WHEN DECISION-MAKING CAPACITY IS A HARD DECISION TO MAKE

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OBJECTIVES

- Describe a foundational approach to evaluating decision-making capacities.
- Identify considerations for the assessment of decision-making capacity at the end of life.
- Discuss how to navigate challenges inherent to the assessment of decision-making capacity.

WHY ASSESS CAPACITY?

"As our society ages, clinical assessment of higher order functional capacities has become increasingly important. In areas like financial capacity, medical decision-making capacity, medication compliance, and driving, society has a strong interest in accurately discriminating intact from impaired functioning."

Marson et al. (2000): Archives of Neurology, vol. 57

CAPACITY AT END OF LIFE

- Increased risk of cognitive deficits and impaired decision-making capacity
- Identification and honoring of patients' wishes and values
- Determination of goals of care
- Improved quality of life and comfort at death

Burton, C.Z. et al. (2012). Undetected cognitive impairment and decision-making capacity in patients receiving hospice care. *The American Journal of Geriatric Psychiatry, 20(4),* 306-316.

Kolva, E., Rosenfeld, B., Brescia, R., & Comfort, C. (2014). Assessing decision-making capacity at end of life. *General Hospital Psychiatry, 36(4),* 392-397.

TERMINOLOGY

Capacity

- A clinical judgment about a patient's ability to do something
- Considered to be situation- and task-specific
- Reflected in a report after a clinical evaluation

Competency

- Legal status of lacking the ability to handle one's affairs due to mental or physical incapacity
- Usually broader perspective
- Reflected in a court order after a hearing

MANY CLINICAL CAPACIT*IES*

- Not a unitary construct
- Multiple capacities with emphasis on retaining maximum autonomy
- Individual who lacks capacity to make one decision does not necessarily lack ability to make all decisions

- Making health care decisions
- Determining code status
- Appointing a surrogate decision maker
- Living at a level of the patient's choosing
- Managing finances
- *And more!*

FUNCTIONAL ABILITIES

Capacity involves four functional abilities:

Expression **Understanding** **Appreciation** **Reasoning**

EXPRESSION

- **Evidencing** a treatment choice
  - Ability to consistently state a choice
  - In some ways the simplest standard
  - Impaired by intubation, aphasia, anxiety

UNDERSTANDING

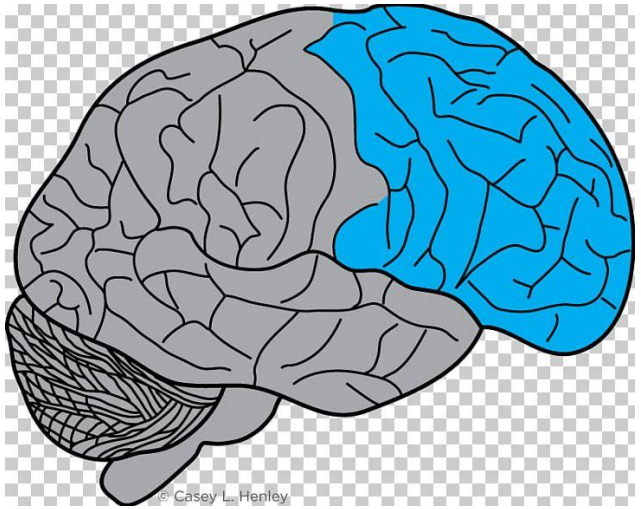
- **Understanding** treatment situation & choices
  - Ability to paraphrase back the information related to a choice
  - Impaired by receptive aphasia, comprehension deficits

APPRECIATION

- **Appreciating** the personal consequences of a choice
  - Recognition that the facts (e.g., diagnosis, treatment options) apply to the self
  - Ability to relate information to one's personal situation
  - Affected by impaired judgment, insight, psychosis

REASONING

- **Processing** information in a logically consistent manner
  - Provide rational reasons for a choice
  - Ability to manipulate information, generate consequences & compare them
  - Affected by executive dysfunction



CONSIDER MANY FACTORS

Capacity evaluations look at the clinical data along with the contextual situation.

- Cognition
- Functional Abilities
- Mental Health
- Physical Health

- Values / History
- Level of Risk
- Ways of Supporting or Enhancing Functioning

CONSIDER MANY FACTORS

- Contextual data can help advocate for the patient's abilities and/or supports to be added

CAPACITY MYTHS

- A diagnosis of dementia automatically means lacking in ability to perform a task or to make a decision
- Lack of one type of capacity means lacking in all other types
- Once capacity is lost, it cannot be restored
- Going against medical advice means the person must lack capacity

DECISIONALITY DETERMINATIONS

- Fully capable, marginally capable, incapable
- DPOAHC versus guardianship
- Expect the unexpected
  - Lack of participation
  - Surrogate rescinds, unavailable, incapable
  - Need for placement
  - Capable of choosing a surrogate but unable or unwilling

