Dementia: A How-To Approach for PCPs

NOVEMBER 17, 2016
MARIAN HODGES, MD, MPH
REGIONAL MEDICAL DIRECTOR, GERIATRICS, PROVIDENCE - OREGON
Statistics from Alzheimer Assn

Quick Facts

- More than 5 million Americans are living with the disease.
- Every 67 seconds someone in the United States develops Alzheimer's.
- Alzheimer's disease is the 6th leading cause of death in the United States.
- There are approximately 500,000 people dying each year because they have Alzheimer's.
- 1 in 3 seniors dies with Alzheimer's or another dementia.
- In 2013, 15.5 million caregivers provided an estimated 17.7 billion hours of unpaid care valued at more than $220 billion.
Alzheimer’s in Oregon

**Oregon Alzheimer’s Statistics**

Number of people aged 65 and older with Alzheimer’s by age

<table>
<thead>
<tr>
<th>Year</th>
<th>65-74</th>
<th>75-84</th>
<th>85+</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>8,900</td>
<td>24,000</td>
<td>27,000</td>
<td>60,000</td>
</tr>
<tr>
<td>2020</td>
<td>12,000</td>
<td>29,000</td>
<td>28,000</td>
<td>69,000</td>
</tr>
<tr>
<td>2025</td>
<td>13,000</td>
<td>40,000</td>
<td>32,000</td>
<td>84,000</td>
</tr>
</tbody>
</table>

Percentage change from 2015

- **40.0%**
- **15.0%**
Dementia: Some Clarifying Points

- Dementia (Major NCD) = impairment of two or more cognitive functions with interruption of person’s ability to live independently safely and effectively.
- Mild Cognitive Impairment (Mild NCD) = impairment of one or more cognitive function but person is still able to live independently; risk for dementia in future.
Brain Functions: What it Does

- Language  (receptive and expressive; talking and reading)
- Memory and Learning  (immediate or recent)
- Visuoconstruction-perceptual ability
- Attention  (sustained, divided and processing speed)
- Executive Function  (planning and completing tasks, decision-making, response to feedback/correction)
- Social cognition (emotions, behavior regulation)
- Calculation/arithmetic
Dementia: Epidemiology

Alzheimer's Disease 70%
Vascular Dementia 17%
Other Dementia 13%

The Other Dementias

- **Vascular dementia** – changes in cognitive function believed etiologically related to previous CVAs
- **Mixed dementia** – combination of two kinds of dementia in brain at once
- **Lewy Body dementia** – early presentation with getting lost, poor job performance, falls, shuffling gait, visual hallucinations, REM sleep disorder, fluctuating LOC ("blank out" spells); diagnosis often missed or confused with NPH
- **Frontotemporal dementia** – presentation in middle-aged adults with personality changes, marked rude behavior, impulsive behaviors, hypersexual or hyper-oral
- **Dementia with Parkinson’s, HIV, alcohol**
Role of PCP in Dementia Management

- I could fill 3 slides worth of stuff!! Such as:
  - Diagnosis
  - Evaluation of causes of reversible cog impairment, esp drugs
  - Discussion of prognosis/treatment options with pt/family
  - Treatment of depression and behavioral symptoms
  - Discussion of home safety issues and driving
  - Advance care planning
  - Caregiver support
  - Maximizing functional independence
  - Preparing for appropriate care settings and navigating system
Today’s focus

- The importance of case-finding and diagnosis
- Making the diagnosis: the SPADO tool for PCPs
- Supporting the caregiver
- Reframing behavioral symptoms as unmet needs
- Preparing the patient and family for end of life from dementia
Oregon Families in 2011 Town Halls: Their Concerns with PCP Care

- My doctor will not even talk me about it because ‘nothing can be done.’"

- “We were not given proper knowledge right from the start. Not told what to expect.”

- “The professionals were not talking about anything but ‘everyone gets dementia if they live long enough.’”

