UCLA Health's Early Experience with AB-15, The California End of Life Options Act: Evidence and Terms of Discussion

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- I am the current Chair of the Test-Writing Committee on Hospice and Palliative Medicine.
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No exam questions will be disclosed in my presentation.

University of California and EOLOA

- President Janet Napolitano directed each of the 5 UC Health units (UCLA, UCSF, UCSD, UCD, UCI) to create its own Policy/Procedure for adhering to the law
- UCLA work group spends 6 months
- “State of the Art” Policy ready when law went into effect in June 2016

Goals of this talk
To address:

- Terminology and definitions
  - “mental disorder”
  - “impaired judgment”
  - “voluntariness and coercion”
- Clinical approaches to DMC
- Evidentiary gaps

When does the attending physician refer to an MHP?

- “If there are indications of a mental disorder, the physician shall refer the individual for a MH specialist assessment”
- “If a MH specialist assessment referral is made, no aid-in-dying drugs shall be prescribed unless the MH specialist determines that the individual has the capacity to make medical decisions and is not suffering from IJ due to a MD….”

443.5(A)(ii)(iii)

Mental Disorder

- California law does not define MD but alludes to most recent version of DSM
- DSM-V:
  - "a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning."
- DSM-IV:
  - "a psychological syndrome or pattern which is associated with distress (e.g. via a painful symptom), disability (impairment in one or more important areas of functioning), increased risk of death, or causes a significant loss of autonomy"

“Mental Health Specialist”

- …a psychiatrist or a licensed psychologist…

443.1(l)

Then What Happens?

443.7. Upon referral from the attending or consulting physician pursuant to this part, the mental health specialist shall:

(a) Examine the qualified individual and his or her relevant medical records.

(b) Determine that the individual has the mental capacity to make medical decisions, act voluntarily, and make an informed decision.

(c) Determine that the individual is not suffering from impaired judgment due to a mental disorder.

(d) Fulfill the record documentation requirements of this part.

What is “capacity”…..

(e) “Capacity to make medical decisions” means that, in the opinion of an individual’s attending physician, consulting physician, psychiatrist, or psychologist, pursuant to Section 4609 of the Probate Code, the individual has the ability to understand the nature and consequences of a health care decision, the ability to understand its significant benefits, risks, and alternatives, and the ability to make and communicate an informed decision to health care providers.

Section 4609. "Capacity" means a person's ability to understand the nature and consequences of a decision and to make and communicate a decision, and includes in the case of proposed health care, the ability to understand its significant benefits, risks, and alternatives.

California Code 813 & 4609: capacity to give informed consent to proposed medical treatment defined....

813. (a) For purposes of a judicial determination, a person has the capacity to give informed consent to a proposed medical treatment if the person is able to do all of the following:
(1) Respond knowingly and intelligently to queries about that medical treatment.
(2) Participate in that treatment decision by means of a rational thought process.
(3) Understand all of the following items of minimum basic medical treatment information with respect to that treatment:
(A) The nature and seriousness of the illness, disorder, or defect that the person has.
(B) The nature of the medical treatment that is being recommended by the person's health care providers.
(C) The probable degree and duration of any benefits and risks of any medical intervention that is being recommended by the person's health care providers, and the consequences of lack of treatment.
(D) The nature, risks, and benefits of any reasonable alternatives.
(b) A person who has the capacity to give informed consent to a proposed medical treatment also has the capacity to refuse consent to that treatment.

4609. "Capacity" means a person's ability to understand the nature and consequences of a decision and to make and communicate a decision, and includes in the case of proposed health care, the ability to understand its significant benefits, risks, and alternatives.

MHP Role under the law has two parts:

- To review and determine the patient's capacity to make medical decisions, act voluntarily and make an informed decision*, AND
- To discern whether or not the patient is suffering from impaired judgment (presumably, judgment related to the crucial decision at hand but this is not specified) due to a mental disorder, which requires:
  - To determine whether or not a mental disorder is present AND
  - To assess for impaired judgment AND
  - To causally link IJ, if present, to the MD

*The law requires the attending physician to do this so the MHP's effort is a review

"…impaired judgment due to a psychiatric disorder…."

