Saying the “D” word: 
Interviewing and providing feedback to patients with dementia

2017 CoxHealth Geriatric Conference
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About me
- Springfield Native
- Outdoor enthusiast
- Neuropsychologist for CoxHealth
  - Outpatient clinic in the Jared Neuroscience Center
  - Primary referrals come from neurology and primary care
  - See primarily adults (16+)
  - 60-70% of referrals are dementia related

Disclosures: None

Fun with Neuropsychology

Fun with Neuropsychology
Critical elements for interviewing patients/families with concerns of dementia

Assessment/Screeners of dementia

Review of different types of dementia

Giving a diagnosis of dementia

Elements for a dementia evaluation

History Gathering

Examination of cognitive, behavioral, medical, and neurological findings

Laboratory testing and brain imaging

Presenting findings and treatment plan to the patient

Interviewing for dementia

Getting an appropriate history is the foundation on which the dementia evaluation is built.

"The expertise that underlies history-taking imply that the historian in the clinical encounter is the clinician, not the patient. The patient is a witness to his or her symptoms and is not responsible for creating a narrative framework that makes sense of events. Those tasks, the historical enterprise, fall to the clinician" (Ovsiew, 2013, p. 310)
Components of a clinical interview for dementia

- Cognitive/physical symptoms
- Emotional symptoms and psychiatric history
- Activities of Daily Living
- Medical
- Family History
- Substance Abuse
- Academic/Occupational
- Social

What is the first and most important question you can ask when assessing for dementia?

- Can I talk to someone who knows you well to get additional information
- Insight is a highly complex cognitive skill that is often affected in dementia
- Low correlation between self-report of memory problems and objective performance on memory tests
- Family report correlated better with objective tests of memory and neuroimaging (Fyock & Hampstead, 2015)
- Assessment of insight is a key component of the dementia evaluation
- Anosognosia (lack of insight) is common feature in Alzheimer’s
- Make sure you get the patient’s opinion first and then ask the collateral source

Cognitive/Physical symptoms:

- Ask about specific domains
  - Memory: details/conversation, appointments, repeating themselves, date, etc
  - Attention: misplacing things, distracted in tasks, purpose of going into a room, losing train of thought
  - Language: word finding/tip of the tongue, word substitution, receptive language
  - Visuospatial: depth perception, misreaching, running into furniture/walls/doorframes
  - Processing speed: cognitive efficiency, reaction time, response time
  - Executive functioning: multitasking, planning/organization, judgement, impulsivity
  - Physical/Motor: balance/falls, gait, tremor, orthostatic dizziness, senses
- Obtain onset and circumstance around onset (medical/medications, life events, stressors/mood, etc)
- Identify first symptom and progression (gradual, fluctuating, stairstep)
Emotional/Psychiatric

- Assess current mood and psychiatric symptoms
- Sleep: REM sleep disturbance, sleep apnea, daytime hypersomnia/insomnia
- Appetite: craving sweets
- History of psychiatric illness and treatment
- Recent behavioral or personality changes
- Psychotic symptoms:
  - Hallucinations: Auditory vs visual; well-formed vs shadows; distressing
  - Delusions
  - Apathy
  - Anxiety
- Mania
- Suicidality: ideation vs intent; access to firearms

Activities of Daily Living

- Driving: Forgetting directions (familiar vs unfamiliar location); more scratches on the car; MVA/traffic violations; night driving problems; driving too cautiously
- Medications: Ask them to name their medical conditions and what medications they are taking; Use of pillbox, do they set this up themselves?; refills on time; double doses or missing doses
- Finances: late payments; double payments; scammed out of money; errors in check writing
- Cooking: Stove/oven; leaving out ingredients; forgetting recipes
- Housekeeping: chores; misplacement of objects; repairs
- Hygiene: Need prompting;

