Program

DEMENTIA: A Comprehensive Update
May 27 – 30, 2020
Livestream

Saturday, May 30, 2020

8:30 - 8:40  Introduction to Symposium and Pre-Test……………………………………………………………Drs. Atri, Dickerson
8:40 - 9:15  Dementia & The Law: Clinical Pearls on Testamentary Capacity and Undue Influence……B. Price, MD
            J. Edersheim, MD, JD
9:15 – 10:15 Principles & Practice of Mental Capacity and Competence in Dementia: From Finances to
          Firearms……………………………………………………………………………………………………………………B. Fogel, MD
10:15 - 10:50 Driving, Home & Community Safety and Dementia…………………………………………………M. O’Connor, PhD, ABPP
10:50 - 11:05  Morning Coffee Break
11:05 - 11:55  Advanced Care Planning & Management of End-stage Dementia, Pain, Palliation & Hospice in Long-Term
              Care………………………………………………………………………………………………………………………M. Norman, MD
11:55 - 12:45pm Post-Test, Panel Discussion, Q & A, and conclusions…………………………………………………All Faculty
Dementia & The Law: Clinical Pearls on Testamentary Capacity and Undue Influence

Bruce H. Price, MD
Judith Edersheim, MD, JD
Testamentary Capacity: The Basics

1. Adults are presumed to have the capacity to undertake legal tasks.
2. The party challenging capacity has the burden of proving incapacity.
3. And the standards of such capacity are transaction specific.
4. For Testamentary Capacity: (see Banks v. Goodfellow 1870 )
   • At the time of will execution, the testator has the capacity to:
     • Know the meaning of a will
     • Know that a class of individuals are natural heirs (“natural objects of one’s bounty”)
     • Know the extent of one’s assets
     • Understand a general plan of distribution to heirs
5. The language varies state to state and cases interpreting standards are also state specific. (see also Model Probate Code)
Testamentary Capacity: The Basics

Caution:
1. Testamentary capacity is a relatively low bar and differentially applied state to state
2. Capacity need only be present during the execution (“Lucid Interval”)
3. General capacity can be negated by an “insane delusion”
4. Courts usually use a sliding scale – complex estates require more capacity than simple ones

Testamentary Capacity: A Cognitive Standard

Understanding a Will:
- Semantic Memory
- Verbal abstraction
- Verbal comprehension

Knowing the Extent of Property (approx value)
- Semantic Memory
- Long term historical memory
- Short Term memory

The objects of one’s bounty:
- Autobiographical Memory

An Asset Distribution Plan
- An integration of above cognitive abilities
- Executive functioning to understand prospective plan

(Marson, Huthwaite & Hebert 2004)
Testamentary Capacity: A Cognitive Standard

• Neurodegenerative Disorders
• Traumatic Brain Injury
• Severe Psychiatric Disorders
• Neurodevelopmental Disorders (Autism Spectrum Disorder)

Testamentary Capacity: A Living Testator

Contemporaneous Evaluation of Testamentary Capacity

1. Interview testator’s spouse, friends, family for information about daily functioning
2. Obtain legal confirmation about the extent of assets and the planned distribution
3. Perform a comprehensive mental status examination of the testator
4. Perform a clinical interview geared specifically to the evaluation of task specific abilities
5. Consider Financial Capacity Instruments (Marson, Lichtenberg)

(Marson, D.C., Herbert T, Testamentary Capacity, 2008)
Testamentary Capacity: Retrospective Evaluation

1. Know the relevant legal standard in the jurisdiction
2. Understand the legal context, mechanics and sequence of execution
3. Obtain Medical records, including of diverse specialties
4. Explore mental status close to the time of will execution
   1. Seek lay judgments about mental abilities (family, friends, caregivers, other professionals)
   2. Seek information about professional interactions (deposition)
   3. Obtain any formal neuropsychological or psychological testing
5. In the case of a dementia, meticulously chart and stage the diagnosis, stage, treatment interventions, responses. (CDR etc)

American Bar Association: Assessment of Older Adults with Diminished Capacity, Moye et al 2008

Undue Influence:

Restatement of Contracts

“Undue Influence is unfair persuasion of a party who is under the domination of the person exercising the persuasion or who by virtue of the relation between them is justified in assuming that that person will not act in a manner inconsistent with his welfare”

• Subversion of will is the central concept
• Typically based in notions of fraud or duress
• Undue influence can be present even with full cognitive capacity
• However impaired capacity increases the vulnerability to undue influence
Models of Undue Influence

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<tr>
<th>Singer/Nievod Factors:</th>
<th>Blum “IDEAL”</th>
<th>Bernatz: “SCAM”</th>
<th>Brandle/Heiser/Stiegel</th>
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<tr>
<td>1. Isolation</td>
<td>1. Isolation</td>
<td>1. Susceptibility</td>
<td>1. Isolate from others</td>
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<td>2. Dependency</td>
<td>2. Dependency</td>
<td>2. Confidential Relationship</td>
<td>2. Create Fear</td>
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<td>5. Sense of Fear</td>
<td>5. Loss</td>
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<td>5. Create lack of faith in own abilities</td>
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ABA Handbook 2008 Moye et al

Undue Influence: The Database

1. Usually in cases of wills and trusts, but can be applied to financial exploitation in general
2. A highly particularized evaluation with a large data base:
   - Personal, Occupational, Social History (IADL, caregiver accts etc.)
   - All medical records, neuropsychological testing, psychological testing, specialized instruments
   - Financial Data Base: Property, Transfers, Habits and Practices
   - Legal Data Base: Estate Planning Documents, Legal Context of Execution
   - Law Enforcement and Social Service/Agency Interventions
   - Collateral Interviews with spouse, family, staff, informants etc
   - Deposition testimony for unavailable informants
Undue Influence: Red Flags

1. A confidential relationship allowed the influencer to control the testator
2. The influencer was active in the procurement of an asset change
3. The influencer received a significant benefit under the procured change
4. The changes were “unnatural” and inconsistent with the testators prior wishes and values
5. The testator had underlying vulnerabilities (neurologic disease, substance use disorder, other psychiatric illness)

Shulman et al, Assessment of Testamentary Capacity and Vulnerability to Undue Influence, Am J Psychiatry 2007

Undue Influence: Vulnerabilities and Susceptibilities

• Medical Vulnerabilities
• Psychological Vulnerabilities
• Social Context Vulnerabilities
• Isolation and Control by the Influencer
• The Distortion of Information by the Influencer
Undue Influence: Medical and Psychological Vulnerabilities

**Medical**
- Cognitive Impairment
- Sensory Deficits (Vision, Hearing)
- Disability or Injury

**Psychological**
- Depression/Anxiety
- Concerns about declining memory/function
- Difficulty getting social needs met
- Emotional Distress (loss of spouse, disruption)
- Underlying Personality Vulnerability (Dependent, Avoidant)

Undue Influence: Social Context and Isolation

**Social Context Permits Isolation, Dependence, Manipulation:**
- Trusted others perform multiple roles for the victim
- The victim views the trusted person as irreplaceable and primary
- The trusted person isolates and controls the victim
  - Physical isolation
  - Controlling who visits
  - Controlling information (mail, phone, email)
  - Controlling access by family and friends
Undue Influence: Promoting False Beliefs

*The trusted person promotes false beliefs about others (family, friends, advisors)*

- Encourages suspiciousness or delusions which emerge in the context of memory deficits
- Encourages negative or hostile feelings towards previous beneficiaries or objects of generosity
- Distorts why trusted others are not visiting when they are prohibited from visiting or communicating.
Principles & Practice of Mental Capacity and Competence in Dementia: From Finances to Firearms

Barry S. Fogel, MD
Mental Capacity and Competence in Dementia - from Finances to Firearms

Barry S. Fogel, MD
Center for Brain/Mind Medicine
Brigham and Women’s Hospital
Harvard Medical School

Themes of This Presentation

- Organizing Principles
- Executive Function and Metacognition
- Why Assessors May Disagree
- Neuropsychological Testing versus Performance in a Natural Setting
- Specific Issues
  - Financial decisions
  - Healthcare proxies and advance directives
  - Research consent
  - Voting
  - Firearms
- Capacity (a medical judgment) and Competence (a legal judgment)
- Communicating the Findings of an Assessment
- Resources and Advice
Capacity, Competence, Consent

- Capacity is a context-specific medical judgment
- Competence is a legal judgment that should be specific to tasks and situations but sometimes is made in an inappropriately general way
- Valid informed consent is expected prior to medical interventions, but –
  - Consent is *presumed* to be valid in many clinical situations
  - Consent is *deemed implicit* in life threatening emergencies
  - Validity of consent is rarely questioned unless the capacity is blatantly diminished, risk is unusually high, there is conflict among interested parties, or consent is for research

Autonomy, Authenticity, Best Interests

- In America a historical ‘paternalistic’ emphasis on the patient’s best interests (as judged by the clinician) has been replaced by an emphasis on autonomy.
- Nonetheless, clinicians will exert themselves to oppose patients’ decisions that they view as against their best interests.
- Authenticity – consistency of a patient’s decisions with his or her personal values and history – should also be considered. Decisions that are neither ‘authentic’ nor in the patient’s best interests should trigger a thorough evaluation of the specific decision-making capacity relevant to the current circumstances.
- Related concepts
  - ‘Critical interests’ versus experiential interests and concurrent desires
  - Intrinsic versus instrumental value
  - ‘Precedent autonomy’
  - Undue influence
Guiding Emergency Care and Life-Sustaining Treatments

- In a true emergency, if there is no known advance directive to limit life-sustaining treatment, a treating physician should act to preserve life.