Clinical Capacity

Has capacity

Diminished capacity

Lacks capacity

Capacity Judgment

Has capacity

Lacks capacity

CASE EXAMPLE #1 – ETOH & PERSONALITY FACTORS

- 80-something year old male
- Advance Directive completed 3/24/2004 (son, stepdaughter)
- History of COPD, PTSD, Alcohol Use Disorder, HTN, GERD, falls
- DPOAHC activated 1/9/2012, deactivated 1/12/2012 – delirium resolved
- Admitted 5/6/2019 with increased confusion, FTT (poor intake, medication noncompliance), DPOAHC activated 5/7/2019
- Team recommended higher level of care – required T19
- Attempt to evaluate circumscribed capacity to name a financial POA 7/26/2019 & 7/30/2019, pt refused

CASE EXAMPLE #1

- Guardianship paperwork completed 8/2019, BUT…
  - Improvements in cognition noted by team, so reassessment 9/11/2019 & 9/19/2019 with neuropsychological testing
  - Marginally decisional – deactivate POA, assistance with medication management, driving eval, outpatient psychology & psychiatry f/u, abstinence from alcohol
  - Pt agreed to recommendations and d/c'd home

CASE EXAMPLE #1

- Interval history - multiple ED visits, reported MVA
- Readmitted 10/12/2019-10/16/2019, c/o chest wall pain and other injuries r/t MVA, admitting MD noted overall poor trajectory, recommended palliative consult for goals of care discussion, son involved, d/c'd home

- Readmitted 10/18/2019 with urinary retention, found to have UTI
- Pt agreeable to higher level of care
- Psychiatry evaluation 10/21/2019 – able to express, but impaired understanding, appreciation & reasoning, DPOAHC activated
- Neuropsychological assessment 11/6/2019 – major neurocognitive disorder, recommended guardianship for placement
- Goals of care discussion – d/c to CNH with hospice 12/10/2019
- But wait! There's more…

CASE EXAMPLE #1

- Readmitted from CNH 1/5/2020 with vomiting – found to have acute right MCA/PCA CVA
- Pt voicing desire to name new DPOAHC agent - reassessed and determined to lack capacity
- Pt dissatisfied with CNH – new facility pursued
- Change in goals of care, no financial POA, guardianship for placement
- Guardian appointed 4/28/2020
- D/C delayed due to COVID, eventually to CNH 12/2020

CASE EXAMPLE #2 – PSYCHIATRIC & INTERPERSONAL FACTORS

- 60-something male, living with brother, reported to be medication & diet noncompliant
- Hx of bipolar disorder, DM2, OSA, CHF, COVID
- Admitted to cardiology 9/4/2019 with CHF exacerbation, MS changes & SI
- Followed by psychiatry & psychology for depressed mood, ongoing risk assessment, CPO
- DPOAHC activated 9/5/2019
- LSTDI discussion with surrogate 9/10/2019 – DNR, goal of comfort
- Palliative care consult 9/16/2019 – appropriate for hospice, transferred 9/18/2019

CASE EXAMPLE #2

- Reassessment of decision-making capacity as activation had only one signature, improved MS
  - Marginally decisional
  - Aware brother making decisions and wants to keep it that way
  - DPOAHC activation continued
- Brother refuses to wear a mask during visits
  - Banned from visiting
- Brother refuses to speak to team, indicates all information should go through patient
  - Assessment of capacity to name a new surrogate 6/29/2020
  - Retained circumscribed capacity, but declined to name a new agent
  - Recommend reassessment of medical decision-making capacity if surrogate continues to refuse to participate

CASE EXAMPLE #2

- 7/2020:
  - Attempt to reassess of medical decision-making capacity – pt declined to participate
  - Attempts to work with the surrogate – brother declined to participate or rescind
- Pt eventually participated – decisional, DPOAHC deactivated 8/2020
- Pt passed away 3/2021

CASE EXAMPLE #3 – FAMILY DYNAMICS

- 80-something male, married – spouse with dementia, pt reported being primary caregiver
- Hx of PTSD, depression, OSA, CHF, CAD, Afib, COPD, dysphagia
- Advance Directive completed 5/2018 (daughter)
- Admitted 2/2019 with SOB, transferred to geriatric rehab unit 6/2019
- Capacity evaluation 6/10/2019
  - Progressive cognitive decline since 2015, although pt refused repeat testing
  - Able to express needs, values, and preferences, but impaired understanding, appreciation & reasoning; DPOAHC activated

CASE EXAMPLE #3

- Pt with increased functional dependence, yet lack of insight. Unwilling to following recommendations re: driving, smoking, thickened liquids
- Disagreement among children re: preferred ways of meeting care needs
- Multiple family meetings, individual meetings with surrogate who displayed caregiver burnout
  - Ex-guilt about removing driving, lack of support from some siblings on this
- D/C home late 6/2019 with home care, family assist, although not recommended 24/7 supervision

CASE EXAMPLE #3

- Readmitted 8/2019 with SOB, aspiration
  - Admits to “sneaking” thin liquids
- Transferred to geriatrics unit again
  - DPOAHC reports burnout with caregiving situation
  - Family against CNH placement for cultural & financial reasons
- Palliative care consult & family meeting
  - Hospice appropriate
  - DPOAHC on board, family unsure, concern about wife, pt “firing” hired caregivers due to unwillingness to spend money
- Eventually able to meet caregiver burden, financial, care/support needs by transfer to VA palliative unit 9/2019
- Pt deceased 10/2019

RESOURCES

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QUESTIONS?

Thank you!

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