3) Such misdiagnoses risk the potential benefits of early intervention and support for both patients and their families/caregivers and thus may increase the possibility of other adverse event types associated with dementia (e.g., wandering, elopement, falls), which may lead to preventable harm, including death.

Patient Aging, Comorbidities, and Surrogacy

Symptoms of dementia are wide-ranging and often present or overlap with the symptoms of several other conditions that can mimic, exacerbate, or directly contribute to dementia onset. Common misdiagnoses and missed diagnoses include:

- Another type of dementia or neurodegenerative disease (e.g., Alzheimer's, Parkinson's, Huntington's, Lewy bodies, vascular, frontotemporal, HIV)(4)
- Mild cognitive impairment(5)
- Delirium(6)
- Normal-pressure hydrocephalus(7)
- Medication side effect or polypharmacy(8)
- Depression or other psychiatric/mood disorders(9)
- Urinary tract infection and other common infections(10)
- Brain tumor(11)
- Subdural hematoma/head injury(12)
- Vitamin B12 deficiency(13)

Although many of these conditions can affect people of any age, they often complicate the diagnostic process when combined with the natural physical and cognitive decline associated with aging. Their impact on a patient's essential functions—such as communication, memory, and hearing—can affect clinicians' ability to determine the patient's medical history, symptom progression, self-management strategies, and comprehension of diagnostic steps or treatment options.

Generational or cultural barriers may also impact the diagnostic process depending on the clinician's and organization's cultural competency and accommodations and the patient's ability to effectively advocate for themselves. For this reason, many older adults are accompanied by a trusted individual—who may also serve as their healthcare surrogate—to assist in medical decision-making and general healthcare management. However, family or surrogacy involvement brings its own benefits and potential complications. Clinicians must navigate the delicate balance of honoring patient autonomy and self-determination within the boundaries of the patient's decisional capacity and legal competence, while avoiding "talking around" the older adult if their surrogate is indeed the decision-maker. Both instances risk the patient's preferences not being heard, especially if dementia is suspected.

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Clinician Training and Bias

Many barriers—though certainly not all—can be alleviated with targeted training in geriatric medicine. Unfortunately, the industry has known about current and looming staffing shortages in geriatrics despite the well-documented expectation of increased demand.(14) Experts project a 42.4% increase in the number of people over the age of 65 in the United States by 2034,(14) and a national shortage of nearly 27,000 geriatricians by 2025, creating a substantial gap in access to quality care.(15) This gap will be more pronounced among patient populations that already experience significant healthcare disparities (including increased rates of misdiagnoses), such as minority and socioeconomically disadvantaged groups.(16) Contributing factors to geriatrician shortages include(17,18):

- Extra year of required targeted training
- Lower average salary—about $20,000 less per year than internists
- Medicare fee-for-service payment models that value patient volume and curative treatments over palliative or holistic care
- Lack of student exposure to geriatrics, fewer geriatric fellowship positions due to vacancies, or reduced recruitment of academic geriatricians

Ageism and other cognitive biases also play a significant role in the shortage of geriatricians, the treatment of older adult patients across the care continuum, and the diagnostic process. Due to agist stereotypes and attitudes, clinicians may dismiss or downplay patient concerns as "normal aging," focus on age-related conditions versus universal conditions, or give unequal importance to medical concerns and functional or lifestyle issues.(19) Such biases can contribute to missed or delayed diagnoses by skewing how clinicians gather and interpret evidence, act, and make decisions.(20)

Challenges with Medical Technology

Medical technology continues to evolve in pursuit of increased access to health information, speed of communication, care coordination, direct patient care support, clinical decision-making support, and general recordkeeping—which can help improve efficiency and quality of care. However, issues such as software malfunctions, interoperability challenges, and usability issues may be associated with patient harm, including diagnostic errors.(21) For example:

- Electronic health record systems were considered a potential contributing factor in approximately 61% of nearly 200 diagnosis-related ambulatory care malpractice claims, with errors in execution, ordering, data interpretation, documentation, and communication.(21)
- While telediagnosis may enhance diagnostic safety by improving access, providing more information about the patient's home environment, and increasing the likelihood of family member participation, these factors cannot replace the benefits of physical examinations and on-site care teams.(22)
- Artificial intelligence (AI) functionality is being rapidly incorporated into a wide range of devices and systems in healthcare, including AI-based diagnostic support systems. However, AI systems are only as good as the algorithms they use and the data on which they are trained. Shortcomings in either area can lead to diagnostic errors.(23)