- When a patient wants to limit future emergency care and/or life-sustaining treatments, he/she should complete an advance directive specifying his/her wishes, and carry a wallet card (or wearable item like an alert bracelet) indicating that there is one and giving relevant details.

- If the directive is simple, the details should be printed on the card.

- If the directive is complex, the card should refer clinicians to it by giving the phone numbers of people with physical copies, by giving a web address and details for a secure download, and/or taping a USB memory stick to the card.

Considerations for Urgent Care

- In urgent but non-emergent situations consent is not implied. If there are legal issues they should be settled rapidly, drawing upon the hospital’s legal, ethical and/or risk management resources.

- When best practice is clear, capacity is diminished, and the patient assents, the trigger for formal capacity assessment is conflict -
  - Within the family
  - Within the staff
  - Between family and staff

- When best practice is not established, capacity is diminished, and the consequences of the medical decision are major, it’s worth the effort to pursue valid consent – either from the patient or a surrogate.
Understanding, Appreciation, Reasoning and Choice

Paul Appelbaum and colleagues have described four essential capacities needed for valid consent. Their model has wide acceptance and underlies the formal capacity assessments often used in research contexts.

The four capacities are:

- **Understanding** what’s proposed
- **Appreciating** of how it applies to one’s personal situation
- **Reasoning** about the situation to reach a decision
- **Expressing** a clear and consistent choice.

Specificity of Capacity; Role of Executive Function and Metacognition

- Capacity is task-specific and context-specific, and can fluctuate over time.
- Executive function and metacognition are essential to instrumental functioning, including rational decision making.
- Executive function and metacognition can decline at disparate rates from each other and from memory and language functions.
  - bvFTD and AD with early prominent right hemisphere involvement often cause a disproportionate loss of metacognition.
- Criteria for capacity/competency (i.e., validity of a patient’s decision) should be more stringent when the patient is making a ‘bad’ decision (i.e., one that most rational adults wouldn’t make, like refusing low-risk treatment for a life-threatening infection when one is otherwise healthy).
- Clinical observation and neuropsychological testing have complementary roles in assessment of decision-making capacity.
Address Legal Issues Early to Avoid Competency Litigation

- Competency-related issues should be addressed as early as possible in the course of a neurodegenerative disease, preferably when the diagnosis is MCI rather than dementia.
  - Patients with MCI usually have some diminution of decision-making capacity while retaining the capacity to express meaningful and valid preferences concerning where they would like to live, whom they would like as a surrogate decision-maker, what medical care they would like if acutely ill, and whom they would trust with their money.
  - Communication about competency-related issues should be clear, redundant, multimodal, and consistent among the professionals involved with the patient.
- Formal legal proceedings to establish incompetency usually are not necessary if the right plans are made early.
- Trusts, durable powers of attorney, healthcare proxies and other mechanisms offer more flexibility than court orders, determinations of incompetency, and guardianships.
- More formality is needed when more is at stake and there is more dissension among stakeholders.
- Patients often are competent to choose an appropriate healthcare proxy or surrogate decision-maker long after they are incompetent to make complex medical or financial decisions.

Executive Function and Metacognition

- Executive function is the most important cognitive factor determining performance of social and instrumental activities by patients with brain diseases.
  - “Memory loss” is the most frequent presenting complaint – but usually not the biggest problem for people with dementia.
- This cuts across diagnoses: Alzheimer’s disease, non-Alzheimer dementia, traumatic brain injury, schizophrenia.
- Patients with equal MMSE scores can show substantial differences in executive function, metacognition, and instrumental performance.
  - The MoCA, Clock Drawing Test and EXIT are more sensitive than the MMSE to declining executive function.
The Role of Executive Function

- Executive impairment, measured quantitatively by instruments such as the EXIT or neuropsychological tests (verbal and figural fluency, trail-making B, clock drawing, etc.), explains much of the variance in multivariate models of instrumental function.

- However, education, culture, and life experience influence performance of specific functions (e.g., managing money, driving, housework) in the earlier stages of dementia.

The Importance of Metacognition

- People aware of their cognitive or sensory impairments will ask others (e.g., family, friends, and paid caregivers) for advice and assistance.

- People unaware of their limitations won’t ask for help, often refuse to accept help when it is offered, and may persist in doing things that have become dangerous.

- People who know their driving abilities are impaired will curtail their driving. Normal old-old people reduce their driving miles per year.
  - Very low annual mileage – less than 3000 per year – is associated with a high risk of accidents.

- People who are aware they have diminished capacity for financial judgments (and/or mathematics) will ask for guidance, oversight by trusted family relatives or professionals, or protective arrangements with their bank. Or, they will accept such assistance and ‘guardrails’ if they are suggested and arranged by someone they trust.
Metacognition and Awareness of Deficits

- Awareness of specific deficits (or, inversely, denial of deficits) is related to the same brain systems as metacognition. Relevant deficits of which patients might not be aware include:
  - Impairments of specific cognitive functions
  - Sensory impairments
  - Somatic diseases and disabilities
  - Behavioral abnormalities
  - Impaired judgment
- Patients with bvFTD or with gross bilateral prefrontal damage from trauma, strokes or tumors typically minimize or completely deny their changes in behavior and judgment.
- In general, right hemisphere lesions cause greater impairment of deficit awareness than left hemisphere lesions.

Metacognition in Neurodegenerative Diseases

- 2014 study from UCSF: 79 patients with neurodegenerative diseases and 46 healthy older controls
- Self-awareness determined by comparing self- and informant ratings on the Patient Competency Rating Scale (Prigatano 1988)
  - Four domains: IADL, cognitive, emotional control, interpersonal functioning
- Brains imaged with structural MRI, patients statistically compared with controls
  - Confirmed importance intact frontal – subcortical circuits for normal metacognition.
  - Right hemisphere lesions had greater impact
UCSF Study: Impairments in Metacognition Varied by Disease

- bvFTD: Overestimated function in all four domains
- AD: Overestimated cognitive function and emotional control
- Right temporal FTD: Overestimated interpersonal functioning
- Non-fluent aphasia: Overestimated emotional control and interpersonal functioning
- Semantic variant aphasia: No overestimation of function or denial of impairment

Metacognition and Driving Safety

- A driving simulator study showed non-demented old people could improve their driving performance with training, if they acknowledged impairment at the outset.
- With adequate self-awareness, cognitively-impaired drivers can avoid situations such as poor lighting, heavy traffic, and fatigue that increase their risk of accidents.
- Of all types of dementia, bvFTD – a condition with disproportionately poor metacognition - has the strongest association with dangerous driving, and behavioral changes can make driving dangerous at a time when an MMSE might be normal, or only slightly below normal.
- People with MCI and intact metacognition may be more likely to accept driver assistance technologies that will enable them to drive safely for a longer time.
- Planning a transition to non-driver status ideally should begin while the patient is aware he/she has a progressive illness.
Metacognition and Safety at Home

- Home safety is sometimes neglected in situations of MCI and early dementia. Fractures, TBIs, and other serious injuries can accelerate the progression of cognitive and behavioral impairment. Addressing home safety is an important part of secondary prevention for patients with MCI and mild dementia.
- Hazards include open flames, sharp objects, toxic substances, slippery floors, poorly-lit areas. Guns kept unlocked and unloaded are common problem in some regions of the U.S.
- The patient’s living arrangements, how the home is configured, what household tasks he/she usually does, and urban/rural status are relevant to risk assessment.
- A home safety assessment by an OT can be arranged through a home health agency.
- Remote monitoring by relatives via webcams will play in increasing role.

Cognition and Metacognition Are Partially Independent

- AD - Patients with relatively more right hemisphere and frontal involvement are more likely to be unaware of their cognitive deficits (or deny their significance)
- FTD varies by type
  - bvFTD: globally impaired metacognition
  - Semantic dementia: relatively preserved metacognition
  - R temporal predominant: overestimation of interpersonal behavioral competence
- Vascular dementia –
  - Metacognition is most impaired with multifocal cortical disease involving frontal or right parietal lobes
  - Deep subcortical small vessel disease is less likely to cause disproportionate impairment of metacognition
Drugs and Metacognition

- Some drugs - e.g., benzodiazepines and opioids – cause cognitive impairment that *usually is accompanied by denial of impairment*.
- Other drugs - e.g., anticholinergics and centrally-acting antihistamines – cause impairment that the patient usually will acknowledge.
- People do not necessarily complain of drug-related cognitive impairment or modify their behavior to adjust for it – even when they might passively acknowledge there is a problem.

