

Decision Making Capacity in Dementia



UW Medicine
HARBORVIEW
MEDICAL CENTER

Kristoffer Rhoads, PhD

Clinical Neuropsychologist

Associate Professor, Department of Neurology

Memory and Brain Wellness Center

Harborview Medical Center/University of Washington School of Medicine

UW Project ECHO Dementia

September 22, 2023



Disclosures

- Private practice in forensic neuropsychology
 - Including capacity evaluations



Capacity - Distinctions

- Civil vs. Criminal

- Consent to healthcare/research
- Independent living
- Testamentary capacity
- Financial decisions
- Driving

NOT – Criminal culpability

Waiving Miranda rights

Ability to stand trial

- Specific vs. Global

- Decision determined vs. competency

- Legal vs. Clinical

- Data in the context of the law
- Determines clinical but perhaps not legal action
- May be evidence but may not impact legal status



Competency vs. Capacity

- Competency
 - Legal findings
 - Judicial decision
- Capacity
 - Clinical findings
 - Cognitive abilities involved in decision making
 - Medical
 - Financial
 - Testamentary
 - Understanding/comprehension
 - Decisional vs executional
 - Threshold levels

Testamentary Capacity

- **Banks v. Goodfellow (1870) criteria**
 - Nature/extent of one's property
 - Beneficiaries of the will
 - How the objects are distributed
 - How these elements relate to form a plan
- **Bottger's Estate (1942)**
 - "A person ... if at the time he [or she] assumes to execute a will he [or she] has sufficient mind and memory to understand the transaction in which he [or she] is then engaged, to comprehend generally the nature and extent of the property which constitutes his [or her] estate and of which he [or she] is contemplating disposition to recollect the objects of his [or her] bounty."

Financial Capacity

- Ability to manage financial affairs in a manner consistent with personal self-interest and values (Marson, 2016)
- Vulnerability
 - Acute vs. Chronic conditions
- Financial Exploitation
- Undue Influence
 - Special relationship based on confidence/trust
 - Intentional and improper influence or persuasion
 - Often involves financial exploitation

Undue Influence – Red Flags and Considerations

- Close, confidential relationship
 - Persuasion, manipulation and deception
- Isolation
 - Physical and emotional
- Level of dependency
 - Physical
 - Cognitive
 - Emotional
- Increased involvement in healthcare/finances
 - Feelings of reciprocity and “owing”
- 'Poisoning of the well'

Medical Decision-Making Capacity



- Communicating a consistent choice
 - Same answer to same question, over time
- Understanding relevant information
 - Paraphrasing pertinent medical facts
- Appreciation of one's situation
 - Sort facts into personal pros and cons
- Rational manipulation of information
 - Weigh pros and cons in a defensible manner
- Number of elements increases with complexity of the decision

Prevalence of Medical Decision Making Incapacity

Table 1. Prevalence of Incapacity in Select Populations

Disease or Patient Care Setting	No. of Studies	No. of Patients	Patients With Incapacity		
			No.	% (95% CI)	Standard Deviation
Healthy elderly controls	16	1817	51	2.8 (1.7-3.9)	0.005
Mild cognitive impairment	1	147	29	20 (14-26)	0.03
Glioma patients	1	26	6	23 (6.9-39)	0.08
Medicine inpatients	8	816	212	26 (18-35)	0.11
Parkinson disease	4	148	62	42 (23-60)	0.13
Nursing home	5	346	152	44 (28-60)	0.08
Alzheimer disease	10	1425	770	54 (28-79)	0.13
Learning disabled	4	208	141	68 (41-97)	0.14

Abbreviation: CI, confidence interval.

JAMA

Cognitive Impairment and MDMC



- People living with Alzheimer's Dementia may or may not have MDMC for treatment decisions
 - 48 very mild to mod AD patients interviewed
 - Highly variable MDMC in sample
 - 40% considered to have decisional capacity
 - Greater awareness of their symptoms, prognosis, and diagnosis.
 - MMSE is helpful only when <19 or >23

Physician Recognition of Impaired MDMC



- 8 studies with physicians blinded to results of formal capacity assessment¹
 - Physicians recognized 42% of patients who lacked DMC
 - Usually correct when they did recognize lack of DMC
- 48% medical inpatients (n= 302) were found to lack capacity to consent to medical treatment²
 - ¼ identified by the treating team

¹Sessums, L. L. et al. *JAMA* 2011;306:420-427

²Raymount V. et al. *Lancet* 2004;364:1421-7



Capacity Evaluations

- Critical concepts and variables
 - Timing
 - “Balancing act”
 - Promoting self-determination
 - Addressing the functional deficit
 - Providing recommendations
 - » Clinical
 - » Legal
 - Functional capacity
 - Prospective vs. retrospective



