THE JOURNEY OF DEMENTIA IN PRIMARY CARE:
From Screening To Management

Malaz Boustani, MD, MPH
Division of General Internal Medicine and Geriatrics
Indiana University Center for Aging Research
Indiana University School of Medicine
Regenstrief Institute, Inc
USA
Objectives

• Highlight the complexity of caring for a dementia patient in a primary care clinic.
  – The Future Impact of Dementia Study
  – The USPSTF Report
  – PREVENT-Memory Loss Study
  – PRISM-PC Study
Dementia?

- Memory impairment
- One or more of the following:
  - Aphasia
  - Apraxia
  - Agnosia
  - Executive dysfunction
- Significant impairment in social or occupational functioning, which represents a decline from a previous level of functioning.

APA, 1994
The Spectrum of Dementia: Chronic Brain Failure

- AD
- MixD
- VaD
- LBD
- MCI
- Gene
- NL Brain Fx
- Env
- Time
Dementia Symptomatology

- Cognitive Deficit
- Behavioral & Psychological Sx
- Caregiver Burden
- Functional Disability
Etiology

- **Reversible:**
  - No more than 1.5% of all dementia cases in memory clinics are fully reversed.

- **Irreversible:**
  - **Neurodegenerative:**
    - *Alzheimer’s Disease 50-70%*
    - Lewy Body Dementia 1-15%
    - Fronto-Temporal Dementia 1-15%
  - Vascular: 10-25%
  - Mixed: 1-15%

Boustani et al, AHRQ, 2003; Boustani et al, Annals IM 2003
So what if your patient is suffering from Dementia!

Why should you and the public care?
Current Dementia Burden:

- Present in 3-11% of persons ≥ 65
- Present in 25-47% of persons ≥ 85
- Contribute 11% of all years lived with disability by people ≥ 60.
- Lead to an annual societal cost of $100 billion
- The eighth leading cause of death in persons ≥ 65 in the US.

Boustani et al, 2003
Projections of AD prevalence based on three models of the effects of significant therapy advances introduced in 2010

Sloane et al, Ann Rev PH 2002
Dementia Burden is high.

Go ahead and screen for Dementia!
Analytic Framework for Screening for Dementia

Primary Care Population

Screening

Dementia identified

Pharmacological treatment

- Effect on function
  - cognitive
  - social
  - physical

- Effect on hospitalization, institutionalization, health care visits

Nonpharmacological treatment

Caregiver intervention

- Effect on behavioral problems

- Effect on caregiver stress; coping

- Effect on auto crashes, falls, other accidents

- Effect on health related quality of life

Adverse effects of screening

Adverse effects of treatment

Boustani et al, Annals IM 2003
Key Questions:

– Prevalence of undiagnosed dementia
– Effectiveness of screening tools
– Effectiveness of Pharmacological treatment
– Effectiveness of Non-pharmacological treatment
– Effectiveness of caregiver interventions
– Adverse effects of screening
– Adverse effects of therapy
– Cost of screening
KQ2: How common is undiagnosed dementia?

- 5 studies:
  - 3 from North America & 2 from non-North American populations

- Findings:
  - North America: 1.8-5.7%
  - Non-North America: 3.2-12%
  - 66% to 80% of dementia cases are unidentified by the current primary care system.

Boustani et al, JGIM, 2005; Boustani et al, Annals IM 2003
KQ3: How accurate are the screening tests?
Potential Screening Tests

• Cognitive tests
  – e.g. Mini-Mental Status Exam (MMSE), Abbreviated Mental Test (AMT), Short Portable Mental Status Questionnaire (SPSMQ), Clock Drawing Test (CDT)

• Functional questionnaires
  – e.g. Informant Questionnaire on Cognitive Decline in the Elderly (IQ-CODE), Functional Activities Questionnaire (FAQ), Instrumental Activities of Daily Living (IADL)

• Genetic screening
  – e.g. Apolipoprotein E (APOE) [ε-4 allele]

Boustani et al, Annals IM 2003
KQ3: How accurate are the screening tests?

• Studies:
  – 1 meta-analysis evaluated cognitive & functional tools
  – 9 further studies evaluated cognitive tools and/or functional tools

• Findings:
  – MMSE: sensitivity 71-92%; specificity 56-96% in primary care settings.
  – MMSE is the best studied clinically feasible screening tool. Other tools are promising, need more study.