Initial Clinical Assessment of Metacognition

- Before and after concluding clinical or laboratory testing of cognition, hearing, or vision, ask the patient whether he/she is having trouble in that area, or what he/she thinks the tests will show.
- Explain test results, then ask again.
- Ask the family if the patient’s behavior reflects awareness of limitations.
- If the patient initially doesn’t acknowledge limitations or make appropriate behavioral adjustments, a written report and educational materials (handouts, website references, etc.) might make a difference, especially if their messages are reinforced by trusted relatives.
Comparison of Self-Rated, Family-Rated, and Clinician-Rated Assessments of Competencies

- Comparison of a patient’s quantitative self-rating of competencies with those of observers (family and clinicians) yields a measure of metacognitive deficit and at the same time contributes to the patient’s functional evaluation.
- The Patient Competency Rating Scale (PCRS; Prigatano, 1986) is a useful public-domain option for quantitative rating. It comprises 30 items rated on a five-point scale from "can’t do" to "can do with ease".
- Sample items:
  - How much problem do I have preparing my own meals?
  - How much problem do I have in taking care of my finances?
  - How much of a problem do I have in remembering important things I must do?
  - How much of a problem do I have in handling arguments with people I don’t know well?
  - How much of a problem do I have in controlling my temper when something upsets me?

The Metacognition Questionnaire (MQ): Focus on Change in IADLs

- The Metacognition Questionnaire (Buckley et al., 2009, *Int. J. Geriatric Psych.*) is briefer than the PCRS and focuses more on IADLs and their cognitive basis, and on changes over time.
- Ask patients and caregivers to rate change over the past three years in patients’ memory and IADLs:
  - Remembering recent events, appointments, or where they put objects
  - Remembering the names and faces of friends and relatives
  - Keeping their train of thought or finding the right words
  - Finding their way around familiar places
  - Operating gadgets, appliances, or machinery
  - Keeping up with household chores, hobbies, and interests
  - Their memory performance in general
- The MQ is especially suited for assessing patients’ awareness of progression of their neurocognitive disorders.
- The PCRS has a special role in assessing metacognition in FTD, pseudobulbar affect, and other conditions with a more ‘psychiatric' flavor.
Increasing Levels of Metacognitive Deficit – (1)

- Acknowledges impairment and appreciates its implications but doesn’t act consistently with that awareness and appreciation
- Acknowledges impairment but doesn’t appreciate its implications
- Acknowledges impairment upon failing a test, before the results are explained, and appreciates its implications
- Acknowledges impairment upon failing a test, but does not appreciate implications

Increasing Levels of Metacognitive Deficit – (2)

- Acknowledges impairment upon failing a test, but only after results are explained
- Acknowledges impairment when results of a test are explained, but offers a lame excuse for a poor performance
- Acknowledges impairment only after repeated explanations
- Acknowledges impairment only after vigorous confrontation
- Denies impairment despite all efforts
Denial of Cognitive Deficit is Associated with Impaired Medical Decision-Making

- Gambina et al. (2014) formally evaluated both anosognosia and capacity to consent to research in a population with mild to moderate AD dementia.
- All patients who denied their cognitive deficits lacked capacity to give valid consent to research.
- Some (but not all) of the patients who acknowledged their cognitive deficits were judged capable of giving valid consent.

Testing of Metacognition by Neuropsychologists and Occupational Therapists

- Neuropsychology and occupational therapy are two disciplines regularly involved in testing metacognition. Not all neuropsychologists and OTs routinely report on metacognition, but all will do so if asked.
- Comprehensive neuropsychological testing should include assessment of metacognition. The assessment can be qualitative or quantitative, the latter being useful if metacognition will be a target of treatment or focus of follow-up.
- An OT assessment of IADLs can include comment on how the patient predicted he/she would do and how the patient judged his/her performance after attempting various tasks.
Why Assessors Might Disagree About Cognitive Capacity

- Different performance criteria or thresholds for determining competence or functional independence
- Different emphasis on the various dimensions of cognitive performance – e.g. memory versus executive function
- Differences in testing methods
- Context-dependency of performance, especially when executive function is impaired
- Fluctuations in performance, especially those related to medical illness or mood

Neuropsychological Testing vs. Observed Performance

Neuropsychological Tests
- Comprehensive
- Quantitative
- Normed
- Standardized context
- May disclose unexpected severity of impairment
- Can be used to measure change over time

Observed Performances
- Face valid
- Results can be more persuasive to family, judges, or other interested parties
- Degree of benefit from contextual cues is observable
- Cue-dependency can have important clinical and practical implications
MacArthur Competence Assessment Tool (MacCAT): A Specialized Test for Capacity to Consent to Research

- Focuses on capacity to make a decision about medical treatment or participation in clinical research
- A vignette is presented to the patient that is tailored to the specific clinical decision.
- The clinician makes ordinal ratings of the patient’s understanding, appreciation of risks and benefits, reasoning, and ability to express a decision.
- Satisfactory psychometric properties
- No fixed cutoff for the judgment of competence
- Useful in the clinical trials context because of its standardization.
- Gives legal and ethical comfort to the investigator.
- Limited value in clinical practice because of its lack of flexibility.

Specific Issues: Financial Capacity

- Financial capacity has been defined as “the capacity to manage money and financial assets in ways which meet a person’s needs and which are consistent with his/her values and self interest” (definition proposed by Daniel Marson, a lawyer/neuropsychologist who has published extensively on the issue).
- Financial capacity is a core element of individual autonomy.
- Loss of financial capacity frequently is the first functional change noticed as cognitive impairment develops.
- Financial capacity has two broad dimensions, which can be dissociated
  - Performance – cash transactions, paying bills, filing tax returns
  - Judgment – involving both decision-making and inhibition
- Patients with dementia are at risk both for financial victimization and for self-inflicted financial injuries.
- Stakes are higher when there is a lot of money .. and when there is not enough money.
Deconstructing Financial Capacity
(Gardiner et al. 2015)

- Basic monetary skills (e.g., naming coins, counting currency)
- Financial conceptual knowledge (e.g., what is interest?)
- Cash transactions (e.g., purchase of single or multiple items)
- Checkbook management
- Understanding bank and credit card statements
- Financial judgment (e.g., recognizing fraud risks)
- Bill payment
- Knowledge of one’s assets and estate plan
- Investment decision making
- Class, culture, gender, education all are relevant to setting expectations and to understanding patients’ baseline and setting appropriate expectations.

Specialized Tests: Financial Capacity Instrument (FCI-9)

- Developed by Daniel Marson PhD, JD – a neuropsychologist and lawyer. No royalty is required to use the test.
- 18 items in 9 domains assess patients’ capacity to make financial decisions.
- The test has broad scope, from making change to reading a bank statement to comparing investment options.
- Performance and judgment both are relevant to scores
- Scores are influenced by baseline financial knowledge, and thus by education and culture.
Financial Capacity Taps Many Cognitive Functions

- Conceptual knowledge
- Procedural learning and memory
- Episodic memory
- Visual memory
- Visual attention
- Calculation
- Executive functions
  - Organization and planning
  - Inhibition of impulses/resistance to inappropriate cues.
- Recognizing inconsistencies and situations ‘too good to be true’ (necessary to avoid victimization by scams and fraud)

Five Roles for the Clinician in Addressing Financial Incapacity

- Education of patients and families
  - Focus on advance planning, especially durable powers of attorney and revocable trusts
- Detection of financial impairment
- Assessment of financial impairment
- Supporting financial independence
- Referrals
  - Neuropsychiatric or neuropsychological
  - Legal
  - Financial services
Warning Signs of Financial Incapacity

- Financial mistakes related to memory issues – e.g., paying bills twice
- Disorganization – e.g., losing documents at home
- Confusion about basic financial terms – e.g., mortgage, interest, will
- Impaired everyday math
- Bad judgment: impulsive purchases, foolish investments, falling for obvious scams
- Examination of financial records such as bank and credit card statements, brokerage account records and notices of overdue bills can provide documentary evidence of impairment – and can help establish a rate of decline

Helping to Preserve Financial Independence with ‘Guardrails’

- Durable powers of attorney and trusts with backup trustees, are much more flexible and far less humiliating than guardianship.
- Arrangements with the bank
  - Joint checking accounts with two signatures required for large purchases
  - Direct deposit of checks
  - Overdraft protection
  - Third-party notification of unusual activity
  - Online access to accounts by a trusted person
- Manual or automated monitoring of credit card transactions
- Automatic payment of recurring bills such as rent and utilities.
Even Guardianship Need Not Be “All or None”

- In many states a guardianship can provide that certain rights are retained by the individual with diminished capacity.
- Examples:
  - Access to pocket money
  - Rights to give gifts or donations (up to a specified limit)
  - Right to modify a will, subject to specified limitations
- The court attempts to balance the patient's best interests, autonomy, and authenticity (consistency with long-term values and relationships).
- Always aim to avoid needless humiliation.

Customizing Management of Decreased Financial Competence: Key Considerations

- Stage of dementia and expected rate and pattern of cognitive loss
- Expected needs for care and their cost
- Whether there is someone trusted (and trustworthy) to make financial decisions on the patient’s behalf
- Assets and income available for the patient’s future care
- Whether the patient is responsible for financial decisions that affect others’ welfare
When There Are Significant Assets

- “Smoke out” issues of trust and trustworthiness.
- Be vigilant with respect to potential financial exploitation – it sometimes is subtle.
- Involve a “neuro-aware” family therapist or social worker when denial is prominent in the patient or the family.
- The estates-and-trusts lawyer must understand the specific issues of neurodegenerative diseases rather than have a crude conception of ‘normal vs. demented’ or ‘mentally ill’ or ‘mentally healthy’.
- If the patient and family are attached to a family lawyer that lacks such understanding, the physician or neuropsychologist might offer to coach the lawyer on the subtleties of the case.