Capacity Evaluations

- A Framework for Capacity Assessment
 1. Legal Standard
 2. Functional Elements
 3. Diagnosis
 4. Cognitive Underpinnings
 5. Psychiatric or Emotional Factors
 6. Values
 7. Risk Considerations
 8. Steps to Enhance Capacity
 9. Clinical Judgment of Capacity



Capacity Evaluations

- Capacity
 - Knowledge
 - Attention
 - Comprehension
 - Language
 - Reasoning
 - Memory
 - Calculation
 - Appreciation
 - Consistency
 - Contingent on need
 - “Right to folly” vs. impairment



Capacity Evaluations- Tools

– Medical Decision Making

- Capacity to Consent to Treatment Instrument (Marson, 1995)
- MacArthur Competence Assessment Tool (Grisso & Applebaum, 1998)
- Hopemont Capacity Assessment Interview (Edelstein, 2000)

– Financial Decision Making

- Financial Assessment and Capacity Test (Black, 2007)
- Financial Capacity Instrument (Marson et al., 2000)
- The Lichtenberg Financial Decision Rating Scale (Lichtenberg, 2013)

– Testamentary Capacity

- Testamentary Capacity Assessment Tool (Papageorgiou et al., 2018)

Capacity Evaluations



- Interventions/outcomes
 - Guardianship
 - Conservator
 - Healthcare proxy
 - Durable power of attorney
 - Representative payee
 - Recommendations to enhance capacity
 - Treat medical/psychiatric/sensory/motor problems
 - Use patient's native language
 - Consult cultural interpreters
 - Involve family & friends
 - Employ different media



Retrospective Evaluations

- “Neuropsychological autopsy”
- Low threshold for presumed capacity
- Strength of the records
 - Medical
 - Legal
- Secondary documents
- Collateral interviews



Actionable Steps

- Identify and document cognitive impairment early
- Don't assume capacity
- Document decisional preferences early and review regularly
- Determine who could help make decisions (e.g., spouse, adult children, family, etc.) and if you can contact
- Complete advance care planning early and review regularly



Resources

- Pacific Northwest Neuropsychological Society
 - www.pnns.org
- Assessment services
 - Geriatric Regional Assessment Team
 - NW Hospital Geropsych
 - DMHPs
 - HMC/UW geropsych/neuropsych services
- Advance Directive for Dementia
 - <https://dementia-directive.org>
- DSHS/Area Agencies on Aging



Thank you for your attention!



Questions?

Contact Information

Memory and Brain Wellness Center

<https://depts.washington.edu/mbwc/>

Harborview Medical Center

325 9th Ave., 3rd Floor West Clinic

Seattle, WA 98104

Phone 206-744-3045

Fax 206-744-5030

krhoads@uw.edu

UW Medicine

HARBORVIEW
MEDICAL CENTER



References/Resources

- Lichtenberg, P. A. (2016). Financial Exploitation, Financial Capacity, and Alzheimer's Disease. *American Psychologist*, 71(4), 312-320. doi: 10.1037/a0040192
- Lichtenberg, P. A., Stoltman, J., Ficker, L. J., Iris, M., & Mast, B. T. (2015). A person-centered approach to financial capacity assessment: Preliminary development of a new rating scale. *Clinical Gerontologist*, 38, 49-67. doi:10.1080/07317115.2014.970318 JGP.0b013e318157cb00
- Marson, D. (2016). Conceptual models and guidelines for clinical assessment of financial capacity. *Archives of Clinical Neuropsychology*, 31(6), 541-553. doi: 10.1093/arclin/acw052
- Moye, J. & Marson, D. C. (2007). Assessment of decision-making capacity in older adults: An emerging area of practice and research. *Journals of Gerontology: Series B, Psychological Sciences and Social Sciences*, 62(1), P3-P11. doi: 10.1093/geronb/62.1.P3
- Bush, S. S., Allen, R. S., & Molinari, V. (2017). *Ethical practice in geropsychology*. Washington, DC: American Psychological Association.
- Allen, R. S., McDonough, I., Albright, A., Erickson, S., Brake, G., & Salekin, K. (in press). Assessment of competency to be executed. In S. S. Bush & A. L. Heck (Eds.), *Forensic geropsychology: Practice essentials*. Washington, DC: American Psychological Association.
- Allen, R. S., Harris, G. M., Burgio, L. D., Azuero, C. B., Miller, L. A., Shin, H., Eichorst, M. K., Csikai, E. L., DeCoster, J., Dunn, L. L., Kvale, E. A., & Parmelee, P. (2014). Can senior volunteers deliver reminiscence and creative activity interventions? Results of the legacy intervention family enactment randomized controlled trial. *Journal of Pain and Symptom Management*, 48(4), 590-601. doi: 10.1016/j.jpainsymman.2013.11.012
- Allen, R. S., Azuero, C. B., Csikai, E. L., Parmelee, P. A., Shin, H. J., Kvale, E., Durkin, D. W., & Burgio, L. D. (2016). "It was very rewarding for me ...": Senior volunteers' experiences with implementing a reminiscence and creative activity intervention. *The Gerontologist*, 56(2), 357-367. doi: 10.1093/geront/gnu167
- Di Napoli, E. A., Breland, G. L., & Allen, R. S. (2013). Staff knowledge and perceptions of sexuality and dementia of older adults in nursing homes.

