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Improving dementia care: The role of screening and detection of cognitive impairment

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This is a report and recommendations from a meeting of a workgroup on screening for cognitive impairment organized by the Alzheimer's Foundation of America and the Alzheimer's Drug Discovery Foundation on November 22, 2011.

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Abstract

The value of screening for cognitive impairment, including dementia and Alzheimer's disease, has been debated for decades. Recent research on causes of and treatments for cognitive impairment has converged to challenge previous thinking about screening for cognitive impairment. Consequently, changes have occurred in health care policies and priorities, including the establishment of the annual wellness visit, which requires detection of any cognitive impairment for Medicare enrollees. In response to these changes, the Alzheimer's Foundation of America and the Alzheimer's Drug Discovery Foundation convened a workgroup to review evidence for screening implementation and to evaluate the implications of routine dementia detection for health care redesign. The primary domains reviewed were consideration of the benefits, harms, and impact of cognitive screening on health care quality. In conference, the workgroup developed 10 recommendations for realizing the national policy goals of early detection as the first step in improving clinical care and ensuring proactive, patient-centered management of dementia.

Keywords

Alzheimer; Dementia; Screening; Detection; Health care; Policy; Priority; Quality; Medicare; Annual wellness visit; Cognitive impairment; Cost-benefit analysis; Management; Patient-centered

1. Introduction

Cognition is a complex group of mental processes that includes memory, attention, language, and decision making, and mild impairment of cognition may be an early sign of a disease that will lead to dementia. More significant cognitive impairment may indicate the presence of dementia. The decades-long debate over whether to screen older persons for dementia has gained momentum with four converging developments: a rapidly growing population at risk for dementia, the U.S. Food and Drug Administration's approval of five pharmaceutical agents for treatment of dementia of the Alzheimer's type, broad media attention to the human suffering associated with Alzheimer's disease (AD) through news coverage of AD diagnoses of well-known individuals, and the growing potential of both basic science and health services research to improve the outlook for affected patients and their families. Until recently, professional and advocacy organizations, and governmental bodies tasked with evidence reviews, stopped short of recommending routine dementia screening of patients in whom cognitive impairment was not "symptomatic" or "suspected" [1,2]. The same bodies endorsed the importance of dementia case detection among patients with cognitive symptoms, but offered no specific method for case detection. In its 2003 statement, the U.S. Preventive Services Task Force concluded that evidence was insufficient to recommend routine screening for dementia in the primary care setting [3]. Since then, new health care priorities and research have suggested that the benefits of routine dementia

screening outweigh its potential harms and have altered how we think about screening for cognitive impairment and its role in the health care of older persons, particularly as an indicator of impending or existing dementia.

The role of cognition in sustaining the autonomy of seniors is now widely recognized, and the critical role of neurodegenerative disease, particularly AD, in causing cognitive impairment has become a major concern in health care. The popularity of National Memory Screening Day, sponsored annually since 2003 by the Alzheimer's Foundation of America (AFA), corresponds to the increased public awareness of AD and acceptance of cognitive screening. Furthermore, the delineation of the early stages of neurodegenerative diseases, in the hope of discovering therapeutic interventions that can delay progression to dementia, has emerged as a major scientific priority. Recommendations for revised research diagnostic criteria for AD dementia and prodromal states have been widely published and discussed [4–7]. In addition, educational campaigns such as those led by the Alzheimer's Association, and disclosure of the AD diagnoses of such well-known public figures as Rita Hayworth, Ronald Reagan, Pat Summit, and Glen Campbell, have greatly increased the awareness of AD. At the same time, a focus on “patient centeredness” has emerged as an important priority in health care and research, formalized in the creation of the federally funded Patient-Centered Outcomes Research Institute, to encourage new research on the role of the patient in medical care and inclusion of patients' and families' values in setting priorities for managing chronic conditions. The Patient-Centered Outcomes Research Institute was established by the same legislation that established the annual wellness visit (AWV; Patient Protection and Affordable Care Act of 2010) [8].

“Detection of any cognitive impairment,” as defined by Medicare for the AWV, requires “direct observation, with due consideration of information obtained by way of patient report, concerns raised by family members, friends, caretakers, or others.” How to operationalize the detection of any cognitive impairment component of the AWV is currently under discussion by the Centers for Medicare & Medicaid Services, with advice from multiple stakeholder organizations including the AFA, the Alzheimer's Drug Discovery Foundation, the Alzheimer's Association, and the National Institute on Aging.

In November 2011, the AFA and the Alzheimer's Drug Discovery Foundation brought together a workgroup of experts in dementia screening, care, and policy, with a threefold aim: to examine the current state of knowledge regarding screening for dementia and clinically important cognitive impairment, to consider how screening can best be implemented, and to evaluate the implications of routine dementia detection efforts for health care redesign. There is substantial literature that reviews and updates the evidence supporting the efficacy of screening in detecting cognitive impairment and dementia [9–14]. The current report summarizes the conclusions and recommendations of the group regarding the role of screening in the health care context, with the primary aim of identifying patients who have unrecognized cognitive impairment or undiagnosed dementia, and determining how screening can be linked usefully to improvements in subsequent patient care. (Note that this workgroup did not address the specific issues regarding the hundreds of screening tests that have been studied for cognitive assessment and dementia screening, including such items as the continual development of such tests, the need for repeated measurement over

time to detect trajectories of change, the selection of at-risk subjects for early screening, and the relevance of biomarkers of dementia).