Telehealth in particular shows general success in increasing access to healthcare services, including among older adults. One study found that 53% of older adults who were surveyed indicated interest in telemedicine; however, top barriers to actual usage included difficulty with technology (especially video platforms), hearing difficulty, language barriers, and lack of desire to see providers outside of the clinic setting.(24) This is another area in which bias may be influencing perceptions of telehealth among both providers and older adult patients. Joint Commission's Video Visits for Elders Project, for example, aimed to promote access to telehealth services and found that about 30% of older adults were already video-enabled and almost 33% declined technological assistance; however, 18% of project participants did not have access to an electronic device, and over 30% either canceled or were no-shows to their telehealth appointment.(25)

While medical technology can be extremely beneficial for both providers and patients, it can also present a barrier to medical processes and decision-making, including diagnosis. Dementia-related diagnostic challenges include cognitive assessments via teleneurological examination and the need to adapt traditionally paper-based tests for virtual administration, in addition to general technological access, literacy, and interference concerns. Telephone-based instruments for cognitive screening—such as the Telephone Interview for Cognitive Status (which is modeled after the Mini-Mental State Exam)—have proved useful, but challenges in evaluating

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visuospatial impairment and naming were identified. Video teleconferencing shows more promise, but challenges remain for those with slower internet connections and those with severe hearing, visual, or cognitive impairment, which may result in overestimated deficits. Notably, physicians in studies evaluating the use of telemedicine for dementia diagnosis often had access to supplementary diagnostic information gained through prior in-person visits.(26)

This is not to say that medical technologies should be avoided—quite the contrary—but it is critical to ensure that technologies clearly align with patient needs and match providers' scope of practice to reduce or eliminate sources of preventable harm. To avoid technological missteps, inherent risks should be considered and addressed during all phases of technology adoption and use as a proactive measure to reduce diagnostic error and associated patient harm.

Systems-Safety Strategies for Improvement

Ideally, geriatric medicine would undergo an infrastructure overhaul including legislative efforts to support innovation in geriatric care models, research, and education programs for all staff levels that would together inherently improve diagnostic excellence. Although efforts have been made in this direction—such as those by the Eldercare Workforce Alliance, the Geriatrics Workforce Enhancement Program, and the Nurses Improving Care for Healthsystem Elders—individual health systems and provider organizations can lend additional support with an all-stakeholder approach to systems-based problem-solving that better supports early detection and diagnosis of dementia.

Work to be recognized as an age-friendly health system. Beginning as a national improvement initiative, the "Age-Friendly Health System" designation is part of a movement to hold all healthcare facilities accountable for advancing quality care of older adults by following evidence-based practices, causing no harm, and aligning care with what matters to older adults and their family/caregivers.(27) Known as the 4Ms framework, essential elements of age-friendly care include(27):

- What Matters – Know and align care with patient-specific health outcome goals and care preferences as they evolve over time.
- Medication – Use age-friendly medication that does not interfere with patient preferences, mobility, or cognitive ability.
- Mentation – Prevent, identify, treat, and manage patient cognitive and mental decline, including dementia, depression, and delirium.
- Mobility – Ensure older adults can safely ambulate and move to maintain function and participate in necessary or wanted activities.

As of January 2024, the Institute for Healthcare Improvement, which manages recruitment and designation, has recognized 3,546 hospitals, ambulatory care practices, and long-term care organizations as age-friendly.(27)

Prioritize patient, family, and caregiver engagement throughout the diagnostic process. Efficacy in the diagnostic reasoning process depends on the quality of the provider-patient relationship and communication. From a systems perspective, problems that exist at the start of the diagnostic process can impact many other areas of an individual's healthcare, thus creating the potential for preventable harm. In order to support patients' values and preferences, proactive engagement strategies such as shared decision-making, teach-back communication, and advance care planning should be implemented. These strategies allow patients and their families or caregivers to be active participants in their own healthcare, which has been shown to improve general health outcomes and satisfaction.(28) Providers should effectively incorporate the following steps into the diagnostic process:

- Elicit accurate information regarding medical status
- Solicit care goals and preferences
- Ensure patients and caregivers have on-demand access to their medical records and related educational materials
- Assess social determinants of health and health literacy concerns
- Provide culturally and linguistically competent care and communication accommodations
- Encourage the completion of advance directives
- Learn how to conduct conversations about serious illnesses (i.e., disclosure)
- Collaborate with other members of the patient's care team to support care coordination
- Provide psychosocial support after diagnosis for both patients and their families/caregivers

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Recognize cognitive biases and their effects on diagnosis; support analytical thinking through system-wide cultural and environmental enhancements. Some studies have shown that certain debiasing strategies, such as guided reflection and cognitive forcing strategies, improved diagnostic reasoning.(20) However, such methods have not been proven to reduce bias-related diagnostic errors.(29) Therefore, experts have recently called for a merging of diagnostic error and clinical reasoning perspectives, frameworks, and methodologies as a more aligned approach to understanding and mitigating diagnostic error.(30) Health systems can also assess environmental factors that may be contributing to biases, such as staffing and scheduling, staff perceptions and attitudes toward care delivery and workflows, system culture of safety, staff collaboration, and resource shortages. System leadership can then work to mitigate these stressors and implement quality improvement initiatives.

Foster a supportive culture that encourages reporting and honest discussion of diagnostic challenges and errors. An effective and just safety culture depends on an organization's willingness to learn from errors. Therefore, clinicians, patients, family members, and informal caregivers must feel safe to voluntarily report diagnostic errors and near misses and hold open, honest discussions about them without fear of retribution. Proper event reporting allows all stakeholders to critically assess system weaknesses and implement improvements to prevent future errors. Organizations can utilize high-reliability and systems analysis concepts, routine culture surveys from staff, patient satisfaction surveys, and peer review process outcomes to inform culture and event reporting system adjustments.

Use a diagnostic error classification system to support enhanced systems analysis and ongoing quality improvement. As with other quality and performance improvement initiatives, organizations should start with an in-depth systems analysis to identify diagnostic errors, near misses, and concerns as an embedded component of their patient safety program. Claims data, adverse event data, patient complaints, autopsy reports, medical record and peer reviews, staff and patient surveys, evaluations of the physical environment using human factors and ergonomics methods, user experience evaluations of diagnostic technology and processes, and proactive risk assessments (e.g., failure modes and effects analysis) can help inform improvement efforts, but the most appropriate method may vary by care setting, type of diagnostic error, or root cause(s).

Organizations can also consider electronic clinical surveillance programs that identify gaps in care, such as potential missed diagnoses, test tracking and follow-up, and identification of at-risk patients. For example, if a patient's medical record notes concern regarding cognitive decline with no record of follow-up care, a tool flags the record, alerting a care manager so they can contact the patient to expedite follow-up. Understanding where in the diagnostic process failures occur, which system factors contribute to their occurrence, what the outcomes are, and how these failures may be prevented or mitigated is essential to improvement.

Be cognizant of the benefits and risks of medical technologies used for diagnostic support and institute pre- and post-implementation risk and quality control processes. Organizations should establish a robust medical technology governance program to assess the risks and establish a plan for assessing, implementing, and managing diagnostic support systems. The governance program should be led by a multidisciplinary committee that defines institutional policies; stays abreast of technological, regulatory, and best practice developments in the field of diagnostic support; and establishes processes for risk assessments, vendor assessments, and quality control.(23)

Explore advancements in dementia diagnostic science for early detection and intervention. Recent advancements in clinical examination techniques, neuroimaging, biomarkers, and digital tools may help improve early detection of dementia-related conditions. AI machine learning algorithms, smartphone apps, and wearable devices are now able to detect subtle changes in cognitive function and behavior (e.g., executive function, cognitive processing, immediate memory, visual attention, recall skills), predict the risk of cognitive decline, and identify changes in physical activity and sleep patterns. These early indicators of dementia can assist in early intervention and management of the disease, which is critical to mitigating preventable harm.(31) As noted earlier, however, all technologies should be tested, validated, and piloted prior to widespread implementation or use to best mitigate potential adverse effects.

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ECRI Resources

- Essentials: Missed Diagnoses
- Safety Break - Provider Cognitive Bias: Impact on Diagnosis
- Diagnostic Errors: Monumental Problem or Enormous Opportunity?
- Dementia Care in Aging Services
- Sample Diagnostic Test Tracking Procedure

Some ECRI resources are publicly available. To obtain other ECRI reports, contact us by telephone at (610) 825-6000, ext. 5891, or by email at clientservices@ecri.org.

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