- Oxford definition of "impaired"
  - Weakened or damaged
  - Having a disability of a specific kind
- Oxford definition of "judgment"
  - The ability to make considered decisions or come to sensible conclusions

Possible examples of IJ due to MD in patients who might otherwise "qualify" under AB-15

Fictional Cases:

- A severely depressed patient who has delusions of deserving punishment or death
- A patient with advanced dementia who cannot recognize the impact of her behavior on others
- A chronically hypomanic patient with recent impulsivity and an inability to appreciate the consequences of most actions
- A polysubstance-dependent man who has been impaired enough in recent years by his addictions so as to have been unable to make other important life decisions

Informed Decision

- (i) “Informed decision” means a decision by an individual with a terminal disease to request and obtain a prescription for a drug that the individual may self-administer to end the individual’s life, that is based on an understanding and acknowledgment of the relevant facts, and that is made after being fully informed by the attending physician of all of the following:
- (1) The individual’s medical diagnosis and prognosis.
- (2) The potential risks associated with taking the drug to be prescribed.
- (3) The probable result of taking the drug to be prescribed.
- (4) The possibility that the individual may choose not to obtain the drug or may obtain the drug but may decide not to ingest it.
- (5) The feasible alternatives or additional treatment opportunities, including, but not limited to, comfort care, hospice care, palliative care, and pain control

443.1.(i)

Voluntariness (for medical consent)

- Most agree that voluntariness requires two conditions:
  - Intentionality
  - Freedom from controlling influences
- Could it be that voluntariness to consent to a proposed procedure is different than voluntariness to request a desired procedure?

Nelson, Beauchamp, Miller, Reynolds, et al. The Concept of Voluntary Consent. Amer J Bioethics 2011; 11: 6-16

The AB-15 Mental Health Specialist Evaluation: Outline

- Examine patient and h/h relevant medical records
- *Screeners: Mood (PHQ-9 or like); Cognition (MOCA or like); others as indicated*
- *Focused history and psychiatric diagnostic interview*
- Capacity Evaluation *(Clinical discussion +/- bedside decision-aide such as ACE or Mac-CAT).* Includes verifying voluntariness and evidence of informed decision.
- Clinical clarification of "Impaired judgment due to mental illness" questions/issues
- *Feedback to patient/family*
- Written report to Attending/Consultant MD

CMA Document #3459: January 2016. Health & Safety Code 443.7

Coercion

- Generally construed to mean undue influence# by another person or entity
- Some scholars* posit “coercion by illness” either:
  - Cognitive difficulties (mainly, “disordered insight) or
  - Mood disturbance
- Garrison advocates application of “Law of Wills” tests:
  - “Insane Delusion” and “Undue Influence” doctrines
  - Some would say that the “impaired judgment” concept addresses this

#There is an “undue influence” clause in the California law

*Garrison M. The Empire of Illness: Competence and Coercion in Health Care Decision Making. Brooklyn Law School Research Papers 2008 #95

Capacity vs Competence

- Health Professionals engage *clinically* in the assessment of decision-making capacity
- Courts make *legal determinations* of competence
- Nothing in AB-15 countenances relying on Courts to make competence determinations….*

*famous last words!!

Components of a Capacity Assessment

- Functional abilities (see next slide)
- Psychopathology
- Task Demands
- Consequences of the Decision
- Reassessment (durability)

Abilities Necessary for Capable Decision-making

- 1. **Understand** treatment information
- 2. **Appreciate** the significance of treatment information for one's own situation
- 3. Ability to **reason** with relevant information: must demonstrate logical weighing of options
- 4. **Express** or communicate a durable choice

Berg JW, Appelbaum PS, Grisso T. "Constructing Competence: Formulating Legal Standards of Legal Competence to Make Medical Decisions." 1995 48 Rutgers L Rev 345

These criteria are broadly reflected in most US States and Canadian Provinces
Eckstein L and Kim SYH. Criteria for Decision-Making Capacity: Between Understanding and Evidencing a Choice. J Law Med 2017;24:678-694

Instruments to Perform Capacity Assessments

- MacCAT (MacArthur Competency Assessment Tool)
- Hopkins Competency Assessment Test (HCAT)
- Competency Interview Schedule (CIS)
- Capacity Assessment Guide (CAG)
- Aid to Capacity Evaluation (ACE)

A more comprehensive summary of tools and their performance characteristics Is available in the Sessums article, next slide