2. Benefits of screening for cognitive impairment in clinical practice

settings: Increased recognition of dementia by health care providers

Multiple studies over three decades, including more recent work [15], have established that many (in some studies most) patients with dementia have received no formal diagnosis. Screening has been shown to increase case identification [16], but the value of screening has been questioned, largely as a result of the lack of data demonstrating improvement in patient outcomes for individuals whose dementia is detected by screening [3]. Despite promising advances in research that may eventually offer more decisive benefits for patients, confidence in the value of existing medical therapies for dementing diseases remains low, and evidence is scant showing improved health outcomes for patients whose dementia is formally recognized, diagnosed, and managed in health care settings. The value of screening, beyond identification of otherwise “silent” cases, must be assessed in terms of the potential benefits to be realized through changes in patient care that follow diagnosis relative to the costs of failing to diagnose, and the costs of the screening and diagnostic processes [12,17].

Although dementia is rarely caused by a fully reversible condition [18], finding treatable conditions that contribute to cognitive or functional impairment may benefit both non-demented and demented patients. Finding cases of AD dementia allows early consideration of both pharmacological and nonpharmacological interventions in a patient-centered decision making process. Although there is broad agreement that current drug treatments for AD dementia and related disorders have modest benefits and that not all patients tolerate available medications, some patients benefit from treatment [19]. Consequently, the choice of when to consider pharmacotherapy is left to the individual physician, patient, family, and/or other persons who have a significant role in ensuring the patient's well-being. This decision-making process is not standardized and is subject to important nonclinical influences [20]. Systematic case finding at the population level can establish a platform for developing evidence-based guidelines for establishing value of early case finding to patients and families as well as to health systems and society.

Beyond questions of whether, when, and with whom to use cognitive enhancing medications, confirmation of a dementia diagnosis validates the concerns that have usually been present before a diagnosis is made, and “naming” the problem is beneficial for patients and family members [21]. Furthermore, confirmation of the presence of dementing disease permits initiation of planning, organizing ongoing care, taking suitable steps toward long-range planning for financial and social well-being for both patient and family care partners, and identifying those who can benefit from supportive interventions such as care-giving training, stress management, and health-promoting activities [22–27]. Ruling out the presence of dementia permits an efficient search for alternate causes of symptoms.

Innovations in health care design and delivery for patients and families can also improve adherence to recommended processes of care and some outcomes [26,28–30], as well as

increase provider capacity to deliver comprehensive dementia care [31]. Early detection, facilitated by screening, may allow proactive, comprehensive management of the patient with dementia to begin at a milder level of impairment, before a crisis disrupts the patient's life and requires urgent intervention. This potential benefit of screening has not yet been tested empirically.

3. Does screening for cognitive impairment cause harm?

Research on the potential harms of screening addresses several issues, including anxiety and depression resulting from knowledge of a dementia diagnosis, fear of negative financial consequences (eg, denial of long-term care insurance, risk to employment), removal of driving privileges, and fear of negative social consequences (eg, abandonment by friends, social isolation) [32–35]. However, screening is not the source or cause of harm. Rather, the potential harms relate to the conditions screening is intended to reveal or to the inappropriate interpretation or use of information derived from the screening process. In research studies investigating acceptance of dementia diagnostic evaluation by researchers after a positive screening test, subjects often refuse that step [10,36]. However, most data from routine health care settings indicates that screening is well accepted by patients when endorsed by their health care providers [9,10,16,33,37]. An important and unanswered question is whether system-level factors, such as screening and referral for further evaluation by the patient's primary care physician, would lead to higher follow-up rates. A critical issue for the future is to develop systems in which patients will follow screening algorithms reliably to move to appropriate diagnosis and recommended treatment.

4. The net value of screening: Benefits, harms, and costs

Efforts to quantify the value of medical interventions have been dominated by econometric methods, which seek to represent nonmonetary values in terms of cost–benefit and cost-effectiveness ratios [38], and cost worthiness [12]. Cost-effectiveness analysis has limited overt impact on policy decisions in the United States, but cost sensitivity is high among all insurers, public and private, and cost consequences of interventions are examined by government and nongovernment insurers alike. It is helpful, therefore, to consider the value of dementia screening from the differing, and often conflicting, perspectives of patients, families, health care practitioners, public and private health systems, and society. However, these perspectives have not been studied sufficiently to identify areas of potential agreement. In the following paragraphs, we highlight some of the relevant theoretical considerations and the current limitations in available data that prevent full assessment of the net value of screening.

The costs of initial screening can be kept quite inexpensive, but the costs of a subsequent diagnostic workup will vary with clinicians' views of how extensive further evaluation needs to be for a given patient. Federal policy guidance has not been developed, but pressures toward greater definition of requirements will likely be called for with broad implementation of the AWW.

The monetary benefits and costs of screening must ultimately be measured in terms of the value of timely and correct diagnosis of individuals with specific dementias, and application

of appropriate medical treatments and care management programs. There are relevant subjects for study along the entire trajectory of care. At the screening and diagnosis phase, costs should be considered in connection with misinterpreted screening results (eg, wrong action on false positives and false negatives), delayed diagnosis (eg, missed opportunities to prevent avoidable emergency department visits and hospitalizations, and to prevent or mitigate delirium in hospital), and incorrect diagnosis (eg, prolonged treatment for the wrong disease, such as treating frontotemporal dementia as attention deficit disorder). The rate of mis-diagnosis is not inconsequential. In one study of experts at specialized Alzheimer disease centers, for the diagnosis of AD at neuropathological examination, sensitivity ranged from 70.9% to 87.3%; specificity ranged from 44.3% to 70.8% [39]. It is likely that diagnostic accuracy of AD is well below these figures across all physicians, particularly those who do not specialize in dementia.