- “We need a protocol in all medical offices for diagnosing Alzheimer’s, and support of the person and their caregiver with proper resource information…. Very necessary.”
Detection in the Office Practice

Opportunities to suspect:

- Hospital stay complicated by delirium, change in mental status
- Family reaching out with concerns – in hallways, on phone, out of earshot
- Patients who consistently show up on wrong day or wrong time for appointment
- Family members begin to accompany patient to appt when they came alone before
The 10 Signs of Dementia

1. Memory disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with works in speaking/writing
7. Misplacing things/getting lost
8. Decreased/poor judgment
9. Withdrawal from social or work activities
10. Changes in mood or personality
Overlooked cases rate – 35-90% in primary care

**To detect, look for:**

- Patient vague on details, decreased engagement
- Patient turns to family for answers or patient can’t answer questions that they should know (family head nodding sideways in background)
- Patient repeats themselves within one conversation
- Frequent joking, evading questions, “everyone I know is like me” or makes excuses
- New anxiety, new psych symptoms (eg depression, paranoia)
- Has functional decline – can’t navigate world independently

Valcour, Arch Intern Med. 2000; 160: 2964-2968
www.oregonspado.org
CLINICAL PROVIDER ROADMAP

COGNITIVE IMPAIRMENT SCREENING

---

**Annual Exam**
Mini Screen may be performed by trained assistant

- **Tools**
  - Mini-Cog or G300C
  - Family Questionnaire (if family makes available)

  **if**

  **Normal**
  Follow up in one year

  **if**
  Score falls outside of normal range

---

**Cognitive Assessment**
(same day or new visit)
  + Include family

- **Tools**
  One of the following:
  - SLUMS or MoCA (may be performed by trained assistant)
  - Family Questionnaire, e.g. AD8
  - Screening Interview for Alzheimer's Association Family Questionnaire

  **if**

  **Normal**
  Follow up in one year

  **if**
  Score falls outside of normal range

---

**Proceed to Dementia Workup**
(page 2)

- **Determine the continuity of care plan**

---

Adapted from ACT on Alzheimer's® developed tools and resources.
MINI-COG™

Instructions:
- Give 3 words, ask client to repeat words
- Do Clock Drawing
- Ask for 3 words previously given
  - If recall 0, or 1-2 words & impaired clock, then likely dementia

Not affected by education level, culture
- Takes 3 – 5 minutes
- 99% sensitive and 93% specific

Clock Drawing

Elements:

- # 1-12
- # are in correct sequence
- Spacing is appropriate
- Hand placement correct
Next Steps: Full Dementia Evaluation

- Takes more than one office visit – usually two at least, sometimes more
- What I do: History
  - HPI – Look for content of what pt says – paragraphs? Single word answers? Detail or no detail? They may or may not see their difficulties.
  - Medical history focusing on:
    - functional assessment (validated by family) – need help with transportation, bills, meds, housekeeping? We need to know that their cognition is affecting their daily life. Review ADLs, IADLs
    - med review, including OTC, alcohol use
    - Detailed review of cognitive deficits, onset, course, behaviors (from family usually – sometimes can’t be said in front of patient) – AD8 helps
  - ROS – assess for depression, anxiety, irritability
### AD8 Dementia Screening Interview

<table>
<thead>
<tr>
<th>Question</th>
<th>YES. A change</th>
<th>NO. No change</th>
<th>N/A. Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Less interest in hobbies/activities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Repeats the same things over and over (questions, stories, or statements)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Forgets correct month or year</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Trouble remembering appointments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Daily problems with thinking and/or memory</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL AD8 SCORE**

---

*Adapted from Gahb, JE et al.: The AD8, a brief informant interview to detect dementia. Neurology 2000;55:599-604
Copyright 2000. The AD8 is a copyrighted instrument of the Alzheimer's Disease Research Center, Washington University, St. Louis, Missouri. All rights reserved.*
PLEASE Study the Medication List and the Brown Bag!!

- Benzodiazepines
- **Anticholinergics** – watch out for OTC drugs
  Opioids, Benadryl and antihistamines, antipsychotics, antispasmodics (incontinence medicines); antiemetics; tricyclic antidepressants
- **Sedatives/Hypnotics**  
  Ambien, Sonata, Lunesta
- **Skeletal muscle relaxants**  
  Soma, Flexeril
- **Any med that reduces BP <120**

Full Dementia Evaluation

**Physical exam:**
General exam plus check ears for wax and overall hearing/vision
Focal neuro deficits? Evidence of prior CVA
Increased motor tone or tremor?
Gait abnormalities?

**Cognitive Testing: SLUMS or MOCA**
SLUMS

- Validated for diagnosis of dementia AND for Mild Cognitive Impairment
- Takes 5-10 minutes
- Tests multiple brain functions
- “I do this with all my patients” – normalize it
- Not validated for repeating over time to follow disease
SLUMS or MOCA?

