Decision Making Capacity: Pearls and Pitfalls

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Disclosures

• I have no disclosures pertaining to this presentation.
Learning Objectives

• Identify frameworks on how to assess decision-making capacity (DMC)
• Recognize when a request to evaluate DMC requires more than the capacity evaluation itself
• Identify misconceptions when evaluating DMC
• Highlight our role as clinical ethicist through some real-world cases
CAPACITY

- Most common reason for a psychiatric consultation in the general hospital
- Relates to MDM
- Can be determined by ANY physician (not necessarily Psychiatrist!)
- Situation, Decision, Time specific
- Context
- Can vary over clinical course
- Ambiguous
- Clinical judgement

Huffman and Stern, 2003
• Key component **Informed Consent** = Info + DMC + lack of coercion
• No diagnosis precludes DMC
• Assessment of DMC demonstrates respect for patient **Autonomy**
• Autonomy when diminished via incapacity, in tension with 3 core Principles of Bioethics
  – **Autonomy**: liberty and agency
  – **Beneficence**: promoting patient wellbeing
  – **Non-Maleficence**: “Do no harm”
  – **Justice**: fair distribution of medical resources
Contd..

- Most common psychiatric diagnoses contributing to incapacity-
  - Cognitive disorders (54.1%)
  - Substance use disorders (37.2%)
  - Psychotic disorders (25%)
- Other medical diagnoses- neurological disorders. Impaired DC in hospitalized patients > 65 years old were
  - Alzheimer’s disease (39.4%)
  - Delirium (19.0%)

Torke 2014
Contd..

- Required for consent or refusal of treatment
- **Frameworks**
  - “Four skills” model
  - “Sliding scale” model
- Generally assessed by clinical interview and MSE
- **Formal assessment tools exist**
  - MacArthur Competency Assessment tool
  - Aid to Capacity Evaluation

CAPACITY: ELEMENTS:

• SHOULD DISPLAY ABILITY TO…
  • Communicate a (consistent) Choice
  • Understand the Relevant information
  • Appreciate the circumstances and consequences
  • Rationally Manipulate the information

Mnemonic: CUAR

Applebaum & Grisso
1998
CAPACITY DETERMINATION

Communicate a choice

- Ask patient to indicate choice
- Response need not be verbal
- Frequent reversals of choice because of psychiatric/neurologic conditions

Understand relevant information

- Awareness/nature of medical condition and proposed treatment
- Grasp the fundamental meaning of information communicated

Appelbaum, NJEM 2007
Appreciate the situation and its consequences

- Orientation to self, situation
- Acknowledge/Appreciate medical condition and likely consequences/risks/benefits of treatment options
- Courts have recognized that patients who do not acknowledge their illnesses ("lack of insight") cannot make valid decisions about treatment

Reason about treatment outcomes

- Rationale for decision
- Focuses on process by which decision is reached, rather than outcome
- Taking into account the past preferences and life decisions
- Assess insight/ denial/ delusions

Appelbaum 2007
Sliding Scale

![Graph showing Sliding Scale with DMC Threshold on the y-axis and Risk if pt's decision is honored on the x-axis.]

- Appoint surrogate decision maker
- Accept rec t/t
- Reject rec t/t
- Research participation
3-dimension model for evaluating capacity

Magid et al 2006
Neurocognitive Model of Capacity

• **Comprehension**- encoding and retrieval of treatment information

• **Short term memory**- limit the amount of encoded information available for further processing

• **Information processing**- internally arriving at a treatment decision

• **Expressive language**- verbal or written communication of the treatment decision

• Can use measures of receptive language, short-term memory, executive functioning, and judgment/reasoning to address them.
Common Scenarios

• Treatment consent/ refusal
• Discharge against medical advice
• Participation in disposition (dispositional capacity)
• Qualification for organ transplantation or major device (LVAD)
• Resuscitation (‘code’) status decisions
• End-of-life medical management decisions
When to Assess

