

EXECUTIVE SUMMARY FOR THE DEMENTIA EDUCATION & TRAINING ACT (DETA) ON DEMENTIA SCREENING

Most persons with dementia remain undiagnosed by their primary care physicians. Families often fail to appreciate the significance of early cognitive symptoms. Screenings are occurring throughout the nation; often with minimal guidance or technical assistance. To correct this problem, the screening of at-risk populations for dementia should become a cornerstone for early treatment or prevention of cognitive decline in older people. Prospective prevention research will not be performed in a timely manner to confirm the value of screening and policy makers must propose the best possible option as a comprehensive approach to cognitive health in elders. Multiple types of screening interventions are effective, including person-to-person, telephone, and of computer-based. Screening should include referral of appropriate individuals to clinicians for further evaluation or promotion of cognitive wellness for normal elders. Screening does not produce adverse outcomes and published screening instruments can be completed in as little as 12 minutes (28). Screening is a safe, cost-efficient intervention that can reassure the healthy elder, promotes successful aging, and directs at-risk individuals to appropriate clinical resources.

PHYSICIAN FACT SHEET ON DEMENTIA SCREENING

1. Most mild dementia goes undiagnosed by primary care providers and families.
2. Dementia is produced by a complex mixture of brain diseases.
3. In the future, dementia is more likely to be prevented than cured.
4. Few elders receive information on successful aging and cognitive wellness.
5. The nation lacks a successful aging program and principles of cognitive wellness.
6. Scientists are unlikely to provide empirical evidence on the clinical efficacy of a successful aging intervention unless studies span multiple decades.
7. Dementia screening can be accomplished with simple, brief, cost-effective instruments.
8. Dementia screening can be accomplished in a reliable manner by persons with basic training.
9. Most persons who undergo dementia screening are reassured by the results.
10. Most available therapies are best used in the early stages of dementia.
11. Early recognition of mild dementia provides opportunities for medical, psychological, social interventions.
12. Dementia screening is a simple, cost-effective intervention that benefits persons with dementia or those individuals who are intellectually normal.

BASIC ISSUES ON DEMENTIA SCREENING

1. WHY SCREEN FOR DEMENTIA?

A. Multiple causes of dementia diminish the likelihood of a specific, predictive test. Dementia is defined as the loss of multiple functions over a prolonged period. Multiple brain diseases produce dementia including Alzheimer's disease, diffuse Lewy body disease, vascular dementia, alcohol-induced dementia, fronto-temporal dementia, and mixed dementia (1,2). Each type of dementia has specific molecular pathologies, e.g., amyloid is involved with Alzheimer's disease as opposed to synuclein which is involved with diffuse Lewy body disease (1). Many patients have several pathologies in their brain at time of death, e.g., Alzheimer's and diffuse Lewy body disease. This complex pathological and molecular picture complicates the creation of a single, specific and sensitive test using blood, spinal fluid or brain imaging to predict the relative risk for dementia. Moreover, future testing batteries will be expensive and clinicians will be more likely to employ molecular genetic or radiological screening on at-risk individuals or those showing some evidence of cognitive decline. Consequently, cognitive screening is a simple, direct cost-effective way to identify individuals at risk for dementia as well as identifying individuals in the future who require further sophisticated testing, e.g., PET scanning.

B. Dementia is under-recognized by physicians and family members.

Prospective longitudinal studies demonstrate serious deficiencies in the healthcare system's ability to recognize dementia. Most dementia remains unrecognized in the primary care setting. Persons with mild dementia are more likely to go unrecognized by physicians and family (over 90%) than persons with moderate to severe dementia (over 70%); however, those with early disease are best treated with available medications (2,3,4). Family members often under-recognize cognitive decline in elders (over 50%). Many elderly live alone and have limited contact with distant relatives. Under-recognition of dementia is a serious, unsolved healthcare problem despite multiple expert panels that have discussed recommendations on dementia screening.