Boustani et al, Annals IM 2003
KQ4: What is the efficacy of pharmacological treatments in improving health outcomes?

• Studies:
  - 10 systematic reviews and 23 additional RCTs

• Findings:
  – ChEI & Memantine reduce the rate of decline in cognition and global clinical change by 3-5 months in people with clinically detected AD; no clear effect on function.
  – The evidence is poor for other drugs in AD or vascular dementia.

Boustani et al, Annals IM 2003
KQ5: What is the efficacy of Non-pharmacological treatments in improving health outcomes?

- **Studies:**
  - No study met our inclusion criteria

- **Findings:**
  - No study evaluated the effectiveness of non-pharmacologic interventions in people with mild to moderate dementia.
KQ6: What is the efficacy of caregiver interventions in improving health outcomes?

- **Studies:**
  - 1 systematic review and 5 further RCTs

- **Findings:**
  - Simple support systems had no effect;
  - Complex, multi-component systems may have some effect;
  - The impact of these intervention on pts with milder dementia detected by screening is not clear.
KQ7: What are the harms of dementia screening?

- No study was found.
- There are several potential harms
  - depression, anxiety, labeling
- A survey of CCRC residents:
  - 48% refused screening
- PREVENT:
  - 50% of PREVENT population did not return to confirm screening results.

Boustani et al, IJGP in press; Boustani et al, Annals IM 2003; Boustani et al IJGP, 2003
KQ8: What are the side effects of pharmacological therapy?

• Drop out rate due to adverse effects in relation to placebo
  – Donepezil: NNH = 12.5
  – Galantamine: NNH = 6.7
  – Rivastigmine: NNH = 5
  – Memantine: NNH = 50

Boustani et al, 2003; Areosa Sastre & Sherriff, 2004
KQ1: Is there direct evidence from a randomized controlled trial (RCT) that screening for dementia improves health outcomes?

- No studies in 2003.

- PREVENT provides some early evidence

Boustani et al, Annals IM 2003
Gaps identified by the USPSTF in 2003

• Early screening is controversial

• No currently available treatments for dementia have been demonstrated with certainty to alter the course of the disease.

• The availability of pharmacological and non-pharmacological management for dementia symptoms & the importance of caregivers argue for early recognition and treatment.

• No data on the feasibility and utility of dementia screening and diagnosis program in primary care.
PREVENT Memory Loss Study
The Goals of PREVENT

• Describes the feasibility and usability of Dementia screening and diagnosis in primary care.

• Test the efficacy of using a system support program to screen, diagnose, and manage dementia in primary care setting.

Boustani et al, JGIM 2005; Callahan, Boustani et al, JAMA 2006
Eligible for screening: Age ≥ 65 and presenting to their primary care physician for a routine visit (3573)

Screened with the six item screener (3340)

Screened Positive: made at least one error (1420)

Screened Positive with CSI-D score ≤ 24 (434)

Neuropsychological evaluation, family interview if possible, and medical chart review (227)

Consensus team assessment by neuropsychologist, psychologist, geriatrician, and geriatric psychiatrist.

CIND (74)  Dementia (107)  Normal (46)


Boustani et al, JGIM 2005
Implementing Dementia Screening & Diagnosis in Primary Care

- 13% screened positive but 50% refused further diagnostic assessment
- Among those who completed the diagnostic assessment:
  - Dementia: 47%
  - CIND: 33%
  - No cognitive deficit: 20%
- The overall prevalence of dementia: 6.0% (95% CI 5.5% -6.6%)
- In dementia: 70% AD, 5% VaD, and 22% mixed
- 19% of patients with dementia had chart diagnosis of dementia
- 1.4% of patients with CIND had a chart diagnosis of dementia
- The overall cost: $4000 per patient diagnosed with dementia

Boustani et al, JGIM 2005
PREVENT Program

• One year of NP based care management working with the family caregiver, primary care physician and supported by geriatric medicine and psychiatry
• ChEI if appropriate
• Symptoms-activated standardized protocols for:
  
  | Personal care | Delusions |
  | Sleep disturbance | Repetitive behavior |
  | Mobility | Agitation/aggression |
  | Depression | Caregiver stress |

• Decrease Anticholinergic burden
• Emphasize non-pharmacologic management

Guerriero-Austrom et al. Gerontologist. 2004
PREVENT Program

• A monthly caregiver support group at the PCP.