Elements of Testamentary Capacity

- Knowing what a will is
- Knowing what one’s assets are
- Knowing the people who have a reasonable claim to be beneficiaries
- Understanding the impact of a particular distribution of the assets
- Not having delusions that would affect the decisions made
- Ability to express intentions and preferences clearly and consistently
The Two Main Threats to the Validity of Wills

- Lack of testamentary capacity
- Undue influence
  - Someone manipulates, intimidates, seduces or otherwise induces a person to do something inconsistent with their best interests and/or authentic wishes.
  - The influencer can be a family member, friend, neighbor, caregiver, household employee or service provider.
  - Environmental dependence and cue-responsiveness of behavior in many people with dementia makes them especially vulnerable to undue influence.
  - In many jurisdictions there is a presumption of testamentary capacity. Establishing undue influence often turns out to be an easier way to invalidate the will of a person with dementia.

Signs of Testamentary Incapacity

- Radical change from previous will(s) or previously stated intentions
- Disinheriting of “natural” heirs
- Decisions made in context of probable delusions, misperceptions, misunderstandings, etc.
- Choices that disregard one’s personal history and reflect only one’s present circumstances
- Special situations
  - No biological children
  - Suspicion of undue influence
Reasons to Suspect Undue Influence

- Physical dependency with caregiver as new beneficiary
- A new or increased bequest to a person with a history of perpetrating abuse
- Apparent sexual bargaining
- Change in will instigated by a beneficiary
- Changes made shortly before death
- Classic example: Deathbed marriage of a centenarian multimillionaire to his young woman caregiver, who then was automatically entitled by marriage to one-third of his estate.
  - In this case the court found the man competent to marry, but determined there was undue influence.

Undue Influence in Patients with Borderline Testamentary Capacity

- Some expressions of dementia make patients highly susceptible to immediate circumstances and cues, and transient emotions, even though they can articulate plausible reasons for their mercurial decisions.
- Such patients are easy targets for self-interested relatives, caregivers, or (occasionally) fundraisers for worthy causes.
- Contemporaneous evidence of unstable decisions or of marked environmental dependency in areas other than the will can help establish that a will is invalid in a borderline case.
- Patients’ executive deficits facilitate other’s self-interested motives.
- A knowledgeable physician can have a helpful ‘undo influence’ in this situations.
False Positive Assessments of Testamentary Incapacity: Pitfalls

- Focusing on diagnosis rather than functional capacity
- Inferring that a patient lacks capacity because he/she does poorly on specific cognitive tests
  - The tests done may not be relevant to the patient’s choices.
  - The tests and the will might be done under different circumstances, at different times.
- Inferring that psychosis implies testamentary incapacity
  - Delusions and hallucinations might concern unrelated matters

Philosophy Gets Real: Autonomy, Authenticity, or Best Interest?

- What is the right basis for making a decision on behalf of an incompetent person?
  - What the person would have wanted under the circumstances when he/she was still competent (‘precedent autonomy’)?
  - What would be most consistent with the person’s lifetime attitudes and beliefs (‘authenticity’ or ‘critical interests’)?
  - What a caring and competent proxy thinks would be in the person’s best interest?
- Local law may dictate that clinicians follow the first option, but if not, the second and third options deserve consideration.
- People’s wishes should be respected when it’s feasible to do so. If it’s not reasonable to respect their current wishes, respecting their previously expressed wishes sounds good. However, what people think they’d want in the future often changes over the course of an illness, and can be influenced by comorbid mood states.
Guns and Dementia: Sobering Statistics

- Older people are more likely to own guns than younger ones.
- As of 2004, 27% of Americans over 65 owned firearms.
- 80% of homicides committed by people over 65 are by firearm - most common homicide scenario is a man killing his wife while depressed and/or cognitively impaired.
- Men over 85 have the highest suicide rate in the U.S. – 43.6 per 100K per year; and >50% of them use firearms. In the population of veterans with dementia, 72% of suicides used guns. Male suicide rates are lower when firearms are less available.
- Neuropsychiatric complications of dementia can make people suicidal or homicidal:
  - Depression
  - Paranoid delusions

Gun Ownership is Prevalent Among Cognitively-Impaired Americans

- 21-State VA study: 40% of veterans with mild to moderate dementia lived in homes where there was a firearm.
  - 21% of those with firearms kept them loaded
  - 61% stored their firearms in an unlocked location
- Study in a university memory clinic
  - 60% of demented patients had a firearm in their home
  - 45% of the firearms were kept loaded
- Gun ownership is more common among men, in the southern and western US, and in rural areas.
America the Exceptional

- In Japan gun owners must be licensed, and licenses must be renewed every three years. Civilians may not legally own handguns. The firearm casualty incidence is 0.06 per 100K. The US rate of firearm casualties is 10 per 100K.
- In Australia physicians are expected to inform police if they believe a gun-owning patient may pose a risk, and they are held harmless for the breach of confidentiality.
- In the US there is no national legal requirement for individuals to be licensed to own a gun. Some states require gun owners to be licensed.
- Some states protect gun rights with admirable vigor
  - Iowa – Blind people may legally purchase handguns.
  - Texas – Patients may carry concealed firearms in hospitals.
  - Florida – Physicians may be fined for recording information about firearms in a patient’s medical record if it is “not relevant to the patient’s medical care, or safety, or the safety of others”.

Male Firearm Suicides by Age, 2017

<table>
<thead>
<tr>
<th>location</th>
<th>age range</th>
<th>Rate per 100,000</th>
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<tbody>
<tr>
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<td>65 to 69</td>
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Physician Attitudes on Concealed Carry Permits (Goldstein et al. 2015)

- In North Carolina physicians are sometimes asked to certify that a person applying for a concealed weapon permit is competent to receive one.
- 222 physicians in NC responded to a mail survey (out of 600 sent) on how they relate diagnoses to competency for concealed carry.
- Men and gun owners were more inclined to approve permits across all diagnostic categories.
- Highest rejection rates were for mild dementia (68%) and Parkinson’s disease (42%).
- Remarkably, 10% of respondents would regard a patient with mild dementia as eligible for concealed carry.

Capacity to Safely Own a Firearm

- Understanding the dangerousness of firearms and the risks of firearm ownership
- Knowing how to safely store and handle firearms
- Demonstrated capacity to store, lock, load and unload a firearm – including securing firearms when young children are around
- Adequate physical and sensory ability to handle and use a firearm safely
- Ability to distinguish appropriate from inappropriate use of a gun, and to inhibit impulsive gun use
- No intent to threaten or to harm others
- No suicidal intent
Like Other Capacities, Firearm-Related Capacities are Contextual and Variable .. and Progressively Lost as Dementia Progresses

- Capacity to safely own a firearm can be lost early in neurodegenerative disease (e.g., from bvFTD) or relatively late, as in some patients with CDR 1.0 Alzheimer dementia whose appropriate gun-related behavior reflects crystallized intelligence of diamond-like hardness.
- This capacity can fluctuate with physical or mental health, alcohol or drug use, or medications.
- Many patients with MCI may lack capacity for safe firearm ownership while a few with AD and CDR 1.0 may retain that capacity.
- Beyond CDR 1.0, no dementia patient can safely own a firearm. This parallels consensus that no one with more than mild dementia can be a safe driver.

Giving Up Guns Can Be Like Giving Up Driving

- For many patients gun ownership, like driving, is a critical element of their autonomy and self-respect, and for a few it is actually relevant to their safety and security.
- Giving up guns may be easier for a patient if:
  - A non-‘mental’ reason such as declining vision or a tremor is applicable.
  - Foregoing guns is framed in terms of anticipation and prevention of potential future harm.
  - It is required because a home health caregiver won’t work in a home with firearms (and NIOSH recommends they don’t!).
  - It is related to protecting others – e.g., visiting grandchildren.
  - Any realistic concerns related to home security or pest control are addressed by some other means.
- Disabling a gun or locking up ammunition may be necessary in some cases, and may be better tolerated by the patient than confiscating the gun.
Firearm Screening is High-Yield

- Incorporate gun-related questions into your standard new patient intake package
  - Is there a firearm in the home?
  - Is it kept loaded? Locked?
- Query family (if the patient consents) – including telephoning family members not present at the visit.
- Utilize the usual face-saving maneuvers
  - Talk about potential future risks, e.g., those related to gun access during a transient delirium.
  - Mention risk to others, e.g., grandchildren, if guns are carelessly left loaded and not secure.
  - Consider taking a gun safety course yourself if you’ve never had a gun. It may help you talk comfortably and knowledgeable about the topic if you are not a current or past gun owner.

The 5 L’s for Geriatric Gun Safety

- Locked? (Either the gun should be locked up or the trigger should be locked – preferably both)
- Loaded? (Best to keep guns unloaded and ammunition stored in a separate locked location)
- Little children? (If children are living in the same home or visiting frequently, they are at risk from an unsecured gun).
- Low (mood)? (Consider temporary “gun control” while a patient is depressed even if he/she otherwise has the capacity to safely own a gun.)
- Learned? (Is the owner knowledgeable about gun safety? Does he/she practice gun safety? When did he or she last take a gun safety course?)
When the Right to Bear Arms May Be Abridged by Plaques and Tangles

- Deal with guns as with other safety issues such as driving and living arrangements.
- Engage concerned family members to lock up, disable, or dispose of guns.
- If risk is imminent, hospitalize the patient (involuntarily if necessary) and have family or police remove the weapons from the home while the patient is in the hospital.
- When dealing with patients who stereotype you as a doctor with a gun control agenda not specifically relevant to them, try to enlist the help of a medical colleague who’s a firearm enthusiast concerned about gun safety but not an advocate of gun control.

