MISSED DIAGNOSES:
LOST OPPORTUNITIES

Dylan Wint, MD
NV Energy Chair for Brain Health Education
Cleveland Clinic Lou Ruvo Center for Brain Health
TOPICS

- The phenomenon of missed diagnosis of dementia
- Benefits of early and accurate diagnosis and disclosure
- Arguments against disclosing diagnosis
- Strategies for disclosing diagnosis
PREVALENCE OF MISSED DIAGNOSIS

On average, about what percentage of elderly patients with dementia are diagnosed by their PCP?

a. 90%
b. 70%
c. 50%
d. 30%
e. Not enough study to know
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample (n)</th>
<th>Sensitivity</th>
<th>Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borson 2006</td>
<td>Elderly volunteers (371)</td>
<td>41% mild dementia</td>
<td>Dementia type</td>
</tr>
<tr>
<td></td>
<td></td>
<td>49% mod dementia</td>
<td>Language barriers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>95% severe dementia</td>
<td></td>
</tr>
<tr>
<td>Olafsdottir 2000</td>
<td>Elderly PCP patients (350)</td>
<td>26%</td>
<td>Duration of dementia</td>
</tr>
<tr>
<td>Valcour 2000</td>
<td>Elderly Asian IM patients (297)</td>
<td>9% mild dementia</td>
<td>Severity of dementia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50% mod dementia</td>
<td>Behavioral syx</td>
</tr>
<tr>
<td></td>
<td></td>
<td>100% severe dementia</td>
<td>ADL dependence</td>
</tr>
<tr>
<td>Eefsting 1996</td>
<td>Elderly PCP patients (375)</td>
<td>14% mild dementia</td>
<td>Visit frequency (mild)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>47% mod/severe dementia</td>
<td>Caregiver burden (mod)</td>
</tr>
<tr>
<td>O'Connor 1988</td>
<td>Elderly with MMSE&lt;23 (444)</td>
<td>22% mild dementia</td>
<td>Visit frequency (mild)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>36% mod dementia</td>
<td>Caregiver burden (mod)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>67% severe dementia</td>
<td></td>
</tr>
</tbody>
</table>
WHY ARE WE MISSING DIAGNOSES?

PROVIDER FACTORS
- Lack of cure
- Difficulty discussing
- Downplaying patient/caregiver concerns
- Discomfort with assessment tools
- Stigma
- Younger age
- Dx increases service demands
- Unnecessary burden on patient
- Specialists unhelpful

PATIENT FACTORS
- Fear
- Age extremes
- “Just getting older”
- Refuse assessment
- Forgetting
- Not a medical problem
- Denial
- Limited access
- Lack of education
- Assume provider will mention

Bradford et al 2009. Alz Dis Assoc Disord
WHY WE SHOULD (OR SHOULDN’T?) DIAGNOSE

- Ethical arguments
  - Autonomy +++/-
    - Patient’s right to information
    - Patient’s right to decision-making
  - Beneficence
    - Doing good for the patient
  - Nonmaleficence
    - Avoiding harm to the patient
RIGHT TO KNOW

% would want diagnosis

Holroyd 1996
Turnbull 2003
Alz-Eu 2011
Other data

- 80% of people would go to a doctor if they had cognitive symptoms
- 65% of people would take a test to predict whether they will get Alzheimer disease
DO NO HARM

Risky behavior in undiagnosed dementia

- 2.5 times as likely to prepare hot meals
- 2 times as likely to manage own medications
- 1.5 times as likely to drive
- 3 times more likely to attend doctors appointments solo
DO NO HARM

Risks of a dementia diagnosis

- Depression
- Anxiety
DO NO HARM

Risks of a dementia diagnosis

- Depression
- Anxiety
BENEFITS OF EARLY DIAGNOSIS

Knowledge

- More accurate diagnosis
- Explanation of troubling symptoms
- Prevention of complications
  - Psychosocial
  - Medical
BENEFITS OF EARLY DIAGNOSIS

Preparation
- Work status
- Financial decisions
- Medical decision-making
- Advance directives
BENEFITS OF EARLY DIAGNOSIS

Life status

- Safety measures
- Connect with resources
- Make important decisions
  - Relocation
  - Downsizing
- “Bucket list”
BENEFITS OF EARLY DIAGNOSIS

Best medical care

- Earlier treatment → Better outcomes
- Participation in research studies
- Prevention of medical errors
BENEFITS OF EARLY DIAGNOSIS

Best medical care

- Earlier treatment → Better outcomes
- Participation in research studies
- Prevention of medical errors
BE AWARE OF YOUR OWN FEARS

Our worries

- Unanswerable questions
- Patient meltdown
- Doubt or anger directed at provider
- Crushing hope
- Uncertainty
- Later complications
BE AWARE OF YOUR OWN FEARS

Setting the scene

- Understand patient expectations
- Know what you want to discuss
- Do not be rushed or tense
  - Face-to-face
  - Sit down
  - Eye contact
- This is a conversation, not an announcement

Baile et al. The Oncologist, Aug 2000
ELEMENTS OF DIAGNOSIS

Symptoms and suspicions

Findings and implications

Testing
  o Purposes
  o Results

Synthesis
A BETTER DISCUSSION

- Explain or avoid medical jargon
- Do not be excessively blunt or emotionless
- Avoid nihilism
  - No cure ≠ no treatment
  - Positive terminology
- Go slowly
  - Small chunks of information
  - Pause
  - Repeat

Baile et al. The Oncologist, Aug 2000
A BETTER DISCUSSION

After the diagnosis

- “What questions do you have?”
- Do not be defensive
- Do not bignore emotional responses
  - Identify outward expressions
  - Ask patients how they feel
  - If the emotion is not “cleared” the patient can’t move on
- Providers can show emotion

A BETTER DISCUSSION

After the diagnosis

- Be prepared with plans
  - Do not assume what the patient will want
  - Offer simple decisions
  - Not every decision needs to be made now
- Encourage future communication
- Provide resources
THE FUTURE

- Disease modifying treatments
- Better diagnostic techniques
- Higher patient/caregiver expectations
- More self diagnosis
CONCLUSIONS

- Patients go undiagnosed for reasons that are not medical
- Lack of diagnosis increases risk to patients
- Delivering a diagnosis is not harmful
- There are ways to make a diagnosis more palatable
- The future will require that we learn to diagnose patients early