• A monthly exercise program for AD pts at the same PCP.

• Informal telephone support.

• Care coordinated across multiple providers.

Austrom et al, Gerontologist 2004
The PREVENT Program in Primary Care

Primary Care Clinician:
- detect and treat delirium
- detect and treat BPSD
- Enhance cholinergic system by
  - Prescribe ChEIs
  - Discontinue Anticholinergic

Caregiver Focus:
- Problem solving skills
- Counseling
- Support group

Expert Team:
- Geriatrician
- Social Psychologist
- GeroPsychiatrist

General Environmental Modification:
- Medication adherence support
- Home safety assessment

Clinical Liaison

Coordinate and Deliver

Dynamic Feedback

Time
Almost half of the screened positive patients refused further diagnostic work-up for dementia!

What is going on?
Factors Associated with Refusal of Dementia Work-up

• Performing well on the temporal orientation:
  – OR 1.37; P = 0.001.

• Race-Age interaction:
  – African-American ≥ 80 yrs: OR 3.1, P < 0.001
  – White-American ≥ 80 yrs: OR = 0.9, P = 0.728.

Boustani et al, IJGP 2006
The comorbidity profile of dementia patients

Are they Sicker?
## Comorbidity & Dementia

<table>
<thead>
<tr>
<th>Variable</th>
<th>No Dementia</th>
<th>Dementia</th>
<th>P Value*</th>
<th>Adjusted P value**</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ICD-9 based</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic Comorbid Condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean number (SD)</td>
<td>2.3 (1.4)</td>
<td>2.4 (1.4)</td>
<td>0.367</td>
<td>0.659</td>
</tr>
<tr>
<td>% Hypertension</td>
<td>73.5</td>
<td>82.2</td>
<td>0.044</td>
<td>0.060</td>
</tr>
<tr>
<td>% Diabetes</td>
<td>34.9</td>
<td>39.3</td>
<td>0.355</td>
<td>0.185</td>
</tr>
<tr>
<td>% Coronary Arteries Disease</td>
<td>20.5</td>
<td>20.6</td>
<td>1.000</td>
<td>0.970</td>
</tr>
<tr>
<td>% Stroke</td>
<td>9.4</td>
<td>10.3</td>
<td>0.735</td>
<td>0.886</td>
</tr>
<tr>
<td>% Heart Failure</td>
<td>14.6</td>
<td>14.0</td>
<td>1.000</td>
<td>0.471</td>
</tr>
<tr>
<td>% COPD</td>
<td>16.7</td>
<td>12.2</td>
<td>0.235</td>
<td>0.328</td>
</tr>
<tr>
<td>% Cancer</td>
<td>12.0</td>
<td>8.4</td>
<td>0.359</td>
<td>0.172</td>
</tr>
<tr>
<td>% Osteoarthritis</td>
<td>36.5</td>
<td>41.1</td>
<td>0.358</td>
<td>0.649</td>
</tr>
<tr>
<td>% Liver failure</td>
<td>0.8</td>
<td>0.0</td>
<td>1.000</td>
<td>0.977</td>
</tr>
<tr>
<td>% Renal Failure</td>
<td>8.3</td>
<td>11.2</td>
<td>0.284</td>
<td>0.768</td>
</tr>
<tr>
<td><strong>Medication based Comorbidity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean CDS (SD)</td>
<td>6.2 (4.7)</td>
<td>5.8 (4.0)</td>
<td>0.387</td>
<td>0.829</td>
</tr>
<tr>
<td>Mean number of medication</td>
<td>6.1 (5.0)</td>
<td>5.1 (3.8)</td>
<td>0.052</td>
<td>0.239</td>
</tr>
<tr>
<td>% Receiving Definite ACH</td>
<td>25.7</td>
<td>21.5</td>
<td>0.368</td>
<td>0.680</td>
</tr>
<tr>
<td>% Receiving possible ACH</td>
<td>46.5</td>
<td>40.2</td>
<td>0.236</td>
<td>0.269</td>
</tr>
<tr>
<td>% Receiving any ACH</td>
<td>55.4</td>
<td>49.5</td>
<td>0.237</td>
<td>0.369</td>
</tr>
<tr>
<td>% Receiving Anxiolytics</td>
<td>7.2</td>
<td>6.5</td>
<td>1.000</td>
<td>0.823</td>
</tr>
<tr>
<td>% Receiving Antidepressants</td>
<td>19.7</td>
<td>11.2</td>
<td>0.033</td>
<td>0.170</td>
</tr>
<tr>
<td>% Receiving Antipsychotics</td>
<td>2.3</td>
<td>3.7</td>
<td>0.313</td>
<td>0.259</td>
</tr>
<tr>
<td>% Receiving any Psychotropic</td>
<td>24.9</td>
<td>19.6</td>
<td>0.254</td>
<td>0.731</td>
</tr>
</tbody>
</table>