- Informally ongoing
- Cognitive impairment
- Refusal of recommended intervention
- Patients with known risk factors that impair decision making ability
- Abrupt mental status changes, irrational behavior
- Decisions- High risk, significant diff in risks/benefits, inconsistent with previous decisions
Challenges

• “You must try to imagine a person very different from yourself.”
• Overly “cognitive”
• Not sufficiently attend to
  • Authenticity
  • Patient values
  • Affect or Emotions
• Extent to which the pt is informed of capacity assessment is unknown.
• Reliability- 33% CL psychiatrists came to same conclusion in standardized scenarios.
• 1 in 5 physicians not aware their personal values have an influence on DMC evaluations
• Black/Hispanic patients, underwent capacity assessments at a disproportionately high rate.

Challenges contd…

- **Medical beneficence** is equated with minimizing risk and maximizing longevity.
- In this framework, any treatment refusal can seem irrational.
- Not every person’s highest values. ‘Health’ is only one value among many.
- **Rationality** has precedence over emotion, by scientists and philosophers.
- Current model emphasizes **individual** making choice in isolation and/or in partnership with the clinician.
- Autonomy being ‘**self constituted**’?
- **Stated vs Demonstrated capacity**
Next Steps

• Capacity assessment as a “dialogue”
• Honest ideas about personal and professional values are exchanged
• Identifying patient’s underlying values, rather than challenging the patient to defend a decision through reasoned argument.
• Create room for negotiation
• People commonly consult with trusted others for help with making choices
• Neuropsychological exam
• Avoid medical jargon
• Can use proportion/percentages
What should the consultant know before seeing the patient?

- Why is the consult being requested?
- Determine the type of DC question
- Why do you think the patient may lack capacity?
- What is the patient’s medical situation?
- What are the treatment choices faced? Risks and benefits of these choices?
- What has already been communicated to the patient?
- Has the pt been told that psychiatry is coming to see him/her?
- Capacity to make what specific decision?
Psychiatric Interview

- Determine a **specific question** for DMC
- Guide psychiatric interview, to understand the risk involved, and ascertain how it may influence the recommended workup
- Chart review
- Collateral history- Family, hospital staff
- Know about the pt, relationships, demographics,
- **Standardized psychiatric interview** and **neurocognitive disorder workup**.
- **Noncognitive factors**- emotions, values
- Workup
  - Focused physical examination
  - Laboratory testing
  - Additional imaging and procedures where needed
  - Cognitive assessments such as MMSE or MoCA

Boettger et al 2015 Kontos 2015
Psychiatric/Neurological Diagnosis

- **MNCDs/dementias** - impairment in DC compared with age-matched elderly persons.
- Unless significant **acute decompensation**, psychotic/bipolar/depressive disorders are less likely to lead to impaired DC.
- Recommend delaying assessment of DC until acute effects of **intoxication and delirium** have resolved.

Hazelton et al 2003
Bipolar Disorder

• 97% of patients admitted to a psychiatric unit during a manic episode were deemed to be incapable of making a treatment decision.

• Low rates of impaired DC in depressed patients

• Decisional incapacity occurring in depressed patients who also demonstrated worse cognitive performance.

• Capacity for research consent- Manic patients performed worse than did non-manic bipolar disorder patients on the first trial, but by the third study consent there were no significant differences between the groups in understanding

• Iterative review of the consent process improved manic patients’ performance

MDD

- **Negativistic/Depressive biases** can produce controversial medical decisions.
- **Suicidal ideation** can inform a depressed patient’s refusal of life-sustaining treatment.
- **Authenticity** - figuring out if the patient’s seemingly pessimistic or morbid decisions are MDD-based.
- Look back at any **previous relevant decisions** made while euthymic
- Depression does **not necessarily invalidate** all seemingly pessimistic or morbid decision making.