- **MMSE**: proprietary, i.e., licensed, longer, not useful for MCI
- **SLUMS**: helps differentiate MCI vs dementia, scored by educational level
- **MOCA**: longer, more useful for the less common dementias
  - Available in ~20 languages
- No significant difference between MOCA and SLUMS for detection MCI and dementia in Veterans study

Full Dementia Evaluation

Lab exam ordered at end of visit:

- CBC, CMP, thyroid, B12, Vitamin D. No RPR unless concern. Consider HIV test.
- Noncontrast CT or MRI recommended unless pt is very advanced
- Brain imaging especially important if these concerns:
  - Neuro exam focality
  - Younger presentation
  - More acute progression of symptoms
  - History of head trauma
- Patients with advanced symptoms with normal neuro exam, age >80, need no imaging
- Biomarkers and PET scans are not advocated for routine use
Disclosing the Diagnosis

Only 45% of people with Alzheimer’s disease or their caregivers report being told of their diagnosis.

More than 90% of people with the four most common types of cancer have been told of their diagnosis.
Importance of Diagnosis AND Disclosure

- Consider medications; modify risks (esp CV risks)
- Empower patients and families to address and plan for future needs
- Patients and families may be relieved to know the reason for the changes they see in the patient
- Realize and support caregiver burden
- Early link for patient and family to informal and formal support; link to you the PCP as an ally
- Advance care planning
Disclosure: Separate Office Visit

- Suggest patient return with family after labs done
- Be straightforward and direct, but compassionate, about diagnosis. It is like telling bad news. Find out how much they want to hear. Find out about their attitudes to dx/stigma.
- “Dementia, probably Alzheimer’s, which means this….. Brain not working…..brain is failing in what it used to do…. You can still have great days, but there will be good days and bad days.”
- Emotional support: “I will support you and your family on your journey”
- Give them tangible resources
Dementia: Brain Failure
Help is Here: When someone you love has dementia
(my book available for free in all PMG clinics: ask your care manager or [www.dementiahelphishere.org](http://www.dementiahelphishere.org); proceeds go to Providence Foundation)

Referrals to clinic Care Manager for social supports, caregiver support groups
HOW TO: What I Tell Families

- Dementia waxes and wanes: some days it will seem “cured”
- Don’t argue! You will never win – and you will spoil the mood.
- Go to their world. Leave yours behind.
- You can have good moments – and treasure them.
- They will turn on you: it is the dementia talking, not the person.
Referral to outpatient OT driving assessment

Elder law attorney

Family members may need individual counselling or support

Aging and Disability Resource Connection of Oregon: www.helpforalz.org

www.oregoncarepartners.com – free online and in-person training for caregivers

Alzheimer’s Association has support groups, information
When you are dealing with dementia in the room, who is the real patient??
Palliative Care and Dementia

- Disease is with the patient
- Suffering is with the caregiver
Caregiver Burden

“The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning.”

In USA, 2013:

- 15.5 million family and friends for persons with dementia
- 17.7 billion hours provided of unpaid care
- $220 billion value
Risk Factors for Caregiver Burden in Dementia

- Decline in patient’s ability to perform ADLs and IADLs
- Caregiver’s age, relationship (spouse at greater risk), living in the same household
- Number of hours devoted to caregiving

What Does the Burden Look Like?

### Figure 9
Proportion of Alzheimer’s and Dementia Caregivers Who Report High or Very High Emotional and Physical Stress Due to Caregiving

<table>
<thead>
<tr>
<th>Percentage</th>
<th>High to very high</th>
<th>Not high to somewhat high</th>
</tr>
</thead>
<tbody>
<tr>
<td>80</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stress</th>
<th>Emotional stress of caregiving</th>
<th>Physical stress of caregiving</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>59%</td>
<td>38%</td>
</tr>
<tr>
<td></td>
<td>41%</td>
<td>62%</td>
</tr>
</tbody>
</table>

Created from data from the Alzheimer’s Association.¹⁷
A Disproportionate Share of Dementia Care Is Funded by Families

How do we help the family or friend with caregiver burden?

- Identify the primary and additional caregivers – in the chart, in your office visit notes
- Improve caregivers’ understanding of their role and teach them the skills necessary to carry out the tasks of caregiving (team up with your office care manager)
- Recognize the need for longitudinal, periodic assessment of care outcomes for the care recipient and family caregiver
This may be the most important thing

▶ You can’t cure the patient of his dementia

BUT.....