Schubert, Boustani et al, JAGS 2006
Did the PREVENT Program change health outcomes?
### Patient Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Augmented Usual Care</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean age</strong></td>
<td>77.7</td>
<td>77.4</td>
</tr>
<tr>
<td><strong>% Female</strong></td>
<td>39.1</td>
<td>46.4</td>
</tr>
<tr>
<td><strong>% Black</strong></td>
<td>58.0</td>
<td>41.7*</td>
</tr>
<tr>
<td><strong>% Married</strong></td>
<td>47.8</td>
<td>48.8</td>
</tr>
<tr>
<td><strong>% Medicaid</strong></td>
<td>70.8</td>
<td>76.0</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>8.6</td>
<td>9.6</td>
</tr>
<tr>
<td><strong>Mean MMSE</strong></td>
<td>17.5</td>
<td>18.6</td>
</tr>
</tbody>
</table>

* * p < 0.05

Callahan, Boustani et al, JAMA 2006
## Frequency of Protocol Use Among Intervention Patients

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Stress</td>
<td>89.3%</td>
</tr>
<tr>
<td>Depression</td>
<td>82.1%</td>
</tr>
<tr>
<td>Repetitive behavior</td>
<td>73.8%</td>
</tr>
<tr>
<td>Aggression</td>
<td>71.4%</td>
</tr>
<tr>
<td>Mobility</td>
<td>61.9%</td>
</tr>
<tr>
<td>Personal care</td>
<td>41.7%</td>
</tr>
<tr>
<td>Sleep disturbances</td>
<td>36.9%</td>
</tr>
<tr>
<td>Delusions</td>
<td>31.0%</td>
</tr>
</tbody>
</table>

Mean # of contacts with NP 14.4
(50% were face-to-face)

Callahan, Boustani et al, JAMA 2006
The Impact of PREVENT

Callahan, Boustani et al, JAMA 2006
The Impact of PREVENT

- NNT = 3.7
- Each 1 point decline in NPI = $250-$400 in health care expenses.
- PREVENT reached 5 NPI point improvement = $1250-$2000.
- Improvement in CG stress.

Callahan, Boustani et al, JAMA 2006
What do Older Primary Care Patients Think about Dementia Screening?

The PRISM-PC Survey
PRISM-PC

- 355 respondents from IU, UNC, UK.
- 80% wanted to know if they had dementia
- 57% would agree to routine testing by a physician.
- < 50% would agree to brain imaging based screening
PRISM-PC

• Perceived harms:
  – Worry about losing insurance (40%),
  – fear of losing driver’s license (81%),
  – becoming depressed (50%) or anxious (45%),
  – and becoming institutionalized (38%).
Who accept dementia screening?
- African American race ($p<0.06$),
- acceptance of routine screening for colon cancer ($p<0.001$),
- acceptance of routine depression screening ($p<0.001$),
- believe that early detection improves treatment of dementia ($p<0.001$),
- believe that early detection would lead to better future planning ($p<0.06$)
- fear that dementia leads to nursing home placement ($p<0.04$).
Conclusions

• Dementia is common and undiagnosed in primary care.
• The only reliable mechanism to establish an accurate diagnosis of dementia is a formal diagnostic assessment.

• Multiple health system and patient-level factors present barriers to this formal assessment.

• Patients with dementia in primary care have a high level of medical and psychiatric comorbidity.

• A significant and innovative modification of the current primary care system led to a decrease in dementia burden.