Competency to Vote

- Relevancy of competency to vote in older voters with mild to moderate dementia has become more politically-relevant recently.
- Voting competency was studied formally by Appelbaum and colleagues:
  - Understanding of voting and ability to express a choice are preserved in the majority of patients
  - Political reasoning and appreciation of personal effects of election results are lost as dementia progresses
- Voting is similar to appointing a healthcare proxy.
  - A person might identify as a lifelong Democrat or Republican even if he/she cannot discuss any political issues.
  - He/she might be a fan of a particular politician or be preoccupied with a single policy issue. Why should the presence of a brain disease matter if similar considerations determine the decisions of cognitively-intact voters?
**Disenfranchisement of Nursing Home Residents**

- Most patients with mild dementia remain competent to vote.
- Political decisions affect healthcare and income security in old age, issues personally important to most people with dementia. Why shouldn’t they have a say about them?
- Yet, less than 5% of nursing home residents vote, and obviously more than 5% of residents can competently express a political preference.
- Getting to the polls (or getting an absentee ballot) and accurately expressing a preference (especially with long ballots and voting machines) may require the assistance of a caregiver.
- There are many opportunities for undue influence. For example, one could imagine an unscrupulous nursing home operator arranging for dozens of demented residents to cast absentee ballots for a politician opposed to regulation of nursing homes.
- Advance directives dealing with voting should be considered for people with MCI for whom political participation in especially meaningful.

**Dementia and Consent to Sexual Relations**

- Sexual relations are a relevant concern for people with dementia
  - Some desire them appropriately. Sexual activity can be a central aspect of a person’s meaning of life, and this might not change with aging and chronic disease.
  - Some desire them excessively, at the wrong time, or with inappropriate partners
  - Some don’t want them and/or vulnerable to injury or pain from sexual activity because of conditions like osteoporosis and atrophic vaginitis
- Sexual relations between dementia patients and professional caregivers (e.g. nursing home or home health staff) constitute abuse and/or exploitation, because the patient cannot validly consent to them.
Relations with Spouses and Life Partners are More Complicated

- If a couple has had a consistent sexual relationship throughout the early stage of the patient’s dementing illness it may be appropriate for them to continue it even after the patient cannot give affirmative consent.
- However, verbal or non-verbal refusal must be honored.
- Advance directives for conjugal intimacy may be in the offing.

Legal Competence

- Competence for what?
  - Deciding on medical procedures (clinical or research)
  - Making or revising a will; establishing, revoking or revising a trust
  - Advance medical directives
  - Making financial decisions
  - Involvement in litigation
  - Consenting to sexual relations
  - Driving a car
  - Carrying a concealed handgun
- The *de facto* standard is higher for ‘unreasonable’ decisions.
- Interviews with lay people show that they understand that competence is task-specific and that a person with dementia may be competent to make a healthcare decision but not a financial one, for example.
Multiple Standards with Different Executive Requirements

- Ability to understand the question and express a preference
- Ability to reason about the question
- Ability to express rational reasons
- Ability to appreciate context and personal significance
- Able to envision likely and potential consequences of a choice, risks and benefits
- Ability to conform behavior to expressed intentions

Why Assessors May Disagree About Competency

- In practice, assessors of capacity/competence often disagree.
- Assessors disagree least often about patients’ capacity to understand the issue at hand.
- They disagree most often about patients’ appreciation of context and quality of reasoning. Some assessors put major weight on declarative memory, while others don’t.
- Overall judgments disagree for any of these:
  - Disagreement about which dimensions of capacity are important.
  - Disagreement about the measurement of individual dimensions of capacity
  - Disagreement about thresholds or cutoffs for impairment.
The Bugbear: Disproportionate Executive Impairment

- Disproportionate executive impairment can be found in FTD, Lewy body dementia, dementia of Parkinson’s disease, dementia associated with late life psychosis, chronic delirium -- and many other conditions.
- Patients with these disorders can give rational reasons but make irrational decisions because of unawareness of inconsistency, and lack of appreciation of context.
- The problem is especially severe when insight (metacognition) is lost.
- Families, lawyers, and courts may to be educated on the concept of selective cognitive impairment, and executive dysfunction in particular.

The Problem of Fluctuation

- Fluctuating deficits are the rule in dementia
  - Intercurrent illness
  - Drugs
  - Stressful situations
  - Depression, anxiety, hypomania
- They can produce intermittent incompetence including state-dependent treatment refusal
- Consider “Ulysses contracts” for cognitively unstable patients scheduled for high-risk surgery.
- Fluctuation due to time of day and medical status interacts with environmental dependency of mood and cognition.
Preventing “Legal Emergencies”

- Gray zones of incapacity can be anticipated based on some patients’ diagnoses, baseline status, and clinical course.
- Problems will always be worse in a crisis situation.
- Therefore, durable powers of attorney, revocable trusts, etc. should be done as early as possible in the course of the illness, when the patient still has insight.
- Advance consultation with a hospital’s risk management, counsel or ethics service makes sense if a competency-related problem is anticipated in an inpatient setting. For outpatients, ‘neuro-aware’ estates-and-trusts lawyers can be a valuable resource.
- Some patients worry that a durable power of attorney or other proxy will be triggered inappropriately and deprive them of control over their lives. Considerations here include:
  - Requiring concurrence of two physicians, one a specialist in neurology or psychiatry, to establish incapacity in a non-emergency situation
  - Requiring reassessment of capacity after a fixed period, e.g., 30 days.
  - Options like these are inconvenient and expensive, but for some patients they are the only way to get them comfortable with any kind of advance planning for incapacity.

Communicating the Findings of a Capacity Assessment

- Identify the interested parties and the key issues -- disability, competence, financial risks, needs for support and assistance, driving safety.
- Get the patient’s permission early on to share information as broadly as might be needed for effective problem solving.
- Getting the patient’s consent for release of medical information can become another complication if it is not dealt with early.
- Estimate the knowledge of the audience and set the stage if necessary -- with an explanation of executive function, need for supervisions, the expected course of illness, etc.
### Aids to Communication

- Create a “roadmap” for the patient’s expected course, anticipating what practical issues might arise at different points along the patient’s course.
- Prepare a written summary of findings and implications.
- Deal early with issues of trust.
- Refer patients and families to specialized resources.
- Continually grow and refine your toolbox for patient and family education. Practices seeing many patients with dementia should accumulate a library of resources – including websites and podcasts – that can educate patients and families about the subtleties of the legal issues of dementia using media and content they find comprehensible and credible.

### Optimally Managing Declining Capacities in Dementia Might Require:

- A family therapist interested in caregiving and legacy issues
- A lawyer with an estates and trusts specialty
- A lawyer with a family law specialty
- An eldercare specialist social worker with broad knowledge of both conventional and unconventional community resources
- A therapist with special skill in managing caregiver stress
- A neuropsychologist experienced in competency-related testing and in explaining results to lawyers and judges
- A driving evaluation specialist, preferably one with access to driving simulation and/or telematics
- An occupational therapist who makes home safety assessments
- A financial advisor
- A medical ethicist
- An expert in technologies for household security and remote monitoring
Dialogue Between Physicians and Lawyers

- Physicians – the evaluators of capacity -- and lawyers – advocates for a determination of competency or incompetency – come from different traditions and perspectives.
- They can learn from one another through joint engagement with challenging cases.
- The physician will learn what the lawyer needs to know, and the lawyer will gain a more subtle understanding of the diverse ways capacity can be impaired.

Village-Building Advice

- Practitioners of various disciplines will more helpful if they understand how executive impairment, loss of self-awareness and metacognition, fluctuation, context-dependency, and depression and/or psychosis can affect patients' decisional capacity.
- Consultants, lawyers, therapists, etc., are most helpful if they're available when you need them.
- You can play a role as an educator to build the knowledge and skills of your human resources: Discuss your challenging cases with them.
- Introduce your resources to one another, and they'll introduce useful colleagues to you.
- Sharing challenging cases builds trust, and helps you understand your resources, strengths and limitations.
- Referring rewarding patients to consultants makes them more open to accepting difficult cases in the future. Accepting difficult patients for consultation leads to future referrals of rewarding cases.
A Vision for the Future: The “Aging and Brain Health Executive Checkup”

- You might share a vision of a prospective approach to potential incapacity with patients in their 80s or 90s who:
  - Are intelligent and well-educated
  - Have substantial means
  - Are highly engaged in their own health care
  - Acknowledge that they are aging and that they have “entered the high maintenance phase of life”
  - Are open-minded
  - Trust you
- “Let’s make the future happier, healthier and safer by doing a comprehensive inventory now ...”

What’s In the Package - 1

- Formal testing of hearing, vision, and olfaction
- Screening neuropsychological examination.
  - Specialized testing of financial capacity if the history and/or findings on screening suggest it is warranted.
- Testing of gait, balance, reaction time, and useful field of view – with a driving simulator test if applicable
- Review of all medications and supplements
- Nutritional assessment
- Assessment of alcohol and drug use
- Check that all health maintenance items are up to date – immunizations, bone density, cancer screening, etc.
- Long-term activity and sleep monitoring with a wearable device – follow up on evidence suggesting sleep disorder or insufficient activity
- Inquiry about firearm ownership and, if applicable, firearm safety issues
### What’s in the Package - 2

- **Home visit and full home safety assessment.**
  - Does maintenance of the home and keeping it safe need more attention and executive function than the patient can devote to it?

