Welcome to the APS Research to Practice Webinar Series!

This webinar is sponsored by the joint research committee of the National Adult Protective Services Association and the National Committee for the Prevention of Elder Abuse, with support from NCCD.

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“An Overview of the Assessment of Capacity for Everyday Decision-Making (ACED)”

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- Director of Penn’s Neurodegenerative Disease Ethics and policy Program
- Associate Director of the Penn Memory Center
- Director of the Alzheimer’s Disease Center’s Education, Recruitment and Retention Core.

Note: A copy of today’s presentation slides will be available along with a recording of the webinar on NCCD’s website within two weeks from today’s presentation.
An overview of the Assessment for Capacity for Everyday Decision Making

NAPSA-NCPEA webinar

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A 85-year-old woman is hospitalized for pneumonia and is now ready for discharge. Her friend and neighbor returns from the patient’s apartment. She’s discovered two mispaid bills, a ledger with cash transfers to her daughter, and two full bottles of medications.

The patient’s daughter says that everything is ok – “I’m looking after my mother fine” – and the patient should go home to her apartment.

The case manager asks you. “Can we send her home?”
The Capacity to Live Independently

You ask the patient whether she’d like a nurse to come over to assist with her medicines and review how things are going at home.

The patient replies, “No. I don’t like that compared to what I do. I don’t like people coming over to my private place, and I don’t want my daughter bothered.”
## The Capacity to Live Independently

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<tr>
<th>Able to perform IADL?</th>
<th>YES</th>
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What does the term “diminished capacity” mean?

• The decision making abilities
  – choice, understanding, appreciation, reasoning

• Capacity and competency
  – Capacity is the continuum of decision making abilities
  – “Being competent” or “having adequate capacity” is a judgment of a person’s decision making abilities

• Assessments of capacity are used to make judgments (not measurements) of competency
Why does this matter?

• It’s good that adults make, or at least participate in, their medical decisions – if they want to
  – The voluntary choice of a competent adult is a core ethic of medicine
  – Noncompetent patients need someone else to protect their well being, such as a family member
• Assessing capacity is a technique to assess the clinical significance of cognitive, and to some degree mental, impairments
• Capacity assessment improves conversations with patients (and families) more efficient and focused – even when capacity is not in question
Why does this matter?

• As people lose cognitive abilities, they are at risk of losing decision-making capacity
Competency by MMSE Score

- **Very Mild Stage**: Incompetent (46%), Competent (77%)
- **Mild Stage**: Incompetent (54%), Competent (23%)
- **Moderate Stage**: Incompetent (t=3.3, p=0.002)
- **Severe Stage**: Competent

**Legend**:
- Blue dots: MMSE Score
- Red square: MMSE Average
<table>
<thead>
<tr>
<th>ACED Understanding subscale</th>
<th>Patients (n=39)</th>
<th>Caregivers (n=13)</th>
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<tr>
<td>0</td>
<td>5 (13%)</td>
<td>0 (0%)</td>
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<tr>
<td>1-2</td>
<td>3 (8%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>3-4</td>
<td>9 (23%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>5-6</td>
<td>7 (18%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>7-8</td>
<td>6 (15%)</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>9-10</td>
<td>9 (23%)</td>
<td>12 (92%)</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>5.2±3.2</td>
<td>9.8±0.6*</td>
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* p<0.001
## ACED Appreciation Subscale

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<tr>
<td>1-2</td>
<td>13 (33%)</td>
<td>0 (0%)</td>
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<tr>
<td>3-4</td>
<td>16 (41%)</td>
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</tr>
<tr>
<td>5-6</td>
<td>3 (8%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>7-8</td>
<td>6 (15%)</td>
<td>13 (100%)</td>
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**Mean ± SD**

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<tr>
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<th>Patients (n=39)</th>
<th>Caregivers (n=13)</th>
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<tbody>
<tr>
<td>Mean</td>
<td>3.5±2.0</td>
<td>7.9±0.3*</td>
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* p<0.001
How is assessing capacity relevant to working with older adults?

- Chronologic age is one of the chief risk factors for developing cognitive and physical impairments.
- Cognitive & physical impairments can impair a person’s ability to perform IADLs.
- Cognitive & physical impairments can put a person at risk for abuse and exploitation.
- We want to protect those who cannot protect themselves.
The decision making abilities*

The ability…

• To understand
• To appreciate
• To communicate a choice
• To reason: comparative and consequential reasoning
What are the features of a capacity evaluation?