At the management phase, the value of screening can be assessed as the net benefit of implementing a treatment and management program after initial screening and case identification have occurred. Relevant cost components include overall health care costs, outcomes of other chronic conditions (including potential for reduction in costs associated with comorbidities and preventable acute care episodes), and clinically supported shifts from high cost (eg, emergency department, hospital, nursing home) to lower cost (eg, ambulatory care, adult daycare, assisted living) services. There are currently no comprehensive data available to make precise calculations of these kinds of benefits, although such information could be used to adjust the screening process carefully to optimize its efficiency [40,41]. A recent economic forecasting study modeled the impact of implementing a dementia screening, diagnosis, and management program for AD in primary care, at varying rates of effectiveness and in constant dollars. The model estimates that direct annual savings for Medicare & Medicaid Services could be as much as \$22 billion in 2025 and \$29 billion in 2050 [42].

5. Can screening promote better dementia care?

Screening by itself does not automatically lead to better clinical care. Although rates of dementia diagnosis and medical treatment by primary care physicians were increased for patients screening positive in a randomized trial [16], persons screening positive often have no further diagnostic assessment by their primary care providers and may not choose to see a specialist. As noted earlier, fewer than half of individuals screening positive sought follow-up diagnosis during the time horizon of the research studies in which they participated [10,37]. Although reasons for not pursuing further follow-up were not evaluated formally, they may include a failure to differentiate between screening and diagnosis, fear of a diagnosis, or system-level barriers to obtaining further care. These studies do not provide guidance regarding how to improve acceptance of screening-derived clinical follow-up recommendations. In one study [37], research consent for further evaluation was required; in another [10], participants were referred to a separate clinic. In both circumstances, the choice was left to the participant. Further testing of the acceptability of dementia screening and diagnosis should embed the process in actual clinical care, with the primary care provider or an experienced assistant guiding the discussion with the patient and family, and should integrate the process with the overall goals of patient care [16]. Then, failure to

pursue diagnostic evaluation after a positive screen would be an index of the quality of care, and rates of follow-up diagnostic evaluation could be used as a clinical performance indicator that could spur more appropriate management.

6. Screening, diagnosis, and improving the quality of care for persons with dementia

Several lines of evidence support the conclusion that ambulatory care for persons with diagnosed dementia is suboptimal. In a cohort of cognitively intact older persons monitored carefully for up to 8 years, adjusted rates of potentially preventable hospitalizations are much higher for those who eventually develop dementia than for those remaining dementia free [43], and recent analyses of Medicare claims data [44] confirm earlier findings [45,46] that overall hospitalization rates are higher for persons with a claims-based dementia diagnosis than those without. Moreover, older persons at risk for dementia are likely to experience accelerated cognitive decline after episodes of severe illness [47]. Such findings challenge health care organizations to focus their efforts on improving ambulatory care for persons at risk or for persons who already have dementia.

Care for patients with dementia requires long-range care management, usually in combination with medical therapeutics, as does care for patients with other chronic conditions that increase risk for poor health outcomes. In hypertension, for example, although antihypertensive drugs have been in use for more than 60 years, no one expects them to cure the patient of the condition; their primary impact on patient outcomes is measured in long-term prevention of the secondary consequences, such as myocardial infarction, heart failure, and stroke. Although hypertension is usually a lifelong disease, most patients take their antihypertensive medications only for short periods of time and are often noncompliant; care management strategies that address individual impediments to adherence and that promote lifestyle changes such as diet, weight loss, and exercise are critical to achieving the best outcomes. Similarly, AD dementia requires both medical therapeutics and care management. Because current symptomatic treatments are only modestly effective, have minimal if any disease modifying effects, and are certainly not curative, effective care management is even more important to overall health care quality for AD dementia than it is for other chronic conditions, yet it is much less often available.

7. Moving from better individual care to better health systems for managing dementia

The National Alzheimer Project Act calls for substantial improvements in comprehensive clinical care for patients with Alzheimer's disease (see Goal 2 [48]). "Medical home" concepts, initially developed to improve care for children with complex medical needs and subsequently extended as an innovation in general adult care, are an ideal approach to conceptualizing dementia care [31,49] but have not been tested in randomized intervention designs. Other approaches to health care redesign include structured partnerships between primary care and community organizations to connect patients and families with educational and support resources after dementia is identified in primary care [26], as well as the use of

nonphysician care managers (nurses or social workers) as bridges between primary and specialty care and community-based services [29,30]. Each model has a particular conceptual orientation and approach to evaluating outcomes.

Although none of these programs has yet been implemented on a wide scale, a brief review of key intervention trials illustrates their variety in implementation and outcome focus. Caregivers receiving education and counseling about dementia [50] or care consultation [51] had lower rates of hospitalization and emergency room visits. Initial in-person followed by as-needed telephonic care management counseling for caregivers of individuals with AD dementia enrolled in an Alzheimer's disease research center has been reported to delay time to nursing home placement by almost 1 year [52]. More recently, a randomized trial of dementia care management by social workers who acted to bridge clinical and psychosocial care [29] found improved quality of care scores on 21 of 23 measures and increased use of community agency assistance in the intervention group. Patient health-related quality of life, overall quality of patient care, caregiving quality, social support, and level of unmet caregiving assistance needs also improved. Last, collaborative care, adding a nurse as care manager for AD dementia patients and families, resulted in significant improvement in the quality of care and in behavioral and psychological symptoms of dementia among primary care patients. These improvements were achieved without increasing the use of antipsychotics or sedative hypnotics significantly [30]. More recently, a simple practice intervention linked screening for dementia in primary care to diagnosis and referral to the local chapter of the Alzheimer's Association [26]. Some improvements in care quality were noted, particularly when adherence to quality measures was low at the outset. These studies show that targeted reorganization of health care for demented patients and their caregivers can have a significant impact on quality of care, quality of life for families, and health care utilization outcomes. Although promising and not yet definitive, these studies are consistent with the likelihood that quality care for the demented patient can be achieved if the patient with dementia can be identified and health systems make the commitment to do so.