- **Comprehensive legal status review**
  - Will, trusts, etc.
  - Durable power of attorney
  - Advance medical directives/ healthcare proxy designation
  - Provisions for adult dependents if any

- **Financial status review**
  - Everyday financial arrangements
  - Investments, income and expenses, etc.
  - Life insurance, mortgages

- **Family assessment**
  - Who’s responsible for whom and for what?
  - Where are there issues of trust? Capacity? Goodwill? Conflict?

### Justifying the Investment

- The sometimes expensive and sometimes emotionally difficult process of comprehensive practical, legal and financial planning for the course of dementia is most bearable if framed as a way to preserve a meaningful life for as long as possible.

- It sometimes helps to show a patient and family the ‘big picture’ – and it is more helpful if you can have the conversation soon after the diagnosis of a neurodegenerative disease. Advise them to:
  - Take care of unfinished business while they can.
  - Prevent additional illnesses and injuries where possible.
  - Acknowledge losses that come with age and age-associated diseases. Accept help when they need it. Not waste energy proving they can still do this or that.
  - Recognize that physical energy, attention span, and executive function are limited, diminishing resources. Use them for the things that matter most.
  - Identify their “critical interests” and plan ahead with those interests in mind.
Driving, Home & Community Safety and Dementia

Margaret O’Connor, PhD, ABPP
Driving, Home & Community Safety and Dementia

Margaret O’Connor PhD/ABPP
Brigham and Women’s Hospital
Harvard Medical School

Issues to consider in the assessment of safety

Need to balance autonomy and safety
Consider values, interests, sources of joy
Complex tasks cannot be deconstructed (e.g., practice of medicine)
Are office based assessments valid?
Does competence vary over time?
Available sources of support at home/work
Basic Safety Concerns

- Self care (hygiene, eating, etc)
- Home health (clean refrigerator, temperature regulation, etc)
- Safety (guns, alcohol, poisonous supplies, safety proofed stove, access to medications, electrical outlets, etc)

Complex Tasks

- Medication management
- Financial management
- Decision making (living situation, health care)
- Social skills
- Driving
- Home management (bills, repairs, shopping)
- Work
Neuropsychology Point of View

• Tasks vary in level of complexity
• Some are procedural
• People vary in terms of preserved skills and personality functions
• Insight is critical!
• Need to operationalize task components
• Competence should be assessed with tests that are as close to the designated task as possible – but don’t neglect the gestalt.

Medications

Ability to identify medications
Coordination w MD and Pharmacy
Organization of pillbox
Memory for taking pills
Knowledge of side effects
Shopping

Travel to the store
Navigation within the store
Memory for list of items
Identification of items
Ability to appraise cost
Capacity for transactions

Finances

Simple transactions: math skills
Balance a checkbook/use credit card
Understand/oversee financial statements
Understand personal portfolio
Capacity for planning (POA, etc)
Vulnerability to undue influence
Decision Making
Comprehension of issue being addressed
Identification of critical factor
Retention of information
Capacity for analytic thinking/integratin
Emotional ability to evaluate and appreciate consequences

Driving
• Right or privilege?
• Central (for many) to self esteem
• Critical for independence, safety
• Provides a sense of freedom
• Well defined entry but no system to exit
Requisite skills for safe driving

• Driving is a complex skill that requires efficient and integrated processing speed, visual scanning, sustained attention, set shifting, mental flexibility, social awareness/theory of mind, motor control, and adequate visual acuity and contrast sensitivity.

• When these abilities are compromised, the risk of a motor vehicle accident increases.

When to stop, who should decide

• Survey of 300 physicians, law enforcement officers, and community members (50+)

• Physicians: neither time nor expertise to evaluate driving

• Each group looks to the other to make the decision about driving

• Nobody wants to be “the bad guy”
Family Comments

• Help parent give up driving? A harder task than helping them decide to move out of the family home

• The driving question brings adult children to their knees - very difficult for the spouse

• Given third party involvement, we did not bear the brunt of her anger

Physician Comments

• “...the hardest news I have to deliver is that he/she is no longer safe to drive. The battle can damage a relationship between spouses, parent and child and patient/doctor. It is a relief to have the ‘court’ of DriveWise.”
Age and “The Silver Tsunami”
74 M Americans will exceed age 65 by 2030
More than 75% carry driving licenses

Increased age is associated with
- More driving errors
- Poor performance on road test
- Increased crash risk and increased mortality

Average man outlives driving by 6 years
Average woman outlives driving by 10 years

HOW AGE AFFECTS DRIVING
Visual changes - scanning, contrast sensitivity, glare resistance
Increased attention deficits and losing focus
Decreased reaction time and speed
Decreased motor coordination and flexibility
Decreased multi-tasking
Episodic memory loss (memory for routes)
Procedural memory?
"Yes, we did see the headline about the 71-year-old driver in the crash. Funny it didn’t mention the age of the SUV driver with the cell phone and Big Mac."

MOTOR VEHICLE CRASH RISK BY AGE

Figure 3: Accident involvement Rate Age Group Comparison by Licensed Drivers and Vehicle Miles Traveled

- Crash Involvement Rate per 1 million VMT
- Crash Rate per 100 Licensed Drivers
THE OLDEST OLD DRIVER
(Hollis et al., 2013)

- 88 individuals; 27 oldest old (90-97), 61 old (80-87)
- Drivers age 90+ were at no greater driving risk than those 10 years younger
- Age, in and of itself, does not predict driving safety

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Does a Diagnosis Of Dementia Preclude Safe Driving?

Procedural memory ages well
Heterogeneity in dementia
Let’s be fair: balance autonomy and safety
Does the risk for mild dementia exceed the crash rate of 16-19 year old males?
Need for evidence based solutions…gives the patient their “day in court”

Mandatory v Voluntary Reporting

Oregon, Delaware, Nevada, NJ, CA, and PA - mandatory reporting dementia
50% of remaining states encourage reporting but not mandatory
30% require additional vision testing
American Academy of Neurology Practice Parameter

- CDR of 0.5 (questionable dementia) equals 16-19 year old or BAC <0.08
- CDR 0.5 - lane boundary violations similar to those seen in BAC <0.08
- CDR of 0.5 - driving exam (Guideline)
- Reassessment every six months (Standard)
- CDR 1 - discontinue driving (Standard)

Dubinsky et al., 2000

AMA GUIDELINES

Public safety - over confidentiality
Physicians - identify and document
If advice ignored - duty to notify RMV
Protect confidentiality
Neurodegenerative Diseases

- PD and AD drivers – impaired/problems during route following tasks
- PD drivers - low contrast sensitivity
- Cognitive performance predictive

Reporting Impaired Drivers

- “Duty to protect”
  - The patient
  - The patient’s passengers
  - The public
- Confidentiality
  - Physician-patient communication and trust.
  - Conflict with duty to protect the patient and others.
**Dementia and motor vehicle crash hospitalizations** (Agimi et al., 2018)

State databases reviewed to determine whether mandatory reporting affected crash rate in people with dementia

136,987 charts: 5,564 people had dementia

State based reporting laws - not associated with fewer crashes by people with dementia

**Overview of Research on Driving and Dementia**

(Jacobs et al, J Neurology, 2017)

Reviewed studies on AD, PD and HD

Identified studies that used road tests and simulators as outcomes.

15% to 65% of AD - failed road test

Lane positioning, changing, checking blind spot, signaling, lane maintenance.

Most common errors are tactical including lane maintenance and changing

Deficits in vision, attention and executive functions predicted competence
AD and Driving
(U Iowa: Uc and Rizzo)

• Use of instrumented vehicle (ARGOS) with sensor to detect lane position, speed, etc.

• AD drivers – more safety errors

• AD drivers - impaired during route following

• AD drivers - problems w low contrast sensitivity

• Visual acuity, contrast sensitivity, attention, spatial, memory, construction, verbal fluency – associated with driving safety

Methodological Limitations

• Noise in the population- selection biases

• Who in their right mind would volunteer?

• Psychometric properties of tests

• Cultural biases of tests

• DriveWise data: best predictors for first 200: Age, BNT, TMT
Limitations of outcome measures

Crash rate: low frequency event, under reporting (due to memory loss, less citations, etc.)

Simulator studies: expensive, cumbersome

Road tests: subjective, limited sampling of driving (no hazardous situations)

Predictive Screening Tests

MMSE <24 - unsafe (O’Connor, 2010)
MoCA <18 - unsafe (Hollis et al, 2014)
TMT-B - 3 X 3 rule; 3 errors v 180” (AMA)
TMT-A > 50”; TMTB > 126” (Duncanson et al., 2015)
Errors - TMTA - NS; TMTB = 3 (Duncanson et al., 2015)
What about the person with PD?