• What is the decision that needs to be made by the person?
• What evidence do you have that raises a concern that a patient has impaired ability to make that decision; that is, impaired decisionmaking capacity?
• Assess capacity
• What factors (cognitive and emotional) may be contributing to the problems the person is having making the decision; that is, impaired decisional abilities?
Does the person understand the functional problem?
Describe the functional problem the person is experiencing.
Ask the person to say this back in his/her own words.
Describe the consequences of the functional problem.
Ask the person to say this back in his/her own words.

Does the person appreciate the functional problem?
Does the person believe that he/she has the functional problem you described?
“Do you have any problems with [state the functional problem]?”
If the person does not believe he or she has it, ask why.
Does the person understand the options to manage the functional problem?
Describe the options to manage the functional problem. Ask the person to say this back in his/her own words.

Does the person appreciate the benefits and downsides of the options?
Describe the advantages to the options. Ask the person to say this back in his/her own words.

Does the person think that one of the options to manage the functional problem will benefit him/her?
“Please consider this choice [state an option to deal with functional problem]. Do you think [option to deal with functional problem] could benefit you?”
Does the person think that one of the options to manage the functional problem might make things worse for him/her?
“Please consider this choice [state an option to deal with functional problem]. Do you think [option to deal with functional problem] might make things worse for you?”
Expressing a Choice

Express a choice to manage the functional problem.
“Among the options you have to take care of [functional problem], which one would you pick?”

Comparative Reasoning

How is the person’s choice better than another option?
“What makes your choice better than [state another option]?”

Consequential Reasoning

What would happen if the person had to choose another option?
“How would [insert option to deal with functional problem] affect your everyday life?”
Final Choice

Final choice to manage the functional problem.
“Now that we’ve had a chance to talk about [functional problem] what would you like to do?”
Some “pearls”

• Unstructured conversations with clients tend to focus on their choice and reasoning (consequences and comparisons)
  – your mission is to structure the conversation, e.g. use the SPACED

• In persons with Alzheimer’s disease, the abilities to express a choice and to reason are well preserved into the moderate to early severe stage
  – but the abilities to understand and appreciate are not as well preserved; troubles knowing and “feeling” the facts
Some “pearls”

• While cognitive impairment often explains why a person has impaired decisionmaking capacity, a measure of overall cognition cannot substitute for an assessment of capacity
What does it mean to be “thoroughly evaluated?”

• The person needs to make a decision
• You have gathered evidence of their decision making capacity
• You have gathered evidence to support impairments, if any, in capacity
• You have identified any remediable barriers to capacity
• You have verified information with a knowledgeable informant
What is the role of a knowledgeable informant?

• The concept of the knowledgeable informant
  – some combination of frequency and type of contact
  – Can assess this by asking: “What is a typical day for [name of person]?”
Mean Scores on Total ADL

- **Comparison Group**
  - **Self**
  - **Family**

- **Alzheimer’s Group**
  - **Self**
  - **Family**

Group: NS
Time: F=6.54, p<.001
Time x Group: NS

Group: F=18.1, p<.0001
Time: F=29.4, p<.0001
Time x Group: F=9.78, p<.0001
Linear Trend: F=19.35, P<.0001
Cubic Trend: F=7.39, p<.01

## The Capacity to LiveIndependently

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<td>Able to decide how to manage IADL impairment</td>
<td>living independently</td>
<td>dependent and not OK</td>
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<td>YES</td>
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What if there is no informant to talk to?

- How to verify whether there is in fact functional impairment?
How to address fluctuating capacity?

• Think carefully about the timing of your assessment
  – watch out for the end of the day when person is fatigued and on the edge of “sundowning”
  – watch out for the person who was recently ill or hospitalized and is likely recovering from a delirium

• In tough cases, multiple data points help. Meaning, come back another day and repeat
Is there training to assess capacity?

- Yes, you’re experiencing it now!
- The ACED and SPACED manuals
  Jason.karlawish@gmail.com
- National Adult Protective Services Association (NAPSA) website has a “Resources” section
  - Click on the “NAPSRC core APS competencies training”
- Talking with your clients is an informal way to train
The Capacity to Live Independently

• Copies of ACED and SPACED:

jasonkarlawish@gmail.com
Save the Date: Thursday, June 12, 2014

Presenter: Jason Schillerstrom, M.D.
Assistant Professor of Psychiatry at The University of Texas Health Science Center at San Antonio (UTHSCSA)

Topic: Neuropsychological Correlates of Performance Based Functional Status in Elder Adult Protective Services Referrals for Capacity Assessments

Thank you!

www.napsa-now.org
www.preventelderabuse.org
www.nccdgglobal.org