

Decision making ability, capacity,  
and competency:  
What they are and how to assess  
them in persons living with dementia

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# Disclosures

- Site PI for joint Lilly/NIA sponsored clinical trial in persons at risk for Alzheimer's disease dementia

# Roadmap for the talk

- Be able to define what is decisionmaking ability, capacity and competency
- Have a working knowledge in how to assess each
- Have a working knowledge in how to incorporate the techniques of assessment into everyday practice

# Case

A 85-year-old woman is hospitalized for pneumonia and is now ready for discharge. Her daughter returns from her mother's apartment. She's discovered two mispaid bills and two full bottles of medications.

The case manager asks you. "Can we send her home?"

# Case

You present this option: “Let’s have your daughter come over to your house and set up your pills on a weekly basis and help you with the finances.”

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.”

# Why does this case 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, of life
  - Noncompetent patients need someone else to protect their well being, such as a family member
  - “in between” the competent and the noncompetent are persons who need support to make a decision, decisional ability can emerge from a relationship

# Why does this case matter?

- What if we thought of decision making capacity as an activity of daily living (ADL)? An assessment of decisional abilities could...
  - be a technique to assess the clinical significance of cognitive impairment
  - add to our knowledge of the nature and extent of a patient's disability
  - be a way to improve how we talk about disability

# Case

A closer look at what she said:

*expression of choice*

“No.”

*comparative reasoning*

“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 ability to make a choice

	Patients (n=39)	Caregivers (n=13)
0	1 (3%)	0 (0%)
1	0 (0%)	0 (0%)
2	38 (97%)	13 (100%)
Mean $\pm$ SD	1.9 $\pm$ 0.3	2.0 $\pm$ 0*

Most patients with even moderate AD can express a choice.

\*exact p=0.59

# The ability to comparatively reason

	Patients (n=39)	Caregivers (n=13)
0	9 (23%)	0 (0%)
1	7 (17%)	0 (0%)
2	22 (56%)	13 (100%)
Mean $\pm$ SD	1.3 $\pm$ 0.8	2.0 $\pm$ 0*

Many patients with even moderate AD can consequentially reason. <sup>\*exact, p=0.02</sup>

# ACED Understanding subscale

	Patients (n=39)	Caregivers (n=13)
0	5 (13%)	0 (0%)
1-2	3 (8%)	0 (0%)
3-4	9 (23%)	0 (0%)
5-6	7 (18%)	0 (0%)
7-8	6 (15%)	1 (8%)
9-10	9 (23%)	12 (92%)
Mean <sub>±</sub> (SD)	5.2 <sub>±</sub> 3.2	9.8 <sub>±</sub> 0.6*

\*z=4.84, p<0.001

# Making a treatment decision: choice

Measure and score	AD Patients (n=48)		Caregivers (n=102)	
	n	%	n	%
2	38	79%	99	97%
1	7	15%	3	3%
0	3	6%	0	0%
<u>Mean (SD)</u>	1.7 (0.6)		2.0 (0.2)	

# The decision making abilities\*

The ability...

We usually ask for this...



- To communicate a choice

- To reason: comparative and consequential reasoning

and, as the case shows, we get back a lot of this.



- To understand

- To appreciate




But we don't ask about this.

\*For a useful summary of these abilities and how to assess them, see Table 1 of Appelbaum. N Engl J Med. 357(18); 2007:1834.

# The decision making abilities\*

## The ability...

- To understand
  - To appreciate
  - To communicate a choice
  - To reason: comparative and consequential reasoning
- The case presented suggests that we need to focus more on these.
- 

\*For a useful summary of these abilities and how to assess them, see Table 1 of Appelbaum. N Engl J Med. 357(18); 2007:1834.

# Background

From the 1970's....

- The focus: “the mentally infirm”
- The concepts: reasonable person, rational reasons, capacity to reach a reasonable result, and competency

To the 1990's....

- The focus: “disorders that impair decisional capacity”
- The concepts: decisional abilities

# Core concepts

- 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
- The decision making abilities
  - choice, understanding, appreciation, reasoning
- Assessments of capacity are used to make *judgments* of competency



## Decision

## Instrument

enroll in research

MacCAT-CR

choose a treatment

MacCAT-T

vote

CAT-V

manage medications

ACED

manage finances

ACED

decide whether to have a  
genetic test

CAT-GT

# The ability to understand

- Definition: Comprehend the meaning of information
- Most common standard for competency used by the law and in theory of informed consent
- Impaired by:
  - Deficits in short term memory, semantic memory, education, literacy

# The ability to understand

- “Can you tell me in your own words what are the [*factual concept under assessment: risks / benefits / reasons to do / reasons not to do*]?”
- Any parrot can repeat verbatim — you are looking for the person to paraphrase the meaning of the facts.

# Making a treatment decision: understanding

Measure and score	AD Patients (n=48)		Caregivers (n=102)	
	n	%	n	%
5-6	13	27%	92	90%
3-4	14	29%	6	6%
1-2	10	21%	4	4%
0	11	23%	0	0%
<u>Mean (SD)</u>	3.0 (2.2)		5.4 (1.1)	

# The ability to reason

- Consequential reasoning: manipulating information in order to identify how it can affect you
- Comparative reasoning: manipulating information in order to identify the relative merits something
- Impaired by illnesses that cause impairments in attention, calculation and memory such as dementia, delirium, extreme emotional states such as mania, thought disorders such as schizophrenia

# The ability to reason

- Comparative reasoning: “Regardless of your decision about treatment, can you tell me how taking this is better than not taking it?”
- Consequential reasoning: “How might [taking this medicine / not taking it] affect your daily life?”