Dementia screening has been a controversial issue for several reasons. The lack of curative therapy coupled with the high level of stigma associated with the term "dementia" diminished the medical communities' interest in screening for this disease (5,6). Several past consensus panels of experts have recommended screening individuals with risk factors or symptoms for dementia; however, none have

explained how those individuals will self-identify and self-refer (7,8). Expert panels have not opposed screening of asymptomatic individuals; however, no national organization recommends routine screening of “normal” elders. The lack of research about the efficacy of screening was the major obstacle to promoting this intervention. This “consensus” process has not included consumer advocacy groups. The screening process assumes that identified patients could be referred to appropriately trained physicians. The number of primary care doctors capable of assessing cognitive function and completing proper assessments has grown over the last decade; however, adequate follow-up continues to be an issue for local organizations.

The definition of effective treatment for dementia has been controversial. Researchers have embraced the silver bullet concept for Alzheimer’s disease where a specific pathology is identified and specific definitive treatment initiated. After a decade of intense research, the silver bullet is not on the horizon (1,2). Now it is time for the federal government to craft strategies to identify impaired patients for aggressive treatment with available therapies while organizing the patient’s strategy for their long-term care.

2. WHAT CONSTITUTES A DEMENTIA SCREENING PROCESS?

Dementia screening has been conducted for years by local organizations throughout America and a general four-step methodology is apparent: 1) marketing and identification of target group, 2) screening instrument selection and use, 3) follow-up advice for screened persons, and 4) quality assurance for the screening process. Screenings are advertised and participants are enrolled based on the goals of the local organization. Multiple screening instruments are available to assess for cognitive decline (9). The length of the screening test ranges from 12 minutes for the 7MS to approximately 30 minutes for the mini-mental status examination. A broad range of statistically validated instruments is available with acceptable levels of sensitivity and specificity as well as interater or rate-rerate reliability (6,9).

Several distinct methodologies include face-to-face screening (6,9,10), telephone-based screening (11,12,13,14), and computer-based screening of at-risk persons (15). All three modalities appear safe, accurate, and effective for the identification of at risk individuals. No methodology produces a diagnosis of dementia, but rather referral of persons who exceed normal limits to a physician for further evaluation. Individuals who fall into the MCI group, i.e., mild cognitive impairment, can undergo re-screening at regular intervals or proceed for further medical evaluation

(16,17,18). Most methodologies should incorporate face-to-face counseling and family support for individuals with positive results (5,6).

There is no national dementia screening policy. Consensus panels affirm the accuracy and validity of this process and encourage screening for at-risk groups; however, the country lacks a proactive policy to provide all citizens with access to an effective, accurate, appropriate service.

3. WHAT IF THE SCREEN IS POSITIVE?

Persons who screen positive are referred to their local physician for follow-up along with the results of the testing. Previous studies demonstrate that over 60% of individuals with positive screens seek follow-up care (19,20). Studies show that 10-20% of individuals will score positive during a routine screening. The percentage of expected positive screening depends upon the age of the screening population, the location, and multiple other variables.

Early identification of at-risk patients provides multiple benefits to the individual, the family, and society. For the affected individual, identification of early stage dementia allows early aggressive use of available treatments. Early stage patients can be offered support groups to diminish the psychological impact of the disorder. Moreover, the total medical care for this individual can be adjusted to meet the needs of a cognitively impaired patient. Issues such as patient education, self-medication, compliance, and hospital care can be adjusted to meet the needs of a mildly demented person who is at risk for common complications such as delirium and depression. The early identification of dementia supports individual patient rights and self-determination. Most mildly impaired patients are capable of charting the future course of their care and making substantial decisions on issues like end-of-life care, resuscitation, disposition of wealth, etc. Informing at-risk patients about abnormal screening does not produce hardship or harm to the patient or family caregiver (21,22,23,24,25).

About one-third of elders live by themselves and these individuals are at risk for accidents, injuries, exploitation, and other adverse outcomes. Early identification allows safeguards and home assistance to assure continued maximization of home placement. Family caregivers derive multiple benefits from early identification. Early identification may reduce the burden of later life decision-making on issues like resuscitation, disposition of wealth, etc. as families can solicit the opinion of the patient while still competent.