Other elements of clinical interview

- Medical:
  - Developmental delays; CNS injuries; medication (e.g. anticholinergic)
  - Substance abuse: Lifetime history, not just current; quantify average daily amount and duration
  - Family history: Ask about memory loss rather than just Alzheimer’s
- Academic/Occupational:
  - Get more than just highest level, such as history of special education, learning disability, grade retention, or ADHD
  - Ask about cognitive problems when working
- Social:
  - Good opportunity to further assess loss of autobiographical information
  - Length of marriage, previous marriages number of kids and grandchildren.
Behavioral Observations

- The clinician should always be looking for behaviors that are consistent with cognitive dysfunction throughout the interview
- Word finding difficulties or circumlocution
- Losing their train of thought
- Difficulties with temporal sequencing of events
- Perseverating to previous topics
- Receptive language difficulties
- Impulsivity/Cursing
- Apathy/lack of interaction

Neurocognitive Assessments/Screeners

- Factors to consider
  - Knowledge of test measures and limitations
  - How scores are derived and what constitutes the normative sample (age, education, etc.)
  - Standardized test administration environment
  - Non organic variables that impact test scores
  - Normal variability
  - Premorbid functioning
  - Education/Occupation History

Assessment/Screeners of dementia
Brief Cognitive Screeners

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<thead>
<tr>
<th></th>
<th>MOCA</th>
<th>SLUMS</th>
<th>MMSE</th>
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<tbody>
<tr>
<td>Sensitivity</td>
<td>90% MCI</td>
<td>92% MCI</td>
<td>92% MCI</td>
</tr>
<tr>
<td>Specificity</td>
<td>87%</td>
<td>81%</td>
<td>100%</td>
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<tr>
<td>Public Domain</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
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- Interpretation is based on global score rather than raw scores of each item
- While sensitive to cognitive impairment, differentiation of cognitive patterns to assist with dementia differentials is more challenging with a brief cognitive screener
- Scores below cutoff warrant further assessment

(Nasreddine et al, 2005)

Montreal Cognitive Assessment (MoCA)

- www.mocatest.org
- Multiple languages (>30) and three versions for repeat testing
- Blind version available
- IPAD version being developed
- 30 point scale similar to MMSE and SLUMS
- Newer research investigating index scores to assist with differentiating dementia diagnoses and conversion rates from MCI to dementia (e.g. MoCA-Memory Index Score)

(Julayanont et al, 2014)
Recommendations

- Cognitive assessments recommended for routine use in primary care were:
  - General Practitioner Assessment of Cognition (GPCOG)
  - Memory Impairment Screen (MIS)
  - Mini-Cog

- These screeners were chosen as “most suitable” for primary care for:
  - <5 minutes to administer and easily administered by non-physician staff
  - Validated in primary care setting
  - Good to excellent psychometric properties
  - Relatively free from educational, language, and cultural bias
  - Free for clinical use

- Informant assessment recommended were:
  - GPCOG-Informant, AD8, and IQCODE

- These tools were selected to determine if further evaluation of dementia is necessary

Review of different types of dementia

- Cognitive impairment this severe is rare in young to middle age (0.5%)<br>
  - 1% at age 60<br>
  - 3-8% for ages 65 to 72<br>
  - 15-20% for ages 74 to 84<br>
  - 30-50% age 85 and older

Prevalence of Dementia

(Schoenberg & Duff, 2011)
General DSM-5 diagnostic criteria for Major Neurocognitive Disorder or Dementia

- Evidence of significant cognitive decline from previous level in one or more cognitive domains based on:
  - Concern from individual, informant, or clinician of significant decline
  - Substantial impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another quantified clinical assessment
  - Deficits interfere with ADLs, social, or occupational functioning
  - Cognitive Deficits do not occur exclusively in a delirium
  - Cognitive Deficits are not better explained by another mental disorder

(McGuffin, 2013)

Mild Cognitive Impairment (MCI)