# Making a treatment decision: reasoning

Measure and score	AD Patients (n=48)		Caregivers (n=102)	
	n	%	n	%
Reasoning				
9-10	7	15%	68	67%
7-8	12	25%	28	27%
5-6	9	19%	5	5%
3-4	10	21%	1	1%
1-2	8	17%	0	0%
0	2	4%	0	0%
<u>Mean (SD)</u>	5.3 (2.9)		8.9 (1.4)	

# The ability to appreciate

- Definition: recognize how facts apply to you.
- You have the problem at hand (e.g. illness), evaluate its effects upon you and the effects of risks and benefits of options for taking care of the problem
- Requires the person to assign values to info
  - Are the values coherent & consistent?
- Impaired by illnesses that distort the perception of reality



# The ability to appreciate

- Appreciate the problem:
  - “Can you tell me in your own words what’s your medical problem?”
- Appreciate risk and benefit:
  - “Regardless of your decision about treatment, can you tell me what you see as the [benefit / risk] of this treatment to you?”
  - “Do you believe it is possible that this treatment might [benefit / harm] you? Why or why not?”

# Make a treatment decision: appreciation

Measure and score	AD Patients (n=48)		Caregivers (n=102)	
	n	%	n	%
<b>Appreciate risk</b>				
2	23	48%	81	79%
1	6	13%	19	18%
0	19	40%	2	2%
<u>Mean (SD)</u>	0.6 (0.7)		1.8 (0.5)	
<b>Appreciate benefit</b>				
2	7	15%	73	72%
1	16	33%	22	22%
0	25	52%	7	7%
<u>Mean (SD)</u>	0.9 (0.9)		1.6 (0.6)	

## Comparison of AD patient and CG insight into patient diagnosis<sup>1</sup>

	Patients (n=68)		Caregivers (n=68)	
	Yes	No	Yes	No
1) Do you have any problems with memory or thinking?	41 (60%)	27 (40%)	68 (100%)	0
2) Will your memory or thinking problems get worse*	24 (35%)	44 (65%)	66 (100%)	0
3) Do you have AD or dementia	23 (36%)	40 (63%)	66 (99%)	1 (1%)

Patients with mild to moderate AD (MMSE 30 to 12)

- Question asked of patients who responded yes to problems or mild problems with memory or thinking.

- <sup>1</sup>Wording of questions changed for CGs. E.g. “Does your relative have problems with memory or thinking?”

# Results of three expert raters' judgments of patient competency

Expert

Proportion competent

Expert 1

Expert 2

Expert 3

Results of three expert raters' judgements of patient competency.

<u>Expert</u>	<u>Proportion competent</u>
Expert 1	29/48 (60%)
Expert 2	16/48 (33%)
Expert 3	22/48 (46%)
Consensus of $\geq 2/3$	19/48 (40%)

Agreement among the three expert raters of competency.

Agreement (kappa)

Expert 1 vs Expert 2

Expert 1 vs Expert 3

Expert 2 vs Expert 3

E1 vs E2 vs E3

Agreement among the three expert raters of competency.

Agreement (kappa)

Expert 1 vs Expert 2	0.42
Expert 1 vs Expert 3	0.47
Expert 2 vs Expert 3	0.66
E1 vs E2 vs E3	0.5

## Relationship between overall cognition and competency

Range of MMSE

Proportion competent

≥24

10/14 (71%)

19 – 23

8/21 (38%)

12 – 18

1/13 (8%)



# Case

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Needs an Assessment of her Capacity to make an Everyday Decision (ACED)

Lai et al. Am J Geriatr Psych. 2007.

Lai et al. Am J Geriatr Psych. 2008.

# Anatomy of the ACED

Describe a problem

Understanding



Do you have this problem?

Appreciation



Describe some options

Understanding



Describe benefits/harms

Appreciation

# Anatomy of the ACED

What would you like to do?



How is this better than choice X?

Reasoning



What would happen if you chose choice Y?

Reasoning



Final Choice

Expressing a Choice

# The ability to make a choice

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# ACED Appreciation Subscale

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3-4	16 (41%)	0 (0%)
5-6	3 (8%)	0 (0%)
7-8	6 (15%)	13 (100%)
Mean <sub>±</sub> SD	3.5 <sub>±</sub> 2.0	7.9 <sub>±</sub> 0.3*

# Conclusions

- Instruments exist that can structure how we decide someone can make a decision
  - They focus us on ability, not status, or “reasonableness,” or simply cognition
  - They specify the abilities we ought to care about
  - They demonstrate where there are impairments
  - They explain the clinical significance of overall cognitive impairment and neuropsychiatric impairment
  - They provide us a coherent language to talk about the IADL of decisionmaking
  - They put assessment into our ethics

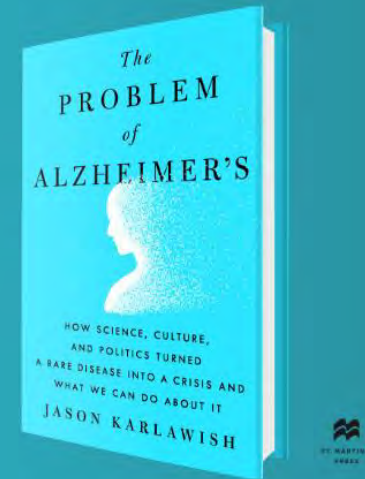


# References

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- ACED and SPACED: [jason.karlawish@gmail.com](mailto:jason.karlawish@gmail.com)

HOW SCIENCE, CULTURE,  
AND POLITICS TURNED  
A RARE DISEASE INTO A CRISIS AND  
WHAT WE CAN DO ABOUT IT

ON SALE FEBRUARY 23



## Part III. Living Well in the House of Alzheimer's

### Chapter 20, "Not Legally Dead Yet"