Assessing Medical Decision-Making Capacity:
The Palliative Care Social Worker’s Role on the Interdisciplinary Team

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Objectives

- Review the basic concepts of decision-making capacity
- Examine the existing strategies and tools for assessing capacity
- Explore how palliative care social workers can bring a more comprehensive approach to the assessment process
Decisional Capacity

Ability to:

Understand: the illness, the proposed treatment options and the risks and benefits;

Appreciate: how the medical information applies to a patient’s personal situation;

Reason: rationally evaluate and compare treatment options and make a decision; and

Express a choice: a relatively consistent decision across time
Why is Capacity Important?

- Social workers have an ethical responsibility to:
  - Provide care only with informed consent
  - Promote self-determination/autonomy
  - Give particular consideration to individuals whose capacity is questioned and those who lack decisional capacity

- An aging population means more people are living with illnesses that can impact capacity

- Decisional impairment is more common in patients with serious illness and at the end of life
General Principles

- Competence vs. Capacity

- Decision and time-specific

- Assess everyone, but evaluate more carefully if a person:
  - shows an abrupt change in mental status;
  - refuses recommended treatment;
  - consents too hastily; or
  - has a known risk factor for impaired capacity: neurocognitive disorder, intractable/untreated mental illness, severe depression, substance abuse, developmental disability, long ICU stay or end of life

- Generally assessed by physicians in health care settings
Assessment Pitfalls

- Don’t assume a lack of capacity based on age, appearance or family opinion

- Assess the decision-making process and not the decision itself

- There is generally no diagnosis that leads to an automatic determination of incapacity

- Be mindful of patients who are accustomed to covering up deficits

- There are often different rules for people with mental illness and developmental delays
Assessment Process

1. **Treat any underlying condition that may impact capacity:** medication, delirium, infection, substance use, depression

2. **Rule out:** speech/hearing/sight impairment, language barrier

3. **Directed Clinical Interview:** based on the four capacity components:
   - Understand the medical information
   - Appreciate how the information applies to one’s situation
   - Ability to reason
   - Communicate a choice
Assessment Process

4. **Standardized Tools**
   - MacArthur Competence Assessment Tool for Treatment (MacCAT-T)
   - Aid to Capacity Evaluation (ACE)
   - Capacity to Consent to Treatment Instrument (CCTI)

**Mini Mental Status Exam:** evaluates orientation, memory, attention, language, etc., but is not a substitute for a formal capacity assessment
Limitations of Standardized Tools

Well-defined, universally applicable and objectively verifiable criteria that focus on cognition, logic and rationality, but...

- People don’t approach decision-making in a strictly rational way: how we make decisions is more complex than the tools reflect

- The tools offer little guidance on how to elicit information on the wide range of factors that influence a patient’s decision-making

- We risk underestimating the decisional capacity of people who are guided more by these other influences
“Social workers bring a unique perspective to capacity assessment by holistically examining the person within the context of his or her social environment and by assessing both functional capacity and risks. It is this ‘person in environment’ that allows for a comprehensive assessment of capacity beyond the traditional medical approach.”

Social Work Roles

Participant in the clinical interview process:
- Link the influences on decision-making that matter to an individual to the specific decision in question
- Sensitive and transparent
- Flexible and attentive to each individual’s needs and preferences

Advocate:
- More explicit mention and discussion of the wide range of factors influencing decision-making
- Patient’s values and beliefs are heard, even if they are determined to lack capacity
- Establish and document wishes if further decline foreseen
Social Work Roles

Mediator: patient, medical team, family
- Coordinate the members of the care team
- Share what we learn in our comprehensive assessments
- Encourage open communication among everyone involved

Enhance capacity:
- Ensure any underlying medical or psychiatric illness is being treated
- Provide information in an easily understandable and culturally sensitive way
- Modify environmental factors when feasible
Regional Capacity Assessment Team (RCAT):

- Advance directives
- Living situation: environment, health, functional status
- Coping skills
- Religious/cultural factors
- Risk of abuse
- Social and family history (losses, relationships, roles, conflicts, support)

Capacity Evaluation Screen-Social Work (CES-SW):

- Sociodemographic variables: gender, age, education, health and finances
- Mental status questionnaire
- Modified ACE

Assessing Mental Capacity - A Checklist for Social Workers
Challenges

- Patient refuses a capacity assessment
- Potential for conflict between personal and professional values
- Finding the balance between the need for a universally applicable, value-neutral, concise tool and the need to recognize the complexity and specificity of each case
Moving Forward

- Advocate for social workers to be an integral part of the decisional capacity assessment process
- Seek out education and training on current and emerging assessment tools and approaches
- Promote an increased focus on a patient-specific approach through comprehensive assessments and patient narratives
- Contribute to research on developing tools that reflect the broad range of influences on decision-making