Survey of 12,000 (Meindorfer et al, 2005)

- 82% held drivers licenses
- 60% still drive
- 15% involved in MVC the prior year
- Risk increase with ESS

Relevant Motor Symptoms

- **Tremor** - not necessarily problematic
- **Bradykinesia**
  - Slower reactions to hazards. Intervention focuses on anticipatory behaviors and use of technology
- **Balance**
  - Problems getting into/out of car. Intervention: use of swivel cushion.
- **Rigidity**
  - Neck rotation limitations: unsafe lane changes. Intervention: parabolic mirror and increased scanning
  - Steering is less fluid
Relevant Non-Motor Symptoms
- Impaired Contrast Sensitivity
- Impaired Visual Awareness (left turns)
- Fluctuations in Attention/Sleep
- Executive Deficits/Judgment
- Reduced Multi-tasking
- Impaired Processing Speed
- Procedural Memory?
- Apathy and Impulsivity
- Loss of confidence

Few research studies on FTD
- DeSimone et al., 2007: 15 people w FTD- more speeding tickets and crashes
- Ernst et al., 2010: 30 people w FTD- more aggression, increased speed, disregard for rules
- Fujito et al., 2016: 28 people w FTD- problems detecting gap between cars and ignored rules; 75% caused accident after diagnosis
DRIVEWISE
Beth Israel Deaconess Medical Center
Division of Cognitive Neurology
Beth Israel Deaconess Medical Center
617-667-4074

Driving Assessment Process

Referral  Social Work Evaluation  Occupational Therapy Evaluation  Road Evaluation  Team Meeting  Feedback Session of Social Work
Who are the clients?

• Over 1,000 individuals tested over 15 years
• Medical, cognitive or psychiatric problems that may impair driving safety
• Alzheimer’s disease, MS, Parkinsons, ALS, Stroke, post ECT, bipolar, orthopedic problems, brain tumors
• Ages: 17-97

Demographics
Breakdown by Age
The Social Work Assessment

• Sign consent form
• Take psychosocial/driving history
• Begin to anticipate negative consequences
• Administer MoCA; complete 4C’s
• Set up feedback session at which time good/bad news delivered in detailed letter

Montreal Cognitive Assessment (MoCA)

• Visuospatial/executive, naming, memory, attention, language, abstraction & orientation

(Nazzredine et al, 2005)
### THE 4 C’S

| 1 | No Crashes | None | Good health | Intact |
| 2 | 1+ fender bend | Mild concern | Mild medical | Mild decline |
| 3 | Major Citation | Moderate concern | Moderate medical | Moderate decline |
| 4 | Crash(es) | Extreme concern | Severe medical | Severe decline |

**4 C’s Outcome**

- Family concerns and cognitive functioning were significantly associated with driving outcome.
- Crash history and clinical condition were not.
- Overall total 4 C score >7 has about 90% sensitivity and 80% specificity.

O’Connor et. al., JAGS 2010
Occupational Therapy Evaluation

• Three key domains of driving are assessed
  • Vision
  • Cognition
  • Physical Function

• Standardized On Road Evaluation

Vision Testing

• Visual acuity- 20/40 or better,
  – Daytime only restrictions available
• Visual Field- 120 degrees of lateral field at eye level
• Tracking
• Depth perception
• Contrast Sensitivity
### Trail Making Test B

![Image of Trail Making Test B](image)

### DRIVEWISE: PASS AND FAIL

<table>
<thead>
<tr>
<th></th>
<th>Pass Mean (SD)</th>
<th>Fail Mean (SD)</th>
<th>Significance (p value)</th>
<th>Effect Size (eta squared)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>68.21 (14.81)</td>
<td>76.40 (12.19)</td>
<td>&lt;0.001</td>
<td>0.07</td>
</tr>
<tr>
<td>Education</td>
<td>15.93 (2.70)</td>
<td>15.34 (3.20)</td>
<td>0.31</td>
<td>0.002</td>
</tr>
<tr>
<td>TMT A Time</td>
<td>48.78 (31.44)</td>
<td>67.88 (41.79)</td>
<td>&lt;0.001</td>
<td>0.06</td>
</tr>
<tr>
<td>TMT B Time</td>
<td>120.17 (73.32)</td>
<td>143.88 (86.18)</td>
<td>0.001</td>
<td>0.02</td>
</tr>
<tr>
<td>TMT A Total Moves</td>
<td>24.0 (8.0)</td>
<td>24.0 (2.0)</td>
<td>0.02</td>
<td>0.01</td>
</tr>
<tr>
<td>TMT B Total Moves</td>
<td>22.0 (5.0)</td>
<td>19.0 (8.0)</td>
<td>&lt;0.001</td>
<td>0.06</td>
</tr>
</tbody>
</table>
Mini-Mental State Examination (MMSE)

- Orientation, recognition, calculation, recall, and language

Folstein MF, Folstein SE, McHugh PR., 1975

MoCA vs MMSE in the prediction of driving test outcome

- 92 adult drivers
- Neither test predictive for cognitively intact
- For dementia - MoCA was a better predictor
- As MoCA score decreased by 1 point, person was 1.36 times more likely to fail
- MoCA “cut score” of 18 or less
Figure 2 MoCA subtest scores by road test outcome (pass/fail) in cognitively impaired (CI) group

Figure 3 MoCA subtest scores by road test outcome (pass/fail) in non-cognitively impaired (NCI) group
Useful Field of View Test

• Measures the size of the visual field in which one can process rapidly presented, complex information with a single glance
• Involves cognitive as well as visual function
Useful Field of View Test (Ball et al. 1988) Test 1 Measures speed identifying a single object.
UFOV Test 2

Measures speed dividing attention between two objects.

After each presentation you will be asked two questions. Which object was inside the white box?

Physical Assessment

- Strength and range of motion
- Coordination
- Sensation
- Functional control
- Mobility
- Brake reaction time
DriveWiseRoad Evaluation

- Road test - gold standard but there are limitations
- OT and certified driving instructor score driving
- Evaluation - only a snapshot of driving
- Challenges vary
- Subjectivity inevitable
- Gives the driver their “day in court”

On Road Evaluation

- Starting and securing the car
- Following instructions and road signs
- Visual awareness
- Positioning, gap detection, lane control
- Maneuvers
- Response to obstacles & situations
- Speed control
- Problem solving
Outcomes of the Evaluations

- Individuals can either pass, fail, or be referred for remediation.
- The decision was not made for a handful of cases.

**Overall Results**

- Pass: 44%
- Fail: 39%
- Remediation: 16%
- Unclear: 1%

**By Gender**

- Female:
  - Pass: 71
  - Fail: 63
  - Remediation: 32
  - Unclear: 1
- Male:
  - Pass: 94
  - Fail: 33
  - Remediation: 4
  - Unclear: 0

---

Case JT

75 year old retired MD - 12 year history of PD

Tremors and impulsive behavior (gambling, over exercising)

Family concerns: referred by wife due to crashes and impulsivity

- 2014 crash; at fault
- 2016 tried to “beat yellow light”—poor speed control on turn
Case JT

February 2017 Office Assessment

- MOCA - 28/30 Normal
- MMSE: Not administered (prior exposure)
- Trails A - 30 secs (70th %ile)
- Trails B - 51 secs (90th %ile, no errors)
- UFOV 1 - 23 ms (normal)
- UFOV 2 - 17ms (normal)
- UFOV 3 - 70 ms (normal)

February 2017 Road Test

- No observed errors during 45 minute road test.
- OT and CDI rated him as a “pass”

Case JT

DW Recommendation: PASS

- Mandated follow up in 6 months or sooner pending change in clinical status.
- Recommendations to limit distractions and avoid highway
- Note on dashboard reminding him not to speed.

Follow up

- June 2017: JT drove into parked truck. He impulsively put car in reverse and “floored it” causing major damage to his car. Driving cessation.
- JT plans to gift his car to adult son.
Case MK

- 83 year old med tech. Lives alone
- Referred by Geriatrician after several minor crashes, getting lost, falls at home
- 2 crashes in prior 2 years; backing into objects
- Other medical conditions: trigeminal neuralgia mixed AD/vascular dementia
- Drives 14 miles/day

Case MK

Office Testing:
- 4C’s = 10
- MOCA = 12 (Impaired); MMSE =23/30 Impaired
- Trails A 67 sec Impaired; Trails B NC 240 secs
- UFOV1 = 187 Impaired; UFOV2 = 247 Impaired

Road Test:
- Poor lane changes, no signals, cars honk her during testing

Decision: FAIL
**Breaking Bad News**

- Enlist family support
- Take time and allow for silences
- Focus on history of resilience
- Define independence broadly
- Focus on actual driving errors
- Discuss safety for self and others
- Medicalize the problem
- Monitor for mood changes

**Driving Cessation**

- Older adults who have relinquished their license make fewer trips and engage in fewer activities
- They experience greater health problems, including a higher incidences of depression
- Although rides may be available, ‘discretionary travel’ for social and recreational needs is often reduced— the “ice cream test”
- Family members struggle to ‘pick up the slack’
The Future: What’s Ahead to Promote Safe Driving

• ROAD DESIGN
  – Protected Left Turn Signals
  – Specified Left Turn Lanes
  – Reflective Pavement Markings
  – Mixed Case Lettering on Road Signs
  – Better Lighting

CAR REDESIGN

– Improved Control Knobs and Door Handles
– Easy to Read Instrument Panel
– Collision Warning Systems
– Automated Brake Support
– V2V: Vehicle to Vehicle Communication Systems
– V2X: Vehicle to Technology Communication
– Lane Sensing Systems
– Side Impact Protection
The Self Driving Car

- Tesla, Volvo, Google (latter two in development)
  - Level 1: Use of cruise control, automatic braking and lane keeping - can only use one function at a time
  - Level 2: Tesla Autopilot. Driver can cede two controls at the same time. Still needs to be vigilant - car does not give advanced warning when authority is needed
  - Level 3: Volvo Intellisafe Autopilot. Driver is somewhat vigilant but cedes full safety to the car.
  - Level 4: Tesla and Google Car. No driver vigilance needed. It includes occupied and unoccupied vehicles.
The Self Driving Car

• 2016 Model S Tesla SD car went under tractor trailer
• NHTSA absolved Tesla – driver error
• Google: Waymo experiment three years ago
• Gave cars to employees with hidden cameras
• Noted that people were very inattentive
• Raised the question of “overtrust”
• Can humans respond for a last minute hand off?
Advanced Care Planning & Management of End-stage Dementia, Pain, Palliation & Hospice in Long-Term Care

Mary Norman, MD
Management of Dementia in Long Term Care and Assisted Living:
Focus on Palliation and Hospice

Mary Norman, MD
5/30/2020

Palliative Care and Hospice Overview

- Prevalence of dementia in LTC and AL
- Prognosis and establishing goals of care
- Palliation
  - Falls
  - Nutrition
  - Pain
  - Infections & fever
- Hospice
2020 Prevalence of dementia in U.S.