Other approaches to improve the care of patients with AD dementia focus on educational programs to encourage primary care physicians to improve their current, usual practice through use of clinical practice guidelines and educational programs. Also, support groups for caregivers can be of great benefit in helping the caregiver to cope with the stress of managing an AD patient. Such groups are sponsored by official government programs at several levels and by voluntary organizations such as the Alzheimer's Association.

8. Recommendations

Following review and discussion of the evidence, the workgroup meeting participants developed the following recommendations for realizing the national policy goals of early detection as the first step in improving clinical care and management of dementia.

1. Promote in-depth education of the public, health care providers, health care organizations, and insurers about screening for cognitive impairment and dementia, and its role in initiating high-quality dementia care (Goal 2b1 [48]). Dissemination should be both “top down” (starting with health care organizations and providers) and “bottom up” (starting with consumers).

Education is needed to increase the depth of knowledge (vertical strategy) as well as to improve the penetration of relevant knowledge (horizontal strategy) into health care environments.

The workgroup recommends a comprehensive program for educating clinicians, health system leadership, and the general public about the importance of identifying cognitive impairment and dementia in older persons, using all efficient forms of media, particularly computer and Internet-based systems.

2. Address the public health impact of diagnostic thresholds as related to the application of screening for cognitive impairment and dementia. Neurodegenerative diseases, like chronic degenerative conditions of other organs, typically have a prolonged asymptomatic phase during which abnormalities and cellular dysfunction are accumulating undetected. This long, silent phase underscores the importance of defining the point on the continuum of cognitive decline at which the value of screening is optimal from the standpoint of improving health care. The early stages of dementia are likely to be ideal points of detection. However, some cognitive loss may only be detectable through detailed memory or cognitive processing tasks, and some cognitive loss may be detectable to patients or family members far in advance of when clinicians would suspect a dementing illness. Evaluation of screening methods based on revealing what is truly “invisible” to the clinician requires recognition that different methods of screening can identify impairments at different points on the neurodegeneration continuum.

The workgroup recommends development of consensus on the degree of cognitive impairment, between states of normal cognition and dementia, at which detection offers the greatest clinical value. Novel, rapid approaches are needed to measure cognitive function, with the capacity for repeatability over extended periods, for the purpose of determining clinically relevant changes over time to detect individuals with developing cognitive problems at the most appropriate point in their progression.

3. Place screening in the context of personalized health care. The development of the Medicare AWV and its required detection of cognitive impairment is a major positive step toward enhancing providers' awareness of cognitive impairment as a focus for clinical attention, and toward further alignment of Medicare benefits with the principles of geriatric care. The AWV is intended to set the stage for proactive, long-term health care planning in terms that are meaningful to individual patients and those individuals supporting them. Recommendations for operationalizing the cognitive impairment detection component of the AWV are a focus of several national efforts, including those by the AFA, Alzheimer's Association, and the National Institute on Aging, and are beyond the scope of this report.

The workgroup recommends continued examination and development of methods for quantifying and communicating the value of routine cognitive measurement in supporting personalized health care for older persons (see, for example, [41]).

4. Develop further the evidence base supporting the value of formal dementia care. Despite substantial evidence on performance of specific cognitive screens [12,53], much less attention has been paid to systematic study of the consequences of detecting cognitive impairment in and across health care settings, and still less to what happens after initial detection of impairment by screening [16]. Evidence-based measures of the quality of dementia care processes have been developed [54]; however, comprehensive, evidence-based, patient-level outcome measures do not yet exist, nor have the costs associated with dementia-focused health care been evaluated systematically in large, representative samples of patients.

The workgroup recommends a formal evaluation of ways to organize dementia case finding and management in health care settings. This evaluation should begin with a coherent definition of which outcomes are desirable and which are undesirable, based on existing evidence combined with review by expert panels. Comprehensive health care cost data should be included in studies of dementia care delivery, including those initiated as part of the National Alzheimer's Project Act implementation plan.

5. Identify and mitigate health system factors that impede high-quality care for cognitively impaired patients and their family caregivers. The families and caregivers of patients with cognitive impairment need to be involved in medical decision making and care planning. Such involvement is critical to the safety and effectiveness of health care for persons with impaired decision-making capacity. Dementing diseases are the principal causes of social dependency in older persons [55], and autonomy is usually eroded gradually. In the absence of initiating events, it is difficult to standardize thresholds to assist patients in making difficult decisions. Patients' abilities to understand and manage their own health care and everyday needs diminish in close relationship to cognitive decline. Engaged care partners can benefit patients substantially in this critical area.

The workgroup recommends continued support for new scholarship and policy analysis to define how the boundaries of patient autonomy and confidentiality should be revised for health care of cognitively impaired persons at stages that precede progression to legally defined decisional incapacity.

6. Support efforts to articulate patient- and family-centered outcomes for assessing the value of screening, case finding, and comprehensive care.