Relative Performance of Instruments

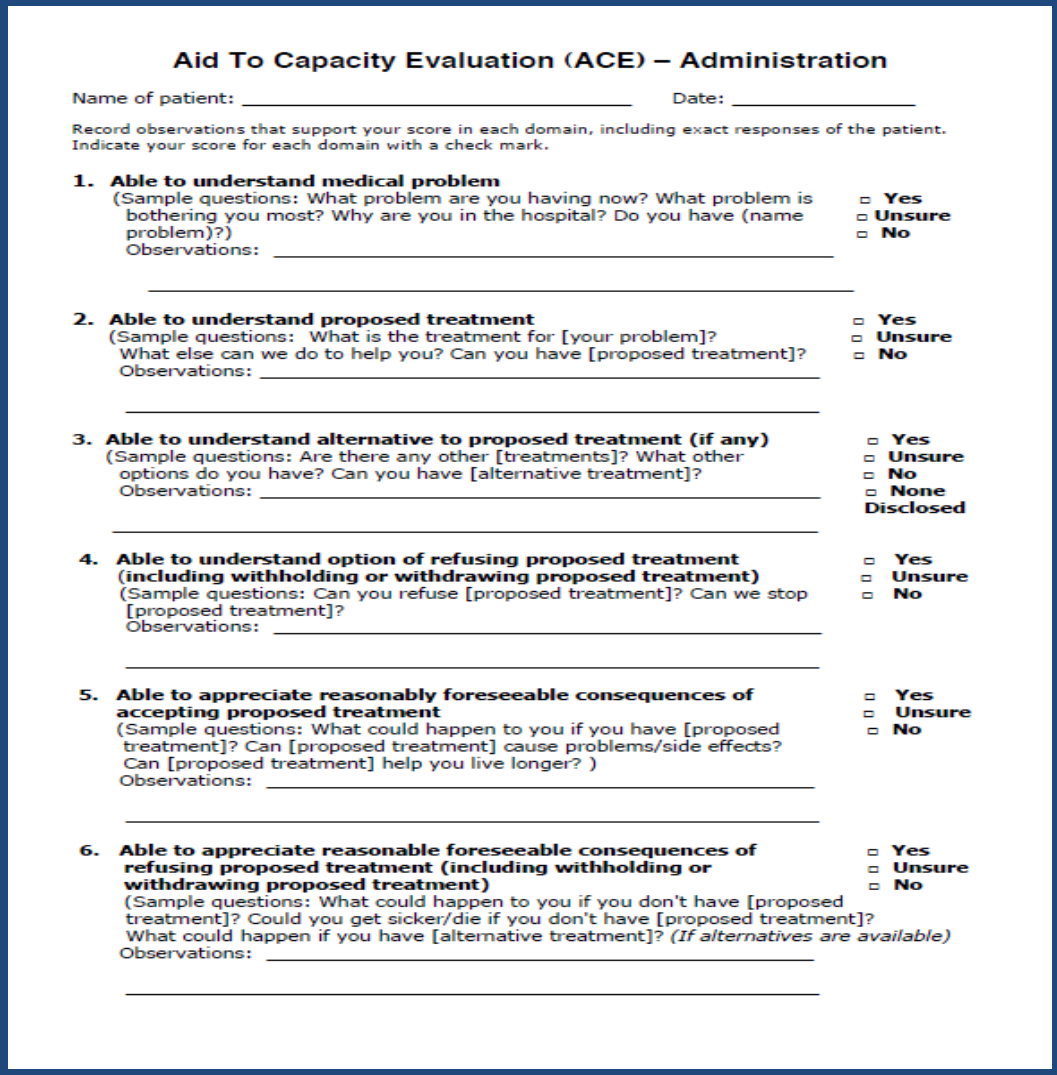
Table 2. Studies Comparing Capacity Instrument With a Gold Standard