References/Resources

- Moye, J., Sabatino, C. P., & Brendel, R. W. (2013). Evaluation of the capacity to appoint a healthcare proxy. *American Journal of Geriatric Psychiatry*, 21(4) 326-336. doi: 10.1016/j.jagp.2012.09.001
- Moye, J., Marson, D., & Edelstein, B. (2013). Assessment of capacity in an aging society. *American Psychologist*, 68(3), 158-171. doi: 10.1037/a0032159
- Moye, J., Wood, S., Edelstein, B., Armesto, J. C., Bower, E. H., Harrison, J., & Wood, E. (2007). Clinical evidence in guardianship of older adults is inadequate: Findings from a tri-state study. *The Gerontologist*, 47(5), 604-612. doi: 10.1093/geront/47.5.604
- Moye, J., Karel, M. J., Azar, A. R., & Gurrera, R. J. (2004). Capacity to consent to treatment: Empirical comparison of three instruments in older adults with and without dementia. *The Gerontologist*, 44(2), 166-175. doi: 10.1093/geront/44.2.166
- American Bar Association Commission on Law and Aging, Commission on Disability Rights, Section on Civil Rights and Social Justice; and Section on Real Property, Trust and Estate Law. (2016). PRACTICAL tool for lawyers: Steps in supporting decision-making. Retrieved from <https://www.americanbar.org/content/dam/aba/administrative/gpsolo/ssfrc%20articles/PRACTICALGuide.authcheckdam.pdf>
- Blanck, P. & Martinis, J. (2015). "The right to make choices": The national resource center for supported decision-making. *Inclusion*, 3(1), 24-33. doi: 10.1352/2326-6988-3.1.24
- Wood, E. (2016). Recharging adult guardianship reform: Six current paths forward. *Touro Law Journal of Aging, Longevity, Law, and Policy*, 1(1), 46. Retrieved from <http://digitalcommons.tourolaw.edu/cgi/viewcontent.cgi?article=1002&context=jallp>
- Wood, E. & Quinn, M.J. (2017). Guardianship Systems. In X. Dong (Ed.) *Elder abuse: Research, practice and policy* (pp. 363 – 386). doi: 10.1007/978-3-319-47504-2
- Wood., E., Teaster, P., & Cassidy, J. (2017). *Restoration of rights in adult guardianship: Research and recommendations*. Retrieved from American Bar Association Commission on Law and Aging website: https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration%20report.authcheckdam.pdf
- Boyle, P. A., Wilson, R. S., Yu, L. Y., Buchman, A. S., & Bennett, D. A. (2012). Poor decision making is a consequence of cognitive decline among older persons without Alzheimer's disease or mild cognitive impairment. *PLOS One*, 7(8), 1-5. doi: 10.1371/journal.pone.0043647
- Conrad, K. J., Iris, M., Ridings, J. W., Langley, K. & Wilber, K. H. (2010). Self-report measure of financial exploitation of older adults. *Gerontologist*, 50, 758-773. doi:10.1080/08946566.2011.584045

Financial Capacity- Exploitation

- Older Adult Self Report Financial Exploitation Measure (Conrad et al. 2010)

1. Theft and Scams

“Has anyone misused your ATM or credit card? “

2. Abuse of Trust

”Has someone convinced you to turn the title of your home over to them?”

3. Financial Entitlement

“Has anyone felt entitled to use your money for themselves?”

4. Coercion:

“Did anyone put pressure on you to get a reverse mortgage?”

5. Signs of Possible Financial Exploitation:

“Has anyone been frequently asking you for money?”

6. Money-Management Difficulties

“Have you forgotten to pay bills or paid them more than once?”

Financial Capacity - Models

- Independent Living Scales (Marson et al,2006)
 1. Basic Monetary Skills
 2. Financial Conceptual Knowledge
 3. Cash Transactions
 4. Checkbook Management
 5. Bank Statement Management
 6. Financial Judgment
 7. Bill Payment
 8. Knowledge of Assets/Estate Arrangements
- Problem Solving: knowledge of relevant facts and abstract reasoning
- Performance/Information: requires general knowledge, short term memory, and completion of simple every day tasks.

Financial Capacity - Models

- Lichtenberg Financial Decision-Making Rating Scale (LFDRS, 2013)