Kontos 2015, Ganzini 1994
Psychotic disorders

• Schizophrenia- **significant heterogeneity** in DC when assessed

• Association between **severity of psychopathology**- correlation with impaired DC was much **lower** than **poor cognitive performance**

• Correlations between **negative symptoms** and impaired DC were stronger than for positive symptoms

• Even in significantly psychiatrically ill, 60%-70% had capacity to make some treatment decisions

Cognitive Impairment

- **Modify** the consent process to facilitate understanding and optimize patient performance
- Simplified written information, extended discussion and test/feedback techniques
- **Correct any reversible factors** in efforts to restore
- **Multimedia**
- **Interpreter service** - limited literacy/ limited English proficiency.
- **Memory and organizational aid** improved DMC in mild AD and Schizophrenia
- **Supported decision making** - independent advocacy or supportive networks of friends and family

Webb et al 2020, Buorgeouis 2019
DC-specific instruments

- Structured or semi-structured interview
- Does not provide a **dichotomous reductionistic decision** about whether a patient has DC or not.
- **Supplement**, but do not replace, clinical assessment and judgment.
- When utilizing a DC specific instrument-
  - Relevant **training required** for its administration
  - **Purpose** of using the instrument- screening vs comprehensive
  - Lack of **consistency** among instruments in defining each domain
  - Use a DC instrument that can incorporate specific medical treatment decision being proposed

“The search for a single test of competency is a search for the holy grail”

(Roth- Am. J. Psychiat.)
Pt refusal

- Lack of **trust** in clinician/medical system
  - Feeling interrogated
  - Questioning individual’s sanity and cognition
  - Personal experience/mistreatment that the medical community has imposed upon that patient’s religious, ethnic, racial, or cultural community.
  - Trauma
    - Religious and cultural minorities who do not accept the principles of allopathic medicine

- Approach to build trust and respect
- Address **interpersonal communication**
- Better **understand values and preferences**
- Align goals
- Judgement will need to be made with the info available.
DOCUMENTATION

- Careful documentation in medical record is essential
- Notes should include
  - Parties present during the evaluation
  - A description of the information disclosed
  - Applebaum & Grisso criteria/Sliding scale (Smart phrase)
  - A brief note on the patient’s mental status
  - Documentation of opinion of capacity (in this case, at this time..)
  - Educating the primary teams
  - Billing
  - Not just limiting the sole focus on the capacity question
THE INCAPACITATED PATIENT

SUBSTITUTE DECISION MAKING HIERARCHY

• Advanced directives/ Living will
• Health Care POA
• Spouse
• Adult Children
• Parents
• Siblings

Follow your state’s hierarchy
THE INCAPACITATED PATIENT

FACILITATING DECISION MAKING

• Law expects a singly surrogate decision maker
• Try to reach a consensus with all family members
• Appointed spokesperson if possible
• Court petition for guardian may be required

Challenges-

• What are the **logistics** of treating over objection?
• What is the **efficacy** of the proposed intervention?
• What is the likely **emotional effect** of a coerced intervention?

Rubin and Prager 2018
COMPETENCE

• Determined by a court of law

• **Legal judgment** (right to make informed decisions regarding self and property)

• If declared incompetent, guardian assigned

• Informed by an assessment of capacity

• Physicians make recommendations only

• May have to write a letter

• Presumed unless proven otherwise
Sample Guardianship Letter

Clerk of Court

Re: [patient name]

DOB: ______________

To Whom It May Concern:

I am writing concerning the aforementioned patient who was admitted to [name of service] on [date]. (He/She) was admitted to the hospital and is being treated for [diagnosis/symptoms]. MD has determined that [patient’s name] lacks capacity, as [he/she] is unable to comprehend the nature and severity of [his/her] medical condition. [Patient’s name] lacks the ability to care for self by evidence of the following [state concerns].

It is our opinion that [patient’s name] is not capable of conducting health, personal, and business affairs in a responsible manner, nor does [he/she] possess the capacity to understand and participate in [his/her] treatment. It would thus be in [patient’s name] best interest for an appropriate and responsible guardian to be appointed.