The workgroup recommends focused initiatives to support both theoretical research and empirical studies on patient-, family-, and provider-centered preferences. Collaborations between social and health scientists and scholars in the humanities should be aimed at improving understanding of the meaning and specificity of outcomes for dementia screening and subsequent care, and communicating its potential benefits and harms. Development of decision aids targeting patients and family caregivers is of high priority to personalize dementia care, including screening for cognitive impairment and dementia.

7. Review health system and health plan barriers to optimal management, including lack of incentives to find patients with dementia and to develop comprehensive care plans. Educate providers about incentives to improve care, when they exist [56]. The workgroup agreed that consensus is lacking for proper attention to the complexities of dealing with cognitively impaired patients in health care settings. Dementia care requires more provider time, in both face-to-face encounters and between visits, than is reimbursed under the formulas used by most private and public insurers in the United States [46,57]. Productivity and revenue generation requirements discourage provision of comprehensive primary care for patients with cognitive impairment. However, the Centers for Medicare & Medicaid Services has taken a step to reduce financial barriers for physicians by authorizing incentive payments to qualified providers who implement specific dementia care quality measures.

The workgroup recommends that health care systems confront and revise the incentive system that impedes proper case finding, evaluation, and treatment, and couple that effort with education of providers and payers on the clinical and economic importance of identifying and managing pro-actively patients with dementia.

8. Move toward a dynamic, participatory cognitive screening, surveillance, and management model facilitated by information technology. Connecting providers, patients, family, and other caregivers with researchers is feasible in ways not possible even 5 years ago with the creation and adoption of Internet-based networking. Within the AD community, the formation of connections between organizations with similar goals is recognized as a “megacommunity” [58–60]. Such groups should be leveraged to improve uptake of successful technologies (eg, [10], avoiding duplication and improving efficiency). There are also efficient computer-based measurement tools for cognitive function [61], intelligent systems for home-based assessment [62], and even audience-based testing of memory [63], which may play roles in screening for cognitive impairment in the future.

The workgroup recommends that health systems, providers, and individuals take an active role in developing personal electronic health records that integrate regular cognitive checkups and treatment plans into routine care. There should be progressive integration of computer assistance into clinical evaluations to meet the AWW requirement for direct observation to detect cognitive impairment. Assessment can also be extended into other medical (eg, hospital) and nonmedical (eg, Department of Motor Vehicles) settings to take some of the burden off of primary care providers.

9. Define “ownership” of dementia in the layout of health care. From the standpoint of health care delivery, initial screening for cognitive impairment is most practical in the primary care setting, as reflected in the design of the Medicare AWW and its cognitive evaluation component. The best setting for further diagnostic evaluation and comprehensive management is unclear, however. In the United States, specialty-based clinical dementia care programs are challenged by the generally low rates of reimbursement for chronic care.

The workgroup encourages systematic consideration of the respective roles of primary and specialty care in the long-range management of dementia patients, as part of the work of the National Alzheimer's Project Act implementation plan [48,64]. The discussion should include consideration of primary care–specialty care partnerships, specialized chronic care manager roles within primary care, and research on identifying specific subgroups of patients and families who require ongoing complex or specialized management.

10. Promote critical system change in health care delivery for dementia. The cognitive impairment detection requirement of Medicare's AWW is an important innovation and could set the stage for broad, national improvements in care. However, detection alone will not improve patient and family outcomes, nor will it influence health care quality or costs positively without further changes in how care is structured, organized, and paid for. Studies in three different primary care settings have demonstrated low rates of follow-up on positive dementia screens in patients without a pre-existing diagnosis of cognitive impairment [10,16,37]. Creating pathways to additional assessment and care requires a series of steps:
 - a. Follow up on any positive indicator of cognitive impairment to define the causes and impacts on everyday life and functioning for both patients and family care partners.
 - b. Recognize the complexity of managing individuals with dementia within health care settings. Multimorbidity is the norm in dementia [65], and multiple pathologic causation is recognized as a hallmark of dementia in advanced age [66]. Furthermore, evidence indicates that dementia is not “just another diagnosis” on a patient's problem list, but an important contextual factor in care that can influence relationships between providers and patients negatively [67–69], which can diminish the quality and effectiveness of general medical care.
 - c. Engage patients, caregivers, providers, health system leaders, and other relevant stakeholders in developing pathways for comprehensive care and choosing high-value outcomes.

The workgroup encourages further development and refinement of models of health care for persons with dementia and their family caregivers. Alternative approaches can be adapted to a variety of different types of health care organizations, from the small primary care office to large, integrated health care systems. Further articulation of the components of good dementia care will promote research on clinical outcomes, allow testing of quality-of-care indicators, and foster steps toward health policy that better serves our current and rapidly growing aging population.

9. Conclusion

Three new national policy initiatives offer an unprecedented stimulus for improving health care for persons with dementia and their families: (1) the requirement for cognitive assessment of older adults as part of the AWW, (2) guidance from the National Alzheimer

Project Act implementation workgroup regarding the components and goals of high-quality health care for demented patients, and (3) new measures for assessing dementia care quality that have been endorsed by the Centers for Medicare and Medicaid services for 2012. Further development of patient-centered measures of health care quality, indices of the impact of clinical quality improvements on health care and related costs, and methods for consistent implementation across health care settings are priorities for future development.

