

# DECISIONAL CAPACITY IN MCI AND DEMENTIA: HOW DO YOU DECIDE WHO DECIDES?

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### **SPEAKER DISCLOSURES**

✓ Any conflicts of interest?



#### **OBJECTIVES**

1. Review decisional capacity versus competency

2. Discuss changes in MCI and dementia that challenge decisions and risks

3. Review strategies to assess and resources for supporting patients with cognitive impairment and decision makers



#### WHY DO WE CARE?

Protecting autonomy and Planning

Loss avoidance—protection from abuse and exploitation

Outcomes—impaired decision making affects medical care

Teachers of patients and caregivers about impact of cognitive impairment



#### **CAPACITY VS. COMPETENCY**

#### CAPACITY:

 clinical determination about a specific decision that can be made by any clinician familiar with a patient's case

#### COMPETENCY:

- global assessment of decision making
- Legal decision determined by a judge
- Input from medical professionals about decision making capacity is considered



#### BE VIGILANT BUT DON'T ASSUME

- No diagnosis or medical condition automatically impairs decision making
- Those with impaired cognition can still make many important decisions
- Substitute decision makers should align with patient values wherever possible
- Those with dementia often feel spoken for or cut out of decisions completely



#### WHO HAS IMPAIRED CAPACITY?

- Healthy older adult populations--2.8%
- Hospitalized patients—26%
- Dementia due Alzheimer's disease—56% (all stages)
- Developmentally delayed –68%

Sessums LL, Zembrzuska H, Jackson JL. Does this patient have medical decision-making capacity? JAMA. 2011;306(4):420–427.



#### **CAPACITY CAN SEEM IMPAIRED DUE TO**

- Sensory deficits
- Language
- Communication barriers
- Cultural differences
- Delirium
- Fear of institutional setting
- Low education/health literacy
- Psychosis/depression/cognitive deficits
- Lack of appropriate education about options by medical personnel



#### RISK FACTORS FOR IMPAIRMENT

- Age <18
- Age >85
- Low education
- Significant language or cultural barriers
- Chronic neurologic or psychiatric conditions
- Voiced mistrust or fear of healthcare setting
- Current medical illness/hospitalization

Barstow C, Shahan B, Roberts M. Evaluating Medical Decision Making in Practice. American Family Physician. 2018; 98(1): 40-46



#### 4 ELEMENTS OF DECISIONAL CAPACITY

- Choice—STABLE
- Understanding relevant information including alternatives
- Rationale--for their decision or choice based on values and culture including making choices others may not agree with
- Insight---ability to express understanding of potential consequences and applying to oneself
- Fewer elements for lower risk decisions, maximum elements for high-risk decisions



## WHAT CHANGES IMPAIR DECISION MAKING IN COGNITIVE DISORDERS?

- Memory
- Language
- Executive functioning
- Inability to shift sets with changes to a situation
- Lack of insight/inability to monitor one's deficits metacognition
- Inability to initiate and maintain goal-directed behavior
- Behavioral changes—e.g. impulsivity with FTD or PD



#### WHY IS EVALUATION SO DIFFICULT?

- Desire to respect autonomy
- Presumed decisional capacity
- Not wanting to tell someone they need help with decisions
- No identified decision maker
- No accepted standardization of evaluation
- Bedside testing, neuroimaging, neuropsychiatric evaluation don't give whole picture



## IMPAIRED, WHO DECIDES?

- Order in Washington:
  - Guardian (if appointed)
  - DPOA (if executed and active)
  - Spouse or registered domestic partner
  - All adult children

Additional persons may be considered after this based on updated 2019 legislation:

https://www.wsha.org/articles/19127/



#### **ELEMENTS OF ASSESSMENT**

- Identify correctable impairments/conditions
- Structured interview and documented responses—quotes that illustrate help
- Montreal Cognitive Assessment (MOCA), MMSE, or SLUMS if able (education, cultural considerations)
- Decide if decision can wait to try to improve where possible (depression, delirium, un/undertreated psychosis, alternate education)
- Consider psychiatric consultation if question involves possible psychiatric or neurocognitive impairment



#### WHAT CAN I DO NOW?

- Identify cognitive impairment early when discussions can occur
- Don't assume capacity
- Find out who could help make decisions and if you can contact (collateral can be helpful)--before needed best
- Discuss advanced care planning early and review regularly
  - This can be billed within the Annual Medicare Wellness Exam now
  - (Billing-for-Advance-Care-Planning.pdf (uw.edu)



#### A FEW RESOURCES

- Examples of structured decisional capacity assessment tools:
- Aid to Capacity Evaluation (ACE)—assesses 4 areas of decisional capacity; for specific decisions
- The Hopkins Competency Assessment Test (HCAT) (http:// criminal-justice.iresearchnet.com/forensic-psychology/hopkins-competency-assessment-test-hcat)—to assess global decisional capacity
- UW Family Medicine site: Cognition in Primary Care
  - <a href="https://familymedicine.uw.edu/cpc/">https://familymedicine.uw.edu/cpc/</a>
- Advance Directive for Dementia
  - https://dementia-directive.org