▶ You can help heal the caregiver
90 year old woman with moderate AD recently moved from assisted living to foster home. In first week hitting caregiver, refusing care, refusing meds, spitting them out, and constantly wandering into other residents’ rooms. You get desperate calls from family and from caregiver about her “agitation.” Caregiver is not sure she can keep your patient.
Behavioral and Psychological Symptoms in Dementia: BPSD

- Occur in 70-90% of patients over course of illness, more common later in disease
- Behavioral: pacing, yelling out, overdressing, wandering, resisting care, disrobing inappropriately, hitting, scratching, inappropriate sexual behaviors, sleep disturbances
- Psych Sx: delusions, hallucinations, depression, psychosis, anxiety
- Common Labels: “agitated,” “aggressive,” “disruptive”
Behavior = Expression of Unmet Need

What would you do if you could not tell somebody what you needed, why you were upset, or how you felt??????
Teach the Caregiver/Family This Framework

Ask them to think about underlying cause:

- Pain (constipation and urinary retention in addition to usual suspect of arthritis pain),
- Physical needs: hunger, thirst, fatigue, cold
- Emotional needs: anxiety, loneliness, fear
- Adverse reaction to med
- Other Triggers – family visit, staff/roommate reaction, driving in car, taking off brief, shower/bathing

Ann Long Term Care, 2012
Non-Pharm Approach to BPSD

- Very few controlled, well-designed, powered studies
- Some suggested techniques:
  - caregiver education
  - sensory stimulation: hand massage, music, aroma-therapy
  - “validate, redirect, re-approach”
- Reality orientation increases frustration
Medication the answer for BPSD?

- Remember there is a RANGE of symptoms we are asked to treat – and you can’t think of them as all the same
- Data show some but minimal benefit for atypicals treating psychotic symptoms and aggression/physical harm – but adverse effects can outweigh benefit (CATIE-AD Trial, NEJM 2006; JAMA 2005; JAMA 2011)
- Haldol compared to risperidone has been equally effective (BMJ 2014)
- Risk for mortality is particularly increased after 90 days of use
- AKI risk increased for atypicals (Ann Intern Med 2014)
- AGS and Choose Wisely Campaign advocate against antipsychotic use for BPSD (JAGS 2013); 2015 Beers criteria also advocate against unless nonpharm options have failed and pt is risk of harm to self or others
2014 study in JAMA – all the rage in geriatrics right now!

RCT in 8 academic centers in US

186 patients randomized to psychological intervention plus citalopram 30 mg (n=94) or placebo for 9 weeks

Results: 40% of citalopram patients had marked/mod improvement from baseline agitation vs 26% control (OR 2.13, p. 01)

Worsening of cognition and QT prolongation in citalopram group: 30 mg dose is now against FDA guidelines in elderly

Anton P. JAMA 2014. 311: 682-691
How To: What I do for BPSD/’Agitation’

- For patient with acute risk for harm to self or others (hitting, shoving, biting) – low dose risperidone 0.25 mg bid or halodol 0.5 mg bid
- For patient who is pacing, undressing, yelling – try to find cause (food, blanket, etc.), redirect, use massage
- For patient sundowning in afternoon, up at night – also redirect, but if necessary, use trazodone 50 mg or melatonin 1-3 mg
- I use depakote 125 mg sprinkles daily or BID in patients who won’t take pills and are hitting/shoving (anecdotal data only)
- I use antidepressants for anxiety, depression sx – esp citalopram
- Consider referral to Prov HH Mental HealthRN; Behavior Support Services
It is a FATAL Illness

Most patients die within 4-8 years of diagnosis

Many die of infection (aspiration pneumonia, UTI with sepsis, decubitus with sepsis)

Infection risk increases with weight loss, which happens as they near end of life and lose appetite

Artificial nutrition does not improve survival or comfort or outcomes
Causes of Death in Oregon: 2012 statistics

1. Cancer
2. Heart disease
3. COPD
4. Stroke
5. Accidental Death

6. Alzheimer’s dementia
Feeding tubes are not recommended…Careful hand feeding should be offered.

Efforts to enhance oral feeding….should be usual care

It is the responsibility of the long term care residence to understand the wishes of the patient…

Institutions…should not exert pressure on individuals or providers to insert tube feeding.
Concluding Takeaways

- Dementia is undetected in many of our primary care patients
- Work to be more comfortable with diagnosing this disease and look for it in your patients – those who are less verbal, have family present who are doing more
- Do evaluation for dementia over multiple visits; normalize what you can (SLUMS, MOCA) as part of your usual care
- Disclose the diagnosis, ideally with family present; DOCUMENT
- Give them resources so they feel they have next steps
- Worry about caregiver burden and assess it
- Look at behavior as expression of unmet need – figure out the need and consider meds as last resort
Additional Geriatric Apps