

Physician Assisted Death, Decisional Capacity, and ‘Slippery Slopes’

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Disclaimer

The views expressed in this talk are my own.

They do not represent the position or policy of the NIH, DHHS, or the US government.

Topics I am asked to address:

- *Decision-making capacity and physician-assisted death*
- *The concept of the slippery slope as applied to the United States*
- *While commenting on evidentiary gaps*

Decision-making capacity (DMC)

(see Kim 2010; Grisso & Appelbaum 1998)

- DMC is the legal term in most modern laws
- What clinicians determine usually carries the day, except for unusual situations → then a judge decides = 'adjudicated DMC'
- Based on functional criteria (e.g., understanding, reasoning, appreciation, etc) that is decision-specific.
- Presumption of intact DMC in adults, but an assessment needed if cannot be presumed.
- Takes into account the context of the decision → the seriousness of the decision's consequences.

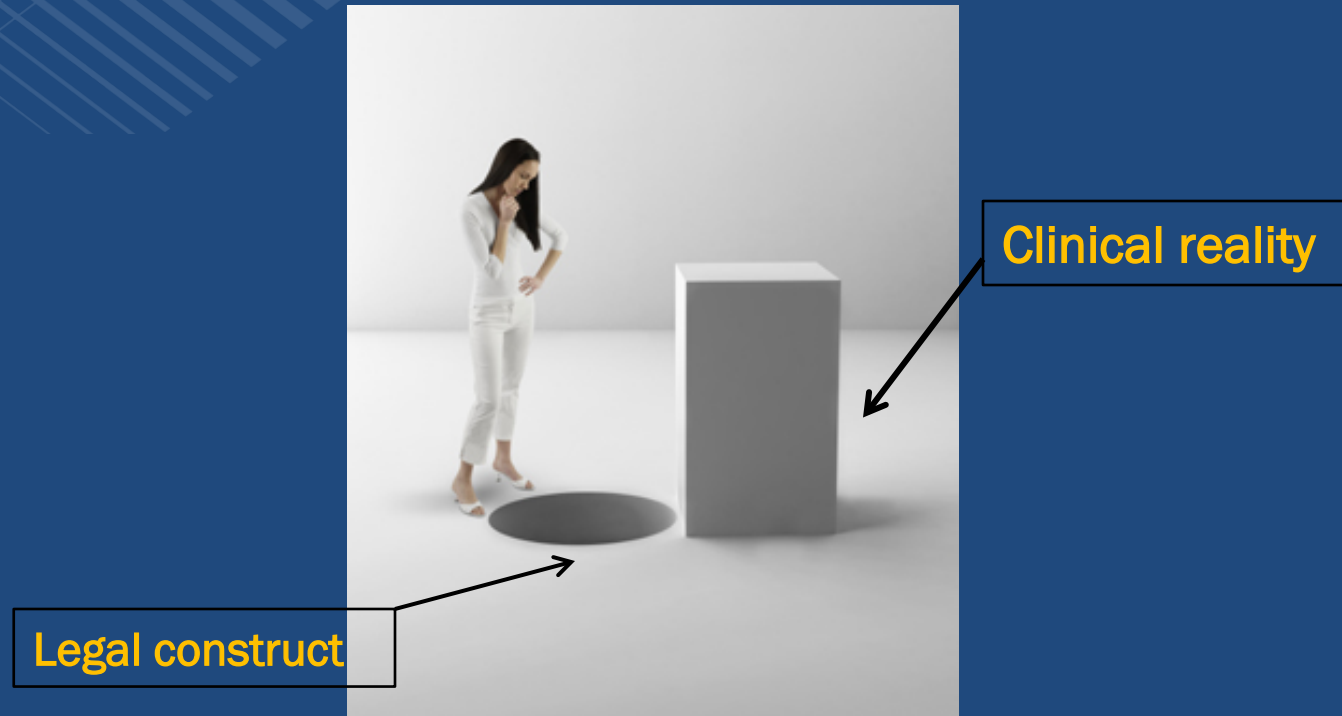
Main points re DMC, end of life, and PAD

- Are DMC assessment difficult or easy? It depends...
- Prevalence of cognitive and DMC *impairment* in terminal illness
- Reliability
- We have very little direct, systematic data on DMC for PAD

Who is right?

- “Competency is easily determined by the patient’s doctor.”
(Judge Dorothy McCarter, in context of PAD case, *Baxter v. Montana*, 2008)
- “The general law on mental capacity is... clear and easily to be understood by lawyers.” However, its “application to individual cases” is “infinitely more difficult to achieve.” (Butler-Sloss J, *Ms B v An NHS Hospital Trust*, 2002)

Legal construct and clinical reality



Legal criteria for DMC: often not very illuminating...

- A nearly tautologous definition:

“‘Incapable’ means that in the opinion of the court... or... the principal’s attending physician, a principal lacks the ability to make and communicate health care decisions to health care providers...”

(ORS §127.505)

Psychiatrists' views

- “Only 6% of psychiatrists were very confident that in a single evaluation they could adequately assess whether a psychiatric disorder was impairing the judgment of a patient requesting assisted suicide.” (Ganzini et al. AJP 1996 survey of Oregon psychiatrists)
- Psychiatrists' own ethical views re PAD may influence the level of scrutiny used in assessment.(Ganzini et al 2000, survey of forensic psychiatrists)
- 2/3 of consultation psychiatrists find DMC evaluations *more* challenging than other types of evaluations they perform. (Seyfried et al. 2013)

DMC in persons with terminal illnesses...