Source	Capacity Instrument	Gold Standard	Level of Evidence[a]	LR+ (95% CI)	LR– (95% CI)
Janofsky et al,[38] 1992 (US)	Hopkins Competency Assessment Test (HCAT)	Forensic psychiatrist	2	54 (3.5-846)	0 (0.0-0.52)
Fazel et al,[3] 1992 (UK)	Fazel Questionnaire	Expert psychiatrist	3	9.4 (4.6-19)	0.07 (0.02-0.26)
Etchells et al,[27] 1999 (Canada)	Aid to Capacity Evaluation (ACE)	Forensic psychiatrist	2	8.5 (3.9-19)	0.21 (0.11-0.41)
Pruchno et al,[54] 1995 (US)	Understanding Treatment Disclosure (UTD)	Forensic psychiatrist	2	6.0 (2.1-17)	0.16 (0.06-0.41)
Fassassi et al,[28] 2009 (Switzerland)	Fazel Questionnaire	Expert psychiatrist	2	4.4 (2.3-8.3)	0.69 (0.56-0.85)
Pruchno et al,[54] 1995 (US)	Hopemont Capacity Assessment Interview (HCAI)	Forensic psychiatrist	2	3.8 (1.5-9.5)	0.38 (0.21-0.68)
Molloy et al,[49] 1996 (Canada)	Specific Capacity Instrument (score <16)	Competency panel	1	2.0 (1.5-2.8)	0.12 (0.04-0.37)
Billick et al,[23] 2009 (US)	Competency Questionnaire–Medicine (CQ-M)	Expert psychiatrist	2	2.0 (0.7-6.1)	0.33 (0.08-1.4)
Schmand et al,[57] 1999 (the Netherlands)	Clinical Vignette	Forensic psychiatrist	1	1.7 (1.1-2.4)	0.29 (0.12-0.71)
Rutman and Silberfeld,[56] 1992 (Canada)	Cognitive Competency Test (CCT)	Multidisciplinary competency panel	2	1.5 (0.87-2.7)	0 (0-3.0)

Abbreviations: CI, confidence interval; LR+, positive likelihood ratio; LR–, negative likelihood ratio.
[a] The Rational Clinical Examination level-of-evidence score rates the quality of studies of diagnostic tests on a scale from 1 (highest) to 3 (lowest).

Sessums et al. JAMA 2011;306: 420-427

Bedside Capacity Assessment Tool



Aid To Capacity Evaluation (ACE) – Administration

Name of patient: _____ Date: _____

Record observations that support your score in each domain, including exact responses of the patient. Indicate your score for each domain with a check mark.

1. **Able to understand medical problem**
   (Sample questions: What problem are you having now? What problem is bothering you most? Why are you in the hospital? Do you have (name problem)?)
   Observations: _____
   ▫ **Yes** ▫ **Unsure** ▫ **No**

2. **Able to understand proposed treatment**
   (Sample questions: What is the treatment for [your problem]? What else can we do to help you? Can you have [proposed treatment]?
   Observations: _____
   ▫ **Yes** ▫ **Unsure** ▫ **No**

3. **Able to understand alternative to proposed treatment (if any)**
   (Sample questions: Are there any other [treatments]? What other options do you have? Can you have [alternative treatment]?
   Observations: _____
   ▫ **Yes** ▫ **Unsure** ▫ **No** ▫ **None Disclosed**

4. **Able to understand option of refusing proposed treatment (including withholding or withdrawing proposed treatment)**
   (Sample questions: Can you refuse [proposed treatment]? Can we stop [proposed treatment]?
   Observations: _____
   ▫ **Yes** ▫ **Unsure** ▫ **No**

5. **Able to appreciate reasonably foreseeable consequences of accepting proposed treatment**
   (Sample questions: What could happen to you if you have [proposed treatment]? Can [proposed treatment] cause problems/side effects? Can [proposed treatment] help you live longer?)
   Observations: _____
   ▫ **Yes** ▫ **Unsure** ▫ **No**

6. **Able to appreciate reasonable foreseeable consequences of refusing proposed treatment (including withholding or withdrawing proposed treatment)**
   (Sample questions: What could happen to you if you don't have [proposed treatment]? Could you get sicker/die if you don't have [proposed treatment]? What could happen if you have [alternative treatment]? *(If alternatives are available)*
   Observations: _____
   ▫ **Yes** ▫ **Unsure** ▫ **No**

Etchells E, Sharpe G, Elliott C, Singer PA. Bioethics for clinicians: 3. Capacity. *CMAJ*. 1996;155:657–61

Conceptual Shortcomings of Capacity Assessment Tools

- Generally conceived / organized around an affirmatively offered / proposed treatment* and refusal or acceptance
- Founded temporally on treater's belief that a specific proposed intervention is now (or will soon be) needed
- Do not account for patient-initiated request for intervention
- Do not measure patient's reasons / motives for seeking PAD
- Their utility has not been studied in the PAD setting

*Most of the tools emerge from conflicts/disagreements regarding physician-Recommended treatments, or sometimes based on concerns about incompetent assent

An across-state comparison….