- Diagnosis that indicates:
  - Cognitive Decline greater than expected for age
  - Essentially independent with ADLs
  - May represent early stages of dementia
  - Broken down into four categories based on profile of cognitive impairment:
    - Amnestic: Single vs Multiple Domain
    - Non-Amnestic: Single vs Multiple Domain
  - Course is variable but generally increases risk of dementia
    - 10-12% convert to dementia annually
    - 3% improve to normal range annually, though may decline in future
  - Prevalence rate: 12-18% of non-demented individuals above the age of 65

(Kaylay & Peterson, 2009)

Alzheimer’s Disease (AD)

- Prevalence: 50% of dementias have an AD pathology. 35% are pure AD with another 15% of mixed dementia (AD and Vascular).
- Risk Factors: Older age, female gender, lower level of education, family history of dementia, APOE4 allele, Down syndrome, history of head injury, psychiatric illness, or alcohol abuse.
- Onset/Course: Generally after age 65. Before 65 has a stronger genetic etiology and more rapid progression. Late onset usually has a course of 10+

(Schoenberg & Duff, 2011)
Alzheimer’s Disease (AD)

- Clinical features:
  - Early in course: Subtle personality changes (less energy, socially withdrawn, greater dependence on others, indifferent), environmentally related depressive symptoms, and minimization or confabulation of cognitive problems.
  - Late in course: agitation, confusion, wandering, apathy, decreased sleep/appetite, emotional blunting, and delusions/hallucinations.

Vascular Dementia (VaD)

- Prevalence: 10% of dementias are pure VaD with another 15% mixed AD and VaD.
- Risk Factors: Stroke, atherosclerosis, hypertension, diabetes, hyperlipidemia, smoking, obesity, male gender, and older age
- Onset/Course: Usually between 60-75. Course is variable due to size and location of ischemic events. Usually stepwise progression, though this may not be identifiable and appears more continuously progressive

- Clinical Features:
  - Highly variable secondary to localization of ischemic event(s).
  - Depression, anxiety, apathy, and social withdrawal are common
  - Disinhibition
  - Urinary incontinence may be present.

(Schoenberg & Duff, 2011)
Dementia with Lewy Bodies (DLB)

- Prevalence: 12-27% of dementias. 2nd or 3rd most common cause of dementia.
- Risk factors: Older age and other causes of dementias (AD and Parkinson's disease often have Lewy bodies)
- Onset/Course: Age 50-70. Course is slow and often mistaken for other dementias (AD and PD), though faster course than AD. 5-7 years.

- Clinical Features: Hallmark features are:
  1. Fluctuating consciousness/cognitions—At times may be confused and disoriented
  2. Parkinsonism—Rigidity and decreased spontaneous movements
  3. Visual hallucinations—Usually well formed
- Other features include depressive symptoms and REM sleep behavioral disorder
- Neuroleptic medications (usually prescribed for hallucinations) can make motor deficits worse and can be fatal
  (Schoenberg & Duff, 2011)

Frontotemporal Dementia (FTD)

- FTD includes behavioral variant FTD (bvFTD) and primary progressive aphasia (PPA).
- Prevalence: 4th most common dementia (5-9% of cases).
- Risk factors: Family history, tau protein gene abnormality in 20-30%, and ubiquitin immunoreactive neuritis in over 50%.
- Onset/Course: Early-between 50-60. Gradual progression over 5-7 years
  (Schoenberg & Duff, 2011)
Frontotemporal Dementia (FTD)
- Clinical features: bvFTD
  - Personality changes including: apathy, withdrawal, loss of social awareness, decreased personal hygiene, affective flattening, and apathy.
  - Less common features include: social disinhibition, impulsivity, impersistence, and perseveration.
  - Right hemisphere pathology has flat affect, socially aloof, and aprosodic speech. Left hemisphere has greater language impairment.
  - As disease progresses personality changes progress involving emotional lability or marked apathy, agitation, and stereotyped behaviors.
  - Pick’s disease is a subtype of bvFTD with features including impulsivity, dysnomia, excessive eating, and compulsive sensory stimulus seeking.