- Loss of DMC is very common at end of life (Silveira, Kim, & Langa. NEJM 2010)
- Nearly half of elderly terminally ill cancer patients failed a measure of capacity (Sorger et al, Behav Sci Law 2007):
 - “Without thorough and reliable evaluation methods, doctors may fail to recognize decision-making impairments even when they are pronounced.”
- ALS—once thought to be purely motor, now known that nearly 50% have cognitive impairment (various subtypes). (reviewed in: Khin et al, JAAPL 2015)
 - A DMC assessment would require more than a conversation.

Undetected cognitive impairment in hospice patients

(Burton et al 2012)

- From the leading DMC research group in geriatric psychiatry (UCSD).
- N=110, (inpt and outpt), mostly white, avg 70yo, 14yrs education.
- Specially selected for no documented or clinically obvious impairment or disorders that could cause incapacity->i.e., persons who would be presumed to have DMC.
- 54% with “significant cognitive impairment” (ie, in more than one domain), and significantly worse on DMC measure.

Data on competency specific to PAD requestors?

- Bannink et al. 2000 found 5/22 (23%) requestors at their hospital had “decreased competence”
- In 2/5 of cases, the primary doctors thought the patients were actually competent and would have assisted in death.

Reliability of DMC assessments

- Can be high:
 - If patient sample has bimodal distribution (Etchells 1999)
 - Familiar clinical decision, all psychiatrists, shared R/B framework (Cairns 2005)
- Can be low:
 - Evaluators of different backgrounds (Armontrout 2016)
 - Middle of distribution rather than the tails among impaired (Kim 2011)
 - **Unsettled areas of decision-making** (e.g., research consent—numerous studies; also, PAD context); differing views of evaluators on contested issues...
- Known disagreements among physicians assessing DMC in psychiatric patients receiving PAD (Kim et al 2016; Doernberg 2016)



***DISCUSS THE CONCEPT OF THE
SLIPPERY SLOPE AS APPLIED TO THE
UNITED STATES.***

“Slippery slope” usually refers to (undesired) expansion of PAD

- Two types of expansion:
 1. Expansion within practices
 2. Expansion of practice categories
- Normative significance of expansions?
 - Requires data for assessment
 - Do jurisdictions that permit PAD collect the type of data needed to evaluate this? (e.g., data on how decisions are made)
- Crucial because there is no natural feedback loop

Expansion of PAD in Application of Laws

- DMC and ‘impaired judgment’ assessments
 - How strong a presumption of capacity used?
 - Thresholds used?
 - Checklist style or in depth clinical interview?
 - Stand-alone community consultant or part of a “PAD evaluation team”?
 - Unless a system in place, the natural flow of referrals to “low threshold” evaluators.
- Determination of “terminal illness”
 - E.g., in Canada, some think 10y life expectancy based on actuarial tables is “reasonably foreseeable death”
- Outside US: assessment of “unbearable suffering” and “hopeless” and “no alternative”

What are the gaps in evidence?

- Because PAD laws' primary function is protection of MDs, no country has a monitoring system that can assess whether these types of expansions in practice occur.
- Currently monitoring in NL>Belgium, US, Canada.
 - But retrospective review of physician self-reports is not rigorous oversight (Miller&Kim 2017)
 - Large national studies are quite informative but they are mostly epidemiological and does not truly evaluate **decision-making** by doctors
- In the US, research funding is disease based; but death and ethics cut across diseases → precarious state of funding for PAD research .

Expansion of PAD: Categories

- Expansion of Categories of Persons
 - Removal of terminal illness requirement
 - Children
 - Decisionally incompetent at time of PAD
- Expansion of Practice:
 - PAD by appointment
 - Euthanasia
- I will make two comments re this.

1. The fragility of the terminal illness requirement?

“[Gardner] sees it as a first step. If he can sway Washington to embrace a restrictive law, then other states will follow. And gradually, he says, the nation’s resistance will subside, the culture will shift and laws with more latitude will be passed...”

–Booth Gardner, former two term governor of Washington, reported by Borgner in **NYT Magazine**, Dec 2, 2007.

POLICY-ISH

Despite Sweeping Aid-In-Dying Law, Few Will Have That Option

Updated October 9, 2015 - 10:00 AM ET
Published October 7, 2015 - 5:48 PM ET

ROBIN MARANTZ HENIG



(October 7, 2015)

“These restrictions might be necessary at this point in the history of aid in dying in this country, according to Judith Schwarz of the advocacy group End of Life Choices New York.

Schwarz said that maybe, very far in the future, there might be some way to cover dementia...

A death with dignity bill [in Utah] tried to broaden the safeguards to include people with a wider range of illnesses.”

2. Consequences of replacing “terminal illness” with “unbearable suffering”?

- The use of “unbearable suffering” criterion...
 - Could in theory require intrusive QOL judgment by an MD
 - To avoid this, most jurisdictions use a *subjective* definition of unbearable suffering
- Implications:
 - In practice, reduces to (or there is constant pressure to) mainly autonomy-based justification: strong libertarianism in practice.
 - Red flags become green flags: reasons for caution reframed as justifications for PAD (e.g., mental illness is a red flag in “terminal illness” based regime; but becomes green flag or justification for PAD under suffering framework)
 - Since terminal illness no longer serves as a natural backstop, and given the inequities in the health care system, futility becomes much more tied to social/health policy priorities.