

Legal and Ethical Issues in Dementia

Daniel Marson, J.D., Ph.D.

Professor of Neurology

Director, Alzheimer's Disease Center

University of Alabama at Birmingham

dmarson@uab.edu

Meeting of the Minds Dementia Conference 2012

Alzheimer's Association/Mayo Clinic

March 17, 2012 St. Paul, Minnesota

Disclosures

- **Grant Funding:**

- *National Institute on Aging (NIH)*
- *National Institute of Child Health Human Development (NIH)*

- **Assessment Instruments:**

- *Capacity to Consent to Treatment Instrument* (royalty)
- *Financial Capacity Instrument* (no royalty)
- *Semi-Structured Clinical Interview for Financial Capacity* (no royalty)

- **Pharmaceutical companies:** *No relationships*

Outline

- Issue Overview
- Ethical Principles in Clinical Practice
- Doctrine of Informed Consent
- Basic Capacity/Competency Concepts
- Loss of Competency in Dementia
- Research on Consent Capacity in MCI and AD
- Forensic Case Study of Competency in AD

Legal and Ethical Issues in Dementia

- Clinicians and scientists working with older adults with dementing illnesses face varied and complex legal and ethical issues.
- These issues include:
 - **decisional autonomy and competency**
 - planning for loss of decisional capacity
 - Proxy directives: DPOA for health care and/or finances
 - Instructional directives: living wills
 - Estate planning: wills, living trusts
 - end of life issues such as quality of life, medical futility
 - physician assisted suicide and euthanasia
 - conflicts of interest
 - Treatment vs. research, relationships with pharmaceutical companies

Ethical Principles in Clinical Practice

Ethical Principles in Clinical Practice and Research

- **Benificence** (duty to promote the good of the patient)
- **Nonmalificence** (duty to “do no harm” to patient)
- **Autonomy** (right of patient to self-determination)
- **Confidentiality** (respect for patient privacy and control over personal information)
- **Veracity** (truth telling)
- **Justice** (fairness of distribution of goods and services)

Morris J. Conflicts of interest. *Alzheimer's Disease and Associated Disorders* (1994).

Competing Ethical Principles in Clinical Practice with Older Adults

AUTONOMY versus PROTECTION

- To what extent should we support older person's autonomy (find her capable to act independently)?
- To what extent should we protect an impaired older person (and ourselves) from risks/dangers caused by her failing capacities (find her incapable and restrict autonomy)?
- Tension informs all competency assessments and protective actions
- Competency loss entails substantial loss of civil liberty

Informed Consent Doctrine

Bioethics Cornerstone

- Cornerstone for protection of rights of medical patients and human research participants
- Applies to all interventions performed by health care professionals, and to all human subjects research protocols and procedures
- No treatment, or research procedures, may be conducted without prior written consent of the patient or research participant
- Heart of doctrine is the ethical responsibility to respect a person's personal autonomy and inherent right of self-determination

Bioethics Cornerstone

- In the absence of valid treatment consent, any action on the part of the health care professional is technically considered a battery , even if benign and intended to benefit
- From a legal perspective, informed consent is considered as essential to the practice of medicine as are patient care and technical skill on the part of the physician

Three Elements of Informed Consent

- The informed consent doctrine specifies that, in order to be legally valid, a consent to medical treatment or research participation must be:
 - Informed
 - Voluntary
 - Competent

(Kapp, 1992).

Some Basic Competency/Capacity Concepts

What is Competency?

“A threshold requirement, imposed by society, for an individual to retain decision making power in a particular activity or set of activities.”

Multiple Competencies:

- not a unitary concept or construct
- “competency to do what?”
- “in what context”?

Capacity: A Medical-Legal Construct

- Capacity/competency is a hypothesized condition that cannot be directly observed or measured
- There is no “capacimeter”
- No “blood test” available
- Only behavioral signs/indications observable, measurable

Civil Capacities/Competencies

- Treatment consent capacity: make medical decisions
- Research consent capacity: research participation
- Financial capacity: manage financial affairs--*conservatorship*
- Live independently: care for self--*guardianship*
- Testamentary capacity: make a will
- Driving capacity: operate a motor vehicle
- Voting capacity: capacity to cast a ballot in election

Capacity vs. Competency

- Capacity--Incapacity:
 - denotes a clinical status determined by clinician
 - clinician makes clinical competency judgment based on patient's functional, cognitive, and behavioral abilities
 - clinical judgment is “evidence” of legal competency
 - clinical judgment does not alter legal competency status
 - clinical judgment does not permit transfer of authority for decision making to another (exception: DPAs)

Capacity vs. Competency

- Legal Competency--Incompetency:
 - denotes a legal status determined by a judge
 - judgment based on clinical/lay evidence, case/statutory law, principles of justice, and other non-clinical factors
 - judgment of “incompetency” alters legal status by removing rights of self determination for specific matter
 - judgment of “incompetency” requires transfer of decisional authority to a court appointed proxy: guardian/conservator