Respectfully,

______________, MD

Wake Forest University Baptist Medical Center

Department of ________________________________________________________________

Notary Public

has been sworn and scribed to me this ____ day of _______________
Unbefriended Patient

• No advance directive and a surrogate decision maker
• Guardianship- **Arduous process**. Approx 1.3 million adult guardianship cases in US
• High rates of **homelessness and psychiatric illness**
• ~70,000 unbefriended patients and long-term care residents in US.
• Involve SW, legal team, consulting services- psychiatry, neuropsychology, ethics, PT/OT
• **Remain hospitalized** for the duration that the hospital

Babb et al 2021
Guardianship Process

1. Medical Opinion
2. Petition to court
3. Hearing
4. Guardian Assigned
What can be done to better the process-

• **Education** of primary teams on assessing DMC and completing guardianship petitions

• **Early and standardized identification** of preferred surrogate decision makers

• Embedded support within the **EHR** to streamline HCP documentation

• **Partnering** with the legal system

• **Real-time review of cases** (especially in temporary guardianship)

• **Hospital-backed financial programs** to support families could eliminate public guardianship

• **Alternate arrangements for medically clear patients** awaiting guardianship- decrease costs and iatrogenic harm

• **Interdisciplinary teams** to make medical decisions for unrepresented patients.

Babb 2021, Syed 2020
Misconceptions

1. DMC and competence are the same
2. Lack of DMC can be presumed when patients go against medical advice
3. There is no need to assess DMC unless patients go against medical advice
4. DMC is an ‘ALL OR NOTHING’ phenomenon
5. Cognitive impairment equals lack of DMC

Ganzini 2004
Misconceptions contd..

6. Lack of DMC is a permanent condition
7. Patients who have not been given relevant and consistent information about their treatment lack DMC
8. All patients with certain psychiatric disorders lack DMC
9. Patients who have been invol committed lack DMC
10. Only mental health experts can assess DMC

Ganzini 2004, Munjal 2016
Scenario 1- DMC for EOL care

- Ms. A: 27 y.o. w/ granulomatosi with polyangiitis c/b by ESRD on HD for 7 years.
- **Psychiatric hx:** MDD; PTSD; tobacco/cannabis/cocaine use disorders.
- Presented to ED w/ passive SI and abdominal pain after 1 wk of missed HD.
- Repeatedly declined medications, diagnostics, and dialysis.
- “I do not want to live like this anymore,” with chronic illness and HD.
- CL psychiatry consulted for concerns about **MDD exacerbation**
- Determined she had DMC to decline dialysis.
- Distress stemmed from **demoralization** over 5 years of declining health + psychosocial stressors.
- **Interdisciplinary team** assembled: clinical ethics, palliative care, and CL psychiatry.
- Code status switched to DNR - her **values were independence and comfort, not longevity.**
- Discharged to hospice

Benjamin D. Smart, Sahil Munjal "I Don't Want to Live Like This Anymore": C-L Psychiatry and Clinical Ethics' Roles in Withdrawing Life-Sustaining Treatment. JACLP, Volume 63, Supplement 2, 2022, Page S170, ISSN 2667-2960,
### Scenario 1- Clinical ethics analysis for Ms. A’s case

| **Autonomy:** Respect for person’s intrinsic power to make choices for self-determination | • Patient expressed **consistent desire** for 2+ years to not pursue dialysis  
 • Despair with **quality of life** and wish to not live in this condition  
 • **Conviction** to pursue hospice care and withdrawal life sustaining therapies  
 • Decision to refuse daily medications respected in hospital |
|---|---|
| **Beneficence:** Act for patient’s benefit and promote welfare | • Metabolic and electrolyte abnormalities 2/2 ESRD **treatable** with dialysis and medications  
 • Physical pain symptoms treatable with opioid and non-opioid therapies  
 • Emergency hold for SI in ED; **Admission** to medical-psychiatric unit for 24/7 care  
 • Per rheumatology, patient could live full life on **immunosuppressants** and against withdrawing care |
**Nonmaleficence:** To not harm patient by avoiding death, pain, suffering, incapacitation, offense, and deprivation