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References

- [1]. Ashford JW, Borson S, O'Hara R, Dash P, Frank L, Robert P, et al. Should older adults be screened for dementia? *Alzheimers Dement*. 2006; 2:76–85. [PubMed: 19595860]
- [2]. Ashford JW, Borson S, O'Hara R, Dash P, Frank L, Robert P, et al. Should older adults be screened for dementia? It is important to screen for evidence of dementia. *Alzheimer Dementia*. 2007; 3:75–80.
- [3]. Boustani M, Peterson B, Hanson L, Harris R, Lohr KN, U.S. Preventive Services Task Force. Screening for dementia in primary care: a summary of the evidence for the U.S. Preventive Services Task Force. *Ann Intern Med*. 2003; 138:927–37. [PubMed: 12779304]
- [4]. Albert MS, DeKosky ST, Dickson D, Dubois B, Feldman HH, Fox NC, et al. The diagnosis of mild cognitive impairment due to Alzheimer's disease: recommendations from the National Institute on Aging and Alzheimer's Association workgroup. *Alzheimers Dement*. 2011; 7:270–9. [PubMed: 21514249]
- [5]. Dubois B, Feldman HH, Jacova C, Dekosky ST, Barberger-Gateau P, Cummings J, et al. Research criteria for the diagnosis of Alzheimer's disease: revising the NINCDS-ADRDA criteria. *Lancet Neurol*. 2007; 6:734–46. [PubMed: 17616482]
- [6]. Sperling RA, Aisen PS, Beckett LA, Bennett DA, Craft S, Fagan AM, et al. Toward defining the preclinical stages of Alzheimer's disease: recommendations from the National Institute on Aging and the Alzheimer's Association workgroup. *Alzheimer Dement*. 2011
- [7]. McKhann GM, Knopman DS, Chertkow H, Hyman BT, Jack CR Jr, Kawas CH, et al. The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging and the Alzheimer's Association workgroup. *Alzheimers Dement*. 2011
- [8]. Patient Protection and Affordable Care Act. [Accessed June 8, 2012] [GovTrack.us](http://www.govtrack.us/congress/bills/111/hr3590) (database of federal legislation). 2010. GovTrack.us Available at: <http://www.govtrack.us/congress/bills/111/hr3590>
- [9]. McCarten JR, Anderson P, Kuskowski MA, McPherson SE, Borson S. Screening for cognitive impairment in an elderly veteran population: acceptability and results using different versions of the Mini-Cog. *J Am Geriatr Soc*. 2011; 59:309–13. [PubMed: 21314650]
- [10]. McCarten JR, Anderson P, Kuskowski MA, McPherson SE, Borson S, Dysken MW. Finding dementia in primary care: the results of a clinical demonstration project. *J Am Geriatr Soc*. 2012; 60:210–7. [PubMed: 22332672]
- [11]. Holsinger T, Deveau J, Boustani M, Williams JW Jr. Does this patient have dementia? *JAMA*. 2007; 297:2391–404. [PubMed: 17551132]
- [12]. Ashford JW. Screening for memory disorder, dementia, and Alzheimer's disease. *Aging Health*. 2008; 4:399–432.
- [13]. Okie S. Confronting Alzheimer's disease. *N Engl J Med*. 2011; 365:1069–72. [PubMed: 21992119]
- [14]. Solomon PR, Murphy CA. Should we screen for Alzheimer's disease? A review of the evidence for and against screening Alzheimer's disease in primary care practice. *Geriatrics*. 2005; 60:26–31. [PubMed: 16287338]