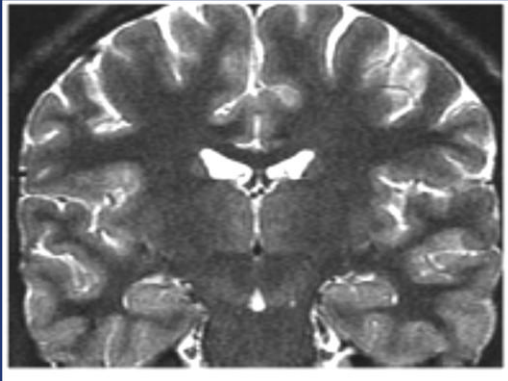
Legal Presumption of Competency

- normal adult achieving age of majority presumed under law to be competent
- in court proceeding, burden of proof lies with party alleging person is incompetent

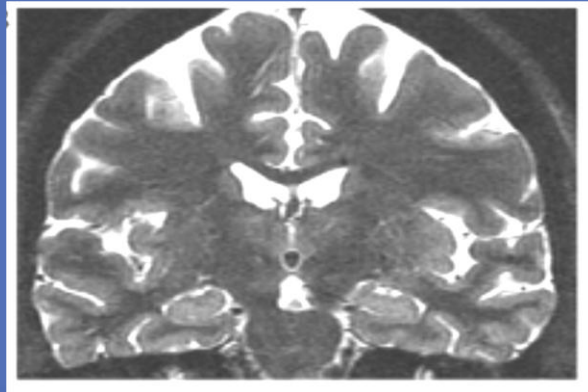
Competency Can Be Intermittent

- competency status can fluctuate over time
- competency can be legally lost and also restored
- competency status/change varies across conditions:
 - Schizophrenia
 - traumatic brain injury
 - AD

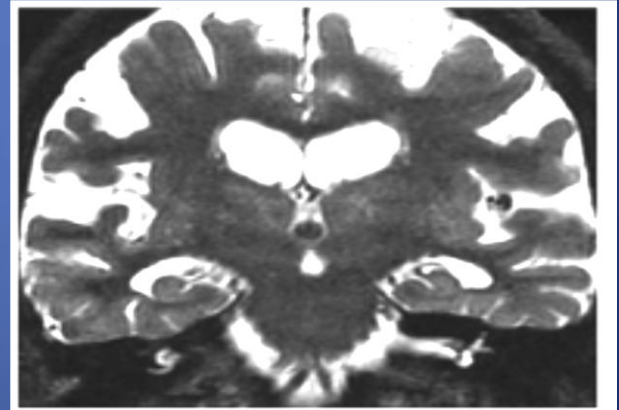
Loss of Brain Tissue on MRI Scan



Normal Aging



**Mild Cognitive
Impairment**



**Alzheimer's
Disease**

Diagnosis Does Not Itself Constitute Incompetency

- *What does a diagnosis of vascular dementia tell you about a person's capacity to drive a car?*
- Diagnosis relevant to driving capacity—but not determinative
- **Key Inquiry:** Examine actual performance--functional abilities constituent to driving
 - Knowledge of rules or road?
 - Operate controls of vehicle?
 - Navigate properly in traffic?
 - Observe and react to driving events?

Cognitive Impairment Does Not Itself Constitute Incompetency

- *What does a MMSE score of 22 out of 30 tell you about a person's capacity to consent to medical treatment?*
- Cognitive impairment relevant to consent—not determinative
- **Key Inquiry:** Have to examine actual performance--
functional abilities constituent to consent capacity
 - Understand the treatment situation and choices, risks/benefits?
 - Reason properly about treatment choices?
 - Appreciate personal consequences of decision?

Competency and Dementia

Definition of Dementia

An acquired clinical syndrome,
marked by loss of multiple cognitive abilities,
in an individual with previously normal (or at
least higher) intellectual abilities,
which impairs social, occupational, and/or
everyday functioning.

Types of Dementia

- Alzheimer's disease
- cerebrovascular dementia (multi-infarct, stroke)
- Pick's disease/frontal lobe dementia
- diffuse Lewy body dementia
- Parkinson's dementia
- Secondary to traumatic brain injury
- Multiple sclerosis
- pseudodementia (major depression)

Impact of Dementia on Competency

- difficulty learning and retaining new information
- difficulty recalling personal history, values
- difficulty understanding simple concepts
- difficulty expressing preferences and choices
- impairment of judgment
- distortion of reality (psychotic delusions)
- vulnerability to undue influence, exploitation/abuse

Impairment and Loss of Competency in Dementia

Treatment Consent Capacity

Capacity to Consent to Treatment

- Specific competency under the civil law
- Capacity to:
 - consent to treatment
 - refuse treatment, or leave AMA
- Crucial element of informed consent doctrine:
 - Informed
 - Voluntary
 - Competent: does pt have mental/emotional capacity to consent?
- Implicates issues of professional liability

Capacity to Consent to Treatment

- **“Medical” competency:**
 - Issue arises in hospital or medical setting
 - Involves a health care decision maker
 - Decisions rarely subject to judicial review