Table. State Laws Authorizing Physician-Assisted Dying

	State, Year of Legislation				
	Oregon, 1997	Washington, 2009	Montana, 2009[a]	Vermont, 2009	California, 2016
Patient request	2 Oral and 1 written request	2 Oral and 1 written request	Court found that the consent of a terminally ill, competent adult to lethal medication protects physicians from liability for homicide; bill has been put forward in the current legislative session to impose rules	2 Oral and 1 written request	2 Oral and 1 written request
Waiting period	15 d between patient's second oral request and prescription; 48 h between written request and prescription	15 d between patient's second oral request and prescription; 48 h between written request and prescription		15 d between patient's oral requests; 48 h must pass between patient's final oral request and written request	15 d between oral requests (statute doesn't specify a timeline for the written request)
Witnesses	2 Witnesses required; 1 witness must not be a relative, beneficiary, employee of patient's health care facility, or attending physician	2 Witnesses required; 1 witness cannot be a relative, beneficiary, attending physician, or employee at patient's health care facility		2 Individuals at least 18 y old and not "interested persons"	2 Individuals, 1 must not be relative, beneficiary, attending physician, or employee at patient's health care facility
Capacity	If either physician suspects psychiatric/psychological disorder or depression, patient must be referred for counseling; no prescription provided without confirmation that the patient does not have impaired judgment	If either physician suspects psychiatric/psychological disorder or depression, patient must be referred for counseling; no prescription provided without confirmation that the patient does not have impaired judgment		If either physician has doubt whether the patient's judgment is impaired, patient must be evaluated by a psychiatrist, psychologist, or clinical social worker; no prescription may be given until capacity is established	If the attending physician suspects a mental disorder, patient is referred to a mental health specialist; no prescription provided until the specialist clears the patient of impaired judgment due to mental disorder
Diagnosis	2 Physicians agree death likely within 6 mo	2 Physicians agree death likely within 6 mo		2 Physicians agree death within 6 mo	2 Physicians agree death within 6 mo
Opt-out	Physicians may refuse to participate	Physicians may refuse to participate		Physicians may refuse to participate	Physicians may refuse to participate

[a] By court decision.

Gostin LO, Roberts AE. Physician Assisted Dying: A Turning Point? JAMA 2016; 315;249-250

UCLA Health Experience to date

- 9 referred for MHP evaluation
  - 2 died of natural causes before completion of EOLOA algorithm and before completion of MHP eval
  - 5 received aid-in-dying medication after MHP evaluation
    - Three ingested / died
    - One holding medication in reserve
    - One “passed” MHP evaluation; prescription pending
  - 1 patient suicided prior to EOLOA algorithm completion
  - 1 lacked capacity (hypercalcemia/brain mets/coma), did not receive aid-in-dying medication, died peacefully

Early Impressions

- Patients referred to MHPs at UCLA under California EOLOA describe reasons for seeking PAD that seem very similar to those reported more formally from Oregon's public database, and from the available scientific literature
- Those reasons focus on durable health values and personal perspectives on QOL, desire to control time/place of death, wishes to avoid prolonged disability/dependency/future symptom burden
- Referrals generally made due to abundance of caution: eg for history of "mental disorder," not necessarily current active symptoms
- Impaired judgment due to mental disorder has thus far not been a disqualifier for these patients*

*Hypercalcemic coma with brain mets led to lack of capacity conclusion, not disqualification due to impaired judgment due to mental disorder

Should requests for PAD be subject to different or similar capacity standards as other medical decisions?

PAD	Other Medical Decisions
Patient's Goal: Death	Patient's Goal: Other Health Outcome (generally)
Who initiates discussion?: Patient (By law)	Who Initiates: Clinician (generally); patient (sometimes)
Capacity/Consent Process specifically outlined by state law? Yes	Capacity/Consent Process specifically outlined by state law: No
Mandated Reporting? Yes	Mandated Reporting? No
Mandated Consultant MD? Yes	Mandated Consultant MD? No
Mandated Mental Health Eval: Yes if evidence of mental disorder	Mandated Mental Health Eval: No

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