- [15]. 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. [PubMed: 19568149]
- [16]. Borson S, Scanlan J, Hummel J, Gibbs K, Lessig M, Zuhr E. Implementing routine cognitive screening of older adults in primary care: process and impact on physician behavior. *J Gen Intern Med*. 2007; 22:811–7. [PubMed: 17447100]
- [17]. Ashford JW, Kraemer HC, Tinklenberg JR, O'Hara R, Taylor JL, Yesavage JA. Statistical and pharmacoeconomic issues for Alzheimer's screening. *Alzheimers Dementia*. 2007; 3:126.
- [18]. Clarfield AM. The decreasing prevalence of reversible dementias: an updated meta-analysis. *Arch Intern Med*. 2003; 163:2219–29. [PubMed: 14557220]
- [19]. Tinklenberg JR, Kraemer HC, Yaffe K, Ross L, Sheikh J, Ashford JW, et al. Donepezil treatment and Alzheimer disease: can the results of randomized clinical trials be applied to Alzheimer disease patients in clinical practice? *Am J Geriatr Psychiatry*. 2007; 15:953–60. [PubMed: 17974866]
- [20]. Franz CE, Barker JC, Kravitz RL, Flores Y, Krishnan S, Hinton L. Nonmedical influences on the use of cholinesterase inhibitors in dementia care. *Alzheimer Dis Assoc Disord*. 2007; 21:241–8. [PubMed: 17804957]
- [21]. Ducharme F, Lévesque L, Lachance L, Kergoat MJ, Coulombe R. Challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer disease: a descriptive study. *Int J Nurs Stud*. 2011; 48:1109–19. [PubMed: 21376317]
- [22]. Olazarán J, Reisberg B, Clare L, Cruz I, Peña-Casanova J, Del Ser T, et al. Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dement Geriatr Cogn Disord*. 2010; 30:161–78. [PubMed: 20838046]
- [23]. Teri L, Gibbons LE, McCurry SM, Logsdon RG, Buchner DM, Barlow WE, et al. Exercise plus behavioral management in patients with Alzheimer disease: a randomized controlled trial. *JAMA*. 2003; 290:2015–22. [PubMed: 14559955]
- [24]. Teri L. Training families to provide care: effects on people with dementia. *Int J Geriatr Psychiatry*. 1999; 14:110–6. Discussion 116–119. [PubMed: 10885862]
- [25]. Gitlin LN, Winter L, Dennis MP, Hodgson N, Hauck WW. A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: the COPE randomized trial. *JAMA*. 2010; 304:983–91. [PubMed: 20810376]
- [26]. Reuben DB, Roth CP, Frank JC, Hirsch SH, Katz D, McCreath H, et al. Assessing care of vulnerable elders: Alzheimer's disease: a pilot study of a practice redesign intervention to improve the quality of dementia care. *J Am Geriatr Soc*. 2010; 58:324–9. [PubMed: 20374405]
- [27]. Gaugler JE, Roth DL, Haley WE, Mittelman MS. Modeling trajectories and transitions: results from the New York University caregiver intervention. *Nurs Res*. 2011; 60:S28–37. [PubMed: 21543959]
- [28]. Judge KS, Bass DM, Snow AL, Wilson NL, Morgan R, Looman WJ, et al. Partners in dementia care: a care coordination intervention for individuals with dementia and their family caregivers. *Gerontologist*. 2011; 51:261–72. [PubMed: 21242317]
- [29]. Vickrey BG, Mittman BS, Connor KI, Pearson ML, Della Penna RD, Ganiats TG, et al. The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial. *Ann Intern Med*. 2006; 145:713–26. [PubMed: 17116916]
- [30]. Callahan CM, Boustani MA, Unverzagt FW, Austrom MG, Damush TM, Perkins AJ. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA*. 2006; 295:2148–57. [PubMed: 16684985]
- [31]. Lessig M, Farrell J, Madhavan E, Famy C, Vath B, Holder T, et al. Cooperative dementia care clinics: a new model for managing cognitively impaired patients. *J Am Geriatr Soc*. 2006; 54:1937–42. [PubMed: 17198502]
- [32]. Holsinger T, Boustani M, Abbot D, Williams JW. Acceptability of dementia screening in primary care patients. *Int J Geriatr Psychiatry*. 2011; 26:373–9. [PubMed: 20845398]
- [33]. Fowler NR, Boustani MA, Frame A, Perkins AJ, Monahan P, Gao S, et al. Effect of patient perceptions on dementia screening in primary care. *J Am Geriatr Soc*. 2012; 60:1037–43. [PubMed: 22690979]

- [34]. Boustani MA, Justiss MD, Frame A, Austrom MG, Perkins AJ, Cai X, et al. Caregiver and noncaregiver attitudes toward dementia screening. *J Am Geriatr Soc.* 2011; 59:681–6. [PubMed: 21438862]
- [35]. Justiss MD, Boustani M, Fox C, Katona C, Perkins AJ, Healey PJ, et al. Patients' attitudes of dementia screening across the Atlantic. *Int J Geriatr Psychiatry.* 2009; 24:632–7. [PubMed: 19115255]
- [36]. Boustani M, Perkins AJ, Fox C, Unverzagt F, Austrom MG, Fultz B, et al. Who refuses the diagnostic assessment for dementia in primary care? *Int J Geriatr Psychiatry.* 2006; 21:556–63. [PubMed: 16783796]
- [37]. Boustani M, Callahan CM, Unverzagt FW, Austrom MG, Perkins AJ, Fultz BA, et al. Implementing a screening and diagnosis program for dementia in primary care. *J Gen Intern Med.* 2005; 20:572–7. [PubMed: 16050849]
- [38]. Gold A, Gold S. Where is the care in managed care? *Shma.* 1996; 27:1–4. [PubMed: 11654665]
- [39]. Beach TG, Monsell SE, Phillips LE, Kukull W. Accuracy of the clinical diagnosis of Alzheimer disease at National Institute on Aging Alzheimer Disease Centers, 2005–2010. *J Neuropathol Exp Neurol.* 2012; 71:266–73. [PubMed: 22437338]
- [40]. Kraemer, H. Evaluating medical tests. Sage Publications; Newbury Park, CA: 1992.
- [41]. Kraemer HC, Frank E, Kupfer DJ. How to assess the clinical impact of treatments on patients, rather than the statistical impact of treatments on measures. *Int J Methods Psychiatry Res.* 2011; 20:63–72.
- [42]. Boustani, MA.; Jermoumi, R. Forecasting the future impact of early detection and management program for Alzheimer disease. In: Rene, TJ.; Wolfgang, H., editors. *Dementia care research: scientific evidence, current issues and future perspectives.* Dustri; 2012.
- [43]. Phelan EA, Borson S, Grothaus L, Balch S, Larson EB. Association of incident dementia with hospitalizations. *JAMA.* 2012; 307:165–72. [PubMed: 22235087]
- [44]. Bynum JP, Rabins PV, Weller W, Niefeld M, Anderson GF, Wu AW. The relationship between a dementia diagnosis, chronic illness, Medicare expenditures, and hospital use. *J Am Geriatr Soc.* 2004; 52:187–94. [PubMed: 14728626]
- [45]. Fillit HM. The pharmacoeconomics of Alzheimer's disease. *Am J Manage Care.* 2000; 6:S1139–44. Discussion S1145–S1148.
- [46]. Fillit H, Hill JW, Futterman R. Health care utilization and costs of Alzheimer's disease: the role of co-morbid conditions, disease stage, and pharmacotherapy. *Family Med.* 2002; 34:528–35.
- [47]. Ehlenbach WJ, Hough CL, Crane PK, Haneuse SJ, Carson SS, Curtis JR, et al. Association between acute care and critical illness hospitalization and cognitive function in older adults. *JAMA.* 2010; 303:763–70. [PubMed: 20179286]
- [48]. National Plan to Address Alzheimer's Disease. [Accessed June 8, 2012] U.S. Department of Health and Human Services. 2012. Available at: <http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml>
- [49]. Boustani MA, Sachs GA, Alder CA, Munger S, Schubert CC, Guerriero Austrom M, et al. Implementing innovative models of dementia care: the Healthy Aging Brain Center. *Aging Mental Health.* 2011; 15:13–22. [PubMed: 21271387]
- [50]. Shelton P, Schraeder C, Dworak D, Fraser C, Sager MA. Caregivers' utilization of health services: results from the Medicare Alzheimer's disease demonstration, Illinois site. *J Am Geriatr Soc.* 2001; 49:1600–5. [PubMed: 11843991]
- [51]. Clark PA, Bass DM, Looman WJ, McCarthy CA, Eckert S. Outcomes for patients with dementia from the Cleveland Alzheimer's Managed Care Demonstration. *Aging Mental Health.* 2004; 8:40–51. [PubMed: 14690867]
- [52]. Mittelman MS, Ferris SH, Shulman E, Steinberg G, Levin B. A family intervention to delay nursing home placement of patients with Alzheimer disease: a randomized controlled trial. *JAMA.* 1996; 276:1725–31. [PubMed: 8940320]
- [53]. Milne A, Culverwell A, Guss R, Tuppen J, Whelton R. Screening for dementia in primary care: a review of the use, efficacy and quality of measures. *Int Psychogeriatr.* 2008:1–16.
- [54]. Feil DG, MacLean C, Sultzer D. Quality indicators for the care of dementia in vulnerable elders. *J Am Geriatr Soc.* 2007; 55:S293–301. [PubMed: 17910550]