Screening and early identification may benefit society by protecting individuals and reducing costs of healthcare. Unrecognized dementia can increase the likelihood of avoidable complications such as delirium, adverse drug reactions, noncompliance, etc. These complications can reduce the autonomy of the patient. Enhancing compliance and protecting demented patients has obvious financial benefits to the healthcare system. Adverse outcomes from screening programs are rarely reported by available literature or experienced by community providers. Published studies on screening for community-based elders demonstrate effectiveness and acceptance (19,21,22). Screening programs detect possible impairment in 10-20% of screened individuals (19). Patient and family satisfaction has been reported as high based on published studies and experience by AFA membership.

The benefits to citizens are clear. Patients can receive available therapy when identified and diagnosed. The healthcare management can be adjusted to incorporate treatment strategies that accommodate a person with cognitive impairment. Home-based support systems can be adjusted to maximize home placement for this person. Safeguards can be taken to prevent avoidable complications such as delirium during hospitalization. In persons with dementia, advanced directives can be discussed that incorporate the wishes of the individuals and reduces the burden of surrogate decision making for the family. Available treatments for Alzheimer's disease and other forms of dementia are most helpful in the early stages of illness. Early identification allows optimal therapy with available and emerging medications.

4. WHAT IF THE PERSON'S SCREEN IS NEGATIVE?

For persons with a normal screen, this intervention provides a valuable opportunity to promote cognitive wellness and successful aging. A simple, direct, cognitive wellness message can be presented to these individuals that may reduce their likelihood for developing dementia at a later age. The emotional boost from a normal dementia screen can be used as an opportunity to discuss basic, preventive interventions such as compliance with anti-hypertensives, responsible drinking, intellectual stimulation and other recommendations that may further protect a patient's cognitive function (26,27).

5. WHAT IS THE ESTABLISHED POLICY ON DEMENTIA SCREENING?

Presently, there is no national policy on dementia screening. Despite the acceptable accuracy of screens as well as the availability of medications for early stage disease, there is no public health policy on assessing for dementia. The present Medicare screening and prevention program does not include cognitive function. Local organizations are left to create their own programs without assistance or guidance.

A national system of dementia screening will require several years for development and implementation. A flexible array of services and instruments will be required. A policy executed today would only be fully available in the field several years from now.

Scientists and researchers are trained to accept treatment strategies that incorporate evidence-based practices. Although, this conceptual model is the gold standard, this strategy has significant limitations that are rarely emphasized by the scientific community. Mass scale public health interventions are tested over a multi-decade period. Researchers are generally preoccupied with conclusive scientific data and the promotion of research. In contrast, public systems must use a pragmatic approach, i.e., “best possible solution”. To date, national policy has been dominated by expert opinions provided by clinical and basic science researchers. The failure of the “magic bullet” approach warrants an alternative strategy that incorporates interventions to limit the impact of this public health problem. No professional organization contends that undiagnosed, unprepared, uninformed patients with dementia are preferable to individuals with accurate diagnoses and appropriate, early interventions.

Dementia Screening

A dementia screening program can occur in any location and the format should be adapted to the needs of the target population and the screeners. Effective screening requires careful organization of resources and familiarity with screening instruments. The DETA program endorses a ten-step method to an effective screening program.

1. DEFINE CLINICAL RESOURCES. During the course of any screening procedure you may identify persons with dementia or other significant problems such as depression, etc., that require follow-up. Many persons will return to their primary care physician; however, some individuals may ask for the name of a physician who can assist with memory problems. Most neurologists, geriatricians, geriatric psychiatrists, and general psychiatrists are capable of assessing and managing dementia. You should not recommend any specific clinician but rather provide choices as well as encouragement for consultation with their primary care doctor. You should avoid the appearance that you are encouraging patients to leave their primary care doctor; however, many physicians do not wish to diagnose or treat dementia. This interaction requires judgment and diplomacy.