Frontotemporal Dementia (FTD)
- Clinical features: PPA
  - Reductions in speech and/or comprehension with withdrawal and depression
  - Personality/behavior changes are usually not associated with PPA until later in the disease course
  - Anxiety may develop related to speech concerns.
- Subtypes include
  - Progressive nonfluent aphasia (PNFA): progressive decline in speech and writing. Non-fluent and increases to phonological and grammatical errors. Articulation is impaired. Comprehension and repetition is intact. Other domains remain intact for several years.
  - Semantic dementia (SD): loss of semantic knowledge which impairs confrontation naming and comprehension. Speech and episodic memory is intact.
  - Logopenic progressive aphasia: word finding problems and impaired repetition and comprehension of sentences; however, single word repetition and comprehension is intact. Semantic knowledge and memory is intact early in the disease.

Parkinson’s Disease with Dementia
- Prevalence: 2% of all dementia, though not all people with PD develop dementia (30%-70% do)
- Risk factors: increased risk for dementia is PD onset is after 60
- Onset/Course: Between 60-70. Slow progression with more rapid progression associated with later onset

(Schoenberg & Duff, 2011)
Parkinson's Disease with Dementia

- Clinical features:
  - Parkinsonism
  - Apathy, depression, anxiety
  - Sleep problems including RBD
  - Visual hallucinations (can be associated with medications)
  - "On-off" fluctuations

(Schoenberg & Duff, 2011)

Clinical Features of Dementia

<table>
<thead>
<tr>
<th>Dementia</th>
<th>First symptom</th>
<th>Cognitive pattern</th>
<th>Neurology examination</th>
<th>Neuroimaging</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>AD</td>
<td>Memory loss</td>
<td>Flattened, fluent</td>
<td>Normal at first</td>
<td>Tau deposition</td>
<td>Cholinesterase inhibitors, memantine</td>
</tr>
<tr>
<td>PD</td>
<td>Parkinsonism</td>
<td>Flattened, fluent</td>
<td>Normal at first</td>
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<td>Dementia with Lewy bodies (DLB)</td>
<td>Cognitive impairment, fluctuating cognition</td>
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<tr>
<td>MCI</td>
<td>Cognitive impairment, fluctuating cognition</td>
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Giving a diagnosis of dementia
Diagnosing dementia/MCI to the patient

- Feedback session allows discussion of the results of testing, including diagnostic impressions and recommended treatment planning
- It should be viewed as a form of treatment
- Considerations with feedback structure are:
  - Severity of dementia and patients comprehension
  - Support system
  - Impact of results on the patient

Why give feedback of dementia to the patient/family

- Provides clarification and explanation to their experiences
- Opens up a dialogue of communication
- Reduces anxiety
- Jump starts treatment planning and preparation
- Linking to resources and empowering them to become better advocates
- Debunk myths
- Foster the grieving process
- Important for other treatment providers to be aware of this diagnosis
- Explain rationale for various restrictions (e.g., driving)

Feedback should be intended to give permission to:

- Expose vulnerabilities
- Ask questions...even the tough ones
- Cry
- Grieve
- For family members to consider their own needs
- Hope

(Postal & Armstrong, 2013)
Effective feedback involves

- Simplicity
- Start with the bottom line
- Unexpectedness
- Unique metaphors improve retention of information
- Concreteness
- Discuss cognitive changes and necessary restrictions in terms of disease process
- Credibility
- Understand the power you hold as an expert
- Emotions
- Empathy is critical
- Stories
- Discuss past experiences with other patients
- Ubiquitous statements are valuable

(Postal & Armstrong, 2013)

Back to Neuropsychology

- Remember when.....
  - Draw the figure that you copied at the beginning of this presentation
  - No peeking at your original copy

Questions

References