- Emotional harm of administering treatment over objection.
- Withdrawal of dialysis and pharmacologic interventions would inevitably **cause death**
- Patient was without permanent **housing** and **transport limitations** and release from hospital would expose to associated risks

**Justice:** Fair, equitable, and appropriate treatment of persons; includes distributive justice of scarce resource

- Kidney transplants are a scarce resource
- Not a transplant candidate

**Informed consent:** DMC + full disclosure (risks, benefits, alternatives) + voluntarily accept/decline

Patient deemed to have medical capacity to refuse dialysis and pursue hospice care

‘We think death is a bad outcome but for patients life may be the bad outcome’
Scenario 2 Code Status, Professional Guardianship, and the Role of C-L Psychiatry in Determining GOC

- 38-year-old male w/ R MCA stroke, substance-induced bipolar disorder.
- Discovered unresponsive, hospitalized, C2-T1 epidural abscess found. Led to ventilator dependence and quadriplegia.
- Professional guardian assigned after family not reached.
- Psychiatry consulted, determined Mr. K had DMC to refuse sacral ulcer dressing changes that previously caused bradycardia and traumatic resuscitation. Despite this, professional guardian consented over patient’s objection.
- Patient requested DNR/DNI after palliative care discussion. Upon guardian request, DMC assessment provided by psychiatry and primary team. After several days delay, code status updated.
- One week later, Mr. K requested reversal to full code status. Guardian quickly agreed to care escalation without DMC assessment.
- Professional guardian consistently escalated Mr. K's care without seeking his input but required multiple professional opinions to consent to care de-escalation.
Professional Guardians

• **Substituted judgment**: when values are known.
• **Best interests standard**: when values are unknown.
• **Quality communication**: Disagreements may lead to prolonged suffering.
• **Conflict and tension**: Discordance between patient’s expressed wishes and guardian’s decision.
• **Patients often change life-sustaining treatment preferences** over time.
• Professional guardian’s **preference for care escalation**
• Providing care to patients against their wishes creates high potential for moral injury among healthcare staff.

Residence Capacity Evaluation of a Cognitively-Impaired Older Adult Requesting an “Unsafe” Discharge to Home

• 89-year F with back-to-back admissions for hypertensive crises and hyperglycemia.
• Family concerned that she is unable to manage medications and do her ADL’s
• Involved family and APS believed that SNF placement was the only safe discharge as she needed assistance with her ADLs due to dementia and frailty
• Pt adamant she wants to go home.
• Denied any risks associated with going home.
• Refused a formal cognitive battery but was fully oriented and named her medications.
Dispositional Capacity

- **Prediction**- behave in the *future*, able to *adhere to recommended medical advice, procedures, appointments, regimens and medications*.
- Hospital-based **OT assessment**- KELS to characterize functional deficits.
- Multidisciplinary team- Provide information to help determine a patient’s **functional status**
- SW can gather facts about **home environment**- filth/utilities are operational/food is available/rent or mortgage is paid.
- SW identify **supports available** in the community- prepared meal delivery or homecare services.
- **OT/PT** assess the patient’s level of mobility, risk for falls, recommending assist devices to improve home safety.
- **Nursing staff** can provide information on ADLs- ability to dress, toilet, and bathe.
- Family or homecare team can elucidate potential risks at home, including wandering, leaving pots burning on the stove, or unsafe driving
- Attempts should be made to find **alternative plans** that may be acceptable to all parties to preserve autonomy.

Schreiber 2018, Bourgeois 2018
Summary

• Four skills and sliding scale models are used in determining DMC
• Avoid misconception that all patients with psychiatric or neurological conditions lacks DMC
• Applying the principles of ethics- Autonomy, Beneficence, Non-maleficence and justice will help think through complex cases
• Answering capacity question leads to a cascade of identifying surrogate decision maker
• Understand the process of guardianship at your institution and the role of professional guardians
• Multidisciplinary approach will be required when answering questions about complex EOL care and dispositional capacity.
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Questions?

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