2. GATHER APPROPRIATE INFORMATION. The screening process will provide three possible outcomes: 1) the patient will screen normal, 2) the patient screening will be unclear, or 3) the screening will suggest further evaluation. The team should collect appropriate printed material for each of the options and decide in advance how it will manage each type of patient. Patients who screen normal should be provided with cognitive wellness information at the consumer level and printed information for their physician if they so choose. We recommend the “Successful Aging” handout for healthy elders.

Printed material is available for individuals who screen positive and wish further information. This material contains a positive, up-beat message that emphasizes fixable problems. Always maintain a positive, up-beat attitude and emphasize that screening does not mean that a person have dementia.

3. SELECT THE PROPER INSTRUMENT. A variety of three cognitive screens are available for use with the public. Screening can be performed by phone, online, or in person. Most people want to deal with another human being. The mini-mental status examination, the brief 7-minute MMS, or the clock drawing can be used. Our program recommends the mini mental status

examination conducted by a person with basic familiarity with the instrument. The most common mistake made with the MMSE is coaching the patient and providing hints.

Based on the location and the intent of the screening program, other basic health screenings can be performed. Depression screening can be very helpful in directing patients to clinicians who can assess and treat depression. Alcohol screening with instruments such as the CAGE can be used although some persons consider this to be intrusive. Medication reviews can be performed by physicians, nurse practitioners or pharmacists to assess accuracy of prescriptive programs. The extent of the screening is based on the familiarity of the staff and the goals of the program.

- 4. MARKET THE PROGRAM.** Screenings don't work if people don't come. In general, the screening program should be marketed to people over the age of 65, although some younger people may appear for a variety of reasons. Screenings can be conducted in physicians' offices, senior centers, health fairs, and a variety of other settings. The intensity of marketing should correspond to the number of staff who will be available to perform the screening. A single person will require about a minimum of 15 minutes discussion to talk about a positive result or health prevention. Be sure that enough staff is present to explain screening results and discuss wellness.
- 5. ORGANIZE THE SCREENING EVENT.** A single person should be in charge and the physical location should be arranged to assure privacy during the screening. Consultations after the fact should also include a private area.
- 6. ADEQUATE STAFFING.** Bring enough properly trained staff to assure that screenings are accomplished on time. The time arrangement for the screening should correspond to the expected flow of individuals and the number of staff. Older persons want to speak with another human being rather than being given a piece of paper with a test score. It is better to not screen an individual than to perform the test and not explain the results. The screening organization has an ethical responsibility to assure that enough staff is present to answer all reasonable questions and reassure individuals who may have performed poorly on the test.
- 7. HAVE A PRACTICED, POSITIVE RESPONSE TO EACH OF THE THREE OUTCOMES FOR THE SCREENING.** The message

for a negative screening is “things are wonderful and you need to do everything possible to hold on to your intellect”. The message for a questionable screening is “this is only a screening and further testing may be indicated. People are often in the borderline zone and you may want to consider a further evaluation”. The message for the positive screen is reassurance and empowerment. Individuals should be informed that many health problems can produce abnormal screens. Even with the worst case scenario that a person has some type of memory disorder, treatment now substantially changes the natural history of the disease. Staff should be prepared to deliver a positive empowering message that encourages appropriate follow-up for each group.

- 8. FOR PERSONS WITH NEGATIVE SCREENS, ENCOURAGE A RE-EVALUATION IN ONE YEAR.** Periodic evaluations provide an opportunity to emphasize prevention as well as an opportunity for early intervention for dementia. Emphasize the value of cognitive wellness programs and provide successful aging information.
- 9. FOLLOW-UP OF POSITIVE SCREENS.** You can send the results to the person’s doctor. You are not obligated to make the person seek follow-up care but you may ask permission to call the person in a week or month to check on their progress.
- 10. QUALITY ASSURANCE.** You may want to have a customer satisfaction survey to perfect your system.

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