Total: 5.8 million
2050 projection: 13.8 million

Total ALF / LTC population: 2.5 million
Prevalence of dementia: 50%

https://www.ncbi.nlm.nih.gov/books/NBK51841/

Prevalence of dementia in U.S.

SOURCES: CDC/NCHS, National Study of Long Term Care Providers and Table 4 in Appendix B.
Establishing Goals of Care

- Only 65% of nursing home patients have completed advance directives
  - Medical power of attorney
  - Directive to family & physicians
  - Out-of-hospital do not resuscitate

POLST/ MOLST: Orders for Life Sustaining Treatment

- Differ from advance directives
- Direct current care:
  - Resuscitation
  - Intubation
  - Hospitalization
  - Artificial nutrition / hydration
  - Comfort measures only


Estimating prognosis

- ADEPT study – Mitchell et. al
  Prediction of 6-month survival in NH residents with Advance Dementia vs. Hospice guidelines
  - Prospective cohort study 606 nursing home residents
  - Bottom line – no significant difference in accuracy of prognosis: patients goals of care should determine care

http://epronosis.ucsf.edu
Mitchell, SI, JAMA 11, 2010
• CASCADE prospective cohort study
  – 323 nursing home residents with advanced dementia in 22 NH Boston
  – Residents whose proxies understood clinical course of dementia were less likely to receive following in last 3 months of life:
    • Hospital transfers
    • Tube-feeding
    • IV therapy

Caregiver / Family Education

Mortality: 55% over 18 months (40% over 12 months)

– Expected complications:
  • 90% eating problems
  • 50% recurrent infections/fever

– Burdensome symptoms: Increase within 3 months preceding death:
  • Pain  25%
  • Dyspnea  30%

Mitchell SL, NEJM 2009
Goals of Care discussion

- Life prolongation
- Maximize function
- Enhance comfort
- Individualized goals
CMS Reimbursement: Advance Care Planning

- New CPT codes effective 1/1/2016 to compensate providers for time spent in advance care planning (ACP):
  
  99497    First 30 minutes (minimum 15 min.)
  +99498   Each additional 30 minutes

New CMS Reimbursement 2017
Prolonged Services – Non Face to Face

- Prolonged evaluation and management services without patient contact
- Service may occur before and / or after direct patient care
  – Must be off the unit / floor for inpatient
  – May occur on a different day than E&M
  – 99358 (30-74 min), + 99359 (75-104 min)

New 2018: Dementia Care Planning Code

- CPT code 99483
- Includes following elements:
  - Cognition–focused evaluation H&P
  - Functional assessment
  - Use of standardized instruments to stage dementia
  - Evaluation of neuropsych and behavioral symptoms
  - Safety evaluation
  - Identification of caregivers
  - Advance care planning
  - Written care plan

Palliation
Person-Centered Focus

Medication Review (Revised 2019)
- Beer’s criteria – potentially inappropriate
- Anticholinergics
  - Antihistamines
  - Incontinence Meds
- Assess benefit of medications
  - Cholesterol lowering
  - Anticoagulants
  - Supplements - calcium
  - Anticholinesterase inhibitors

Where to Start

JAGS 00:1-21, 2019
Palliation: Gait and falls

- Fall rates increase dramatically with progression of dementia
- Causes:
  - Orthostatic hypotension
  - Gait apraxia
  - Poor judgment
  - Co-morbid conditions: poor vision / hearing / arthritis
  - Medications

Fall prevention

- PT / OT
- Daily exercise programs
- Activities programming
- Training staff
- Footwear
- Assistive devices
- Medication review

http://www.cdc.gov/homeandrecreationalsafety/falls/
What’s out

• Chair / bed alarms
• Restraints
  – Physical
  – Chemical (COVID impact)

Hip Fracture - Surgery?

• Cohort study: 3083 NH residents with advanced dementia with hip fracture: with or without surgical repair
• 6 month mortality rate: 31.5% -surgical vs. 53.8% non-surgical
• 2 year mortality rate – 12% lower surgical
Surgical vs. non-surgical treatment hip fracture

• Among 2007 6 month survivors:
  – Less documented pain (29% vs. 30.9%)
  – Fewer pressure ulcers (11.2% vs. 19%)
  – Few remained ambulatory (10.7% vs. 4.8%)
  – No difference between anti-psychotic use and restraint use.

Berry, SD, JAMA 2018; 1178(6)774-780
https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2680317

Palliation: Nutrition

• Dysphagia
• Hydration
• Weight loss
• Comfort feedings vs. tube feedings
Oral versus tube feeding

- Data - lack of evidence to support use of tube feedings
  - Does NOT prevent
    - Death
    - Pneumonia / aspiration
  - Does increase risk of:
    - Agitation
    - Decubitus ulcers


What about modified diets?

JAMA, June 2016
Pain management

• 37% nursing home residents report pain, but with dementia, may be harder to detect

• CNPI (Checklist for Non-verbal pain indicators)

• PAIN- AD (Pain Assessment in Advanced Dementia)

Pain modalities

• Non-medication strategies:
  – Massage, positioning, music

• Medications
  – Non-opioid medications
    • Acetaminophen, anti-inflammatory, topical gel, patches
  – Opioid medications
  – Injections


http://www.geriatricpain.org/Content/Assessment/Impaired/Pages/PAIDADTool.aspx
Pain Assessment IN Advanced Dementia- PAINAD (Warden, Hurley, Volicer, 2003)
Infections & Fever

- Pneumonia
- UTI
- Fever, despite antibiotics
What to Expect:

![Graph showing cumulative incidence over days from baseline for eating problem, death, febrile episode, and pneumonia.](image)

Mitchell, NEJM 2009, October 15

Treatment

- Do antibiotics help?
  - Confirm infection
  - Consider benefit (life prolongation) vs. burden (MDR, colonization vs. infection, side effects – drug interactions, c.diff)
  - IV / IM not superior to PO
- Palliative approach
  - Acetaminophen
  - PO antibiotics in lieu of hospitalization / IV
Treatment

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  – Confirm infection
  – Consider benefit (?life prolongation) vs. burden (MDR, colonization vs. infection, side effects – drug interactions, c.diff)
  – IV / IM not superior to PO

• Palliative approach
  – Acetaminophen
  – PO antibiotics in lieu of hospitalization / IV

Hospice
Hospice Criteria: End stage dementia

- Functional Assessment Staging Scale (FAST) $\geq 7$
- Unable to walk, bathe, dress without assistance
- Bowel and bladder incontinence
- Speaks $\leq 6$ intelligible words/ day


Hospice Criteria: Dementia

- Had at least one of following in last 12 months:
  - Aspiration pneumonia
  - Pyelonephritis
  - Sepsis
  - Multiple stage 3 or 4 decubiti
  - Poor nutritional status (10% weight loss or albumin $< 2.5$)
  - Fever, recurrent after antibiotics
Medicare Criteria

• Consider – other co-morbid conditions
  – End stage lung disease
  – Parkinson’s
  – CHF
  – End stage renal disease
• MD certification of life expectancy < 6 months

Hospice Team
Benefits of hospice care: observational studies

- Lower rates of hospitalization in last 30 days of life (19% vs. 39%)
- Improved pain control (44% vs. 27%)
- Greater family satisfaction with care

Miller, Am J Med 2001
Miller, JAGS 2002
Kiely, JAGS 2010

Bottom Lines

- Establish goals of care – how do we partner to honor our loved ones
- Assist families in understanding progression of disease
- Provide palliation at every step – maximize quality of life
- Consider hospice when appropriate
'I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.'
Maya Angelou —

References & Resources

- [http://caringinfo.org](http://caringinfo.org)
- [http://www.nhpco.org/resources-access-outreach/dementia-resources](http://www.nhpco.org/resources-access-outreach/dementia-resources)

- **UptoDate: Review articles**
  - Mitchell, SL, “Palliative care of patients with advanced dementia,” 11/2019
  - Winzelberg, GS, “Palliative care: Nursing home,” 3/2018