- [55]. Agüero-Torres H, Thomas VS, Winblad B, Fratiglioni L. The impact of somatic and cognitive disorders on the functional status of the elderly. *J Clin Epidemiol*. 2002; 55:1007–12. [PubMed: 12464377]
- [56]. Quality improvement in neurology. Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology, T.A.G.S., the American Medical Directors Association, the American Psychiatric Association and the AMA–convened Physician Consortium for Performance Improvement, 2012, in *Dementia Management Quality Measures*.
- [57]. Fillit H, Geldmacher DS, Welter RT, Maslow K, Fraser M. Optimizing coding and reimbursement to improve management of Alzheimer's disease and related dementias. *J Am Geriatr Soc*. 2002; 50:1871–8. [PubMed: 12410910]
- [58]. Gerencser, M.; Van Lee, R.; Napolitano, F.; Kelly, C. How leaders of government, business and non-profits can tackle today's global challenges together. Palgrave Macmillan; New York: 2008.
- [59]. Meagher, B.; Penfield, S.; Van Lee, R. Alzheimer's disease megacommunity: the path ahead. 2008.
- [60]. Van Lee R, Meagher B, Fritz P, Penfield S. Commentary on “A road-map for the prevention of dementia II: Leon Thal symposium 2008”: the megacommunity approach to Alzheimer's disease. *Alzheimers Dement*. 2009; 5:163–5. [PubMed: 19328452]
- [61]. Wild K, Howieson D, Webbe F, Seelye A, Kaye J. Status of computerized cognitive testing in aging: a systematic review. *Alzheimers Dement*. 2008; 4:428–37. [PubMed: 19012868]
- [62]. Kaye JA, Maxwell SA, Mattek N, Hayes TL, Dodge H, Pavel M, et al. Intelligent systems for assessing aging changes: home-based, unobtrusive, and continuous assessment of aging. *J Gerontol B Psychol Sci Soc Sci*. 2011; 66:i180–90. [PubMed: 21743050]
- [63]. Ashford JW, Gere E, Bayley PJ. Measuring memory in large group settings using a continuous recognition test. *J Alzheimers Dis*. 2011; 27:885–95. [PubMed: 21908910]
- [64]. National Alzheimer's Project Act. [Accessed June 8, 2012] [GovTrack.us](http://www.govtrack.us/congress/bills/111/s3036) (database of federal legislation). 2010. GovTrack.us Available at: <http://www.govtrack.us/congress/bills/111/s3036>
- [65]. Sadak T, Kukull W, Borson S, Logsdon R, Cochrane B, Herting J. Multidimensional complexity in the dementias: diagnosis, stage, comorbidity, and neuropsychiatric symptoms. *Neurology*. 2012; 78:P07–160.
- [66]. Schneider JA, Aggarwal NT, Barnes L, Boyle P, Bennett DA. The neuropathology of older persons with and without dementia from community versus clinic cohorts. *J Alzheimers Dis*. 2009; 18:691–701. [PubMed: 19749406]
- [67]. Fortinsky RH. Health care triads and dementia care: integrative framework and future directions. *Aging Mental Health*. 2001; 5:S35–48. [PubMed: 11513496]
- [68]. Harris DP, Chodosh J, Vassar SD, Vickrey BG, Shapiro MF. Primary care providers' views of challenges and rewards of dementia care relative to other conditions. *J Am Geriatr Soc*. 2009; 57:2209–16. [PubMed: 19943831]
- [69]. Hinton L, Franz CE, Reddy G, Flores Y, Kravitz RL, Barker JC. Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives. *J Gen Intern Med*. 2007; 22:1487–92. [PubMed: 17823840]