Death with Dignity: The Oregon Experience and Future Implications

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DISCLOSURES

- Expert witness consulting and testimony in capital punishment cases proposing to use death with dignity drugs

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Death with Dignity in Oregon

- Introduction
- Background and implementation of DWD acts in United States
- Brief compare and contrast with Canada + Netherlands
- Pacific NW utilization of MAID
- Presentation of anecdotes, with attendant lessons learned
- Take home points

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Clarification of Terms

- Acceptable: physician-assisted death or dying; physician-hastened death/dying; (physician or medical) aid in dying (MAID); death with dignity (DWD); lawful physician-hastened death (LPHD)

- Incorrect: (doctor- or physician-) assisted *suicide*; *euthanasia*; mercy *killing*

Background: Implementation of United States MAID Initiatives

- By mid-1970's, all US states had decriminalized suicide
  - Significant number ruled withdrawing life-sustaining treatment also not murder/suicide

- 1976 *Quinlan* case: "Right to die" = Right to control one's body in setting of imminent death (father asking for ventilator to be turned off) New Jersey Supreme Court decision actually based on right to *privacy*
  - Ms. Quinlan breathed on own for 9 yrs after ventilator removed

Background: Implementation of United States MAID Initiatives (cont.)

- Oregon is both liberal and libertarian
  - First state to implement citizens' initiative process
  - Mandatory health care coverage for low income families
  - *But,* denounced compulsory vaccination and fluoridation ~10,000 times

Select Arguments Made for MAID Decades Ago

- Could increase patient autonomy
- Relieves suffering
- Patient inability to engage in enjoyable daily activities
- Life can technologically be extended when no longer meaningful

Adapted *Prof Psych: Research and Practice* 1999

Not-so-Select Arguments Made Against MAID

- “First, do no harm”
- May be utilized when physicians do not know how to manage a medical problem
- Slippery slope to active euthanasia
- Abuse of the disadvantaged
- Solely the province of “the divine”/diminishes sanctity and value of human life
- No such thing as rational suicide

Arguments Made Against MAID (cont.)

- Lose potential for personal growth during adverse time of life
- We cannot prognosticate well, so MAID leads to deaths in patients who would have otherwise survived
- The “system” and/or doctors are more interested in its/their pocketbooks than patient welfare

Adapted *Pediatrics 2018*

Background: Implementation of United States' DWD Initiatives

- Oregon state senator Frank Roberts (prostate cancer) introduced 3 PAD bills:'89,'91,'93
  - None got out of committee

- Washington (1991) and California (1992) tried/failed legalizing PAD
  - *But,* both allowed lethal injection

- 1993: Political committee Oregon Right to Die formed

Background: Implementation of United States' DWD Initiatives (cont.)

- 1994: Measure 16, "Oregon Death with Dignity Act" introduced
  - Squeaked by, with 51.31% of public's vote
- December 1994: First legal challenge: Oregon v. Lee
  - Temporary legal injunction placed on implementation
  - 1995+: Variety of district and circuit court rulings
- Truly became a legal option October 27, 1997
  - Implemented 1998

More State Opposition to Death with Dignity

- November, 1997: Measure 51 (Oregon Repeal of DWD) put on ballot
  - This time, 59.91% voters upheld PAD
    - By party: 72% Democrats; 51% Republicans; 83% independents
    - By religion: 34% Catholics; 40% Protestants; 89% “No religion”

Implementation: Next up, Trouble at the *Federal* Level

- 1997: US House Representatives Hatch and Hyde urged the DEA to penalize prescribing doctors
  - DEA Chief Thomas Constantine agreed

- 1998: Attorney General Reno reversed position, saying Department of Justice would not prosecute
  - Same year: Rep Hyde sponsored the Lethal Drug Abuse Prevention Act, designed to overturn OR law
    - President Clinton refused to sign

Oregon DWD Implementation: Still More

- 1999: US House passed Pain Relief Promotion Act, which barred physicians from following OR DWD
  - Failed to reach Senate floor
- 2001: US Attorney General Ashcroft issued directive: Prescribing schedule 2 medications under DWDA violates the Controlled Substances Act ("suicide is not a legitimate medical purpose")
  - Oregon countered medical practice is a state responsibility, not function of CSA; DEA should not dictate to physicians

Oregon DWD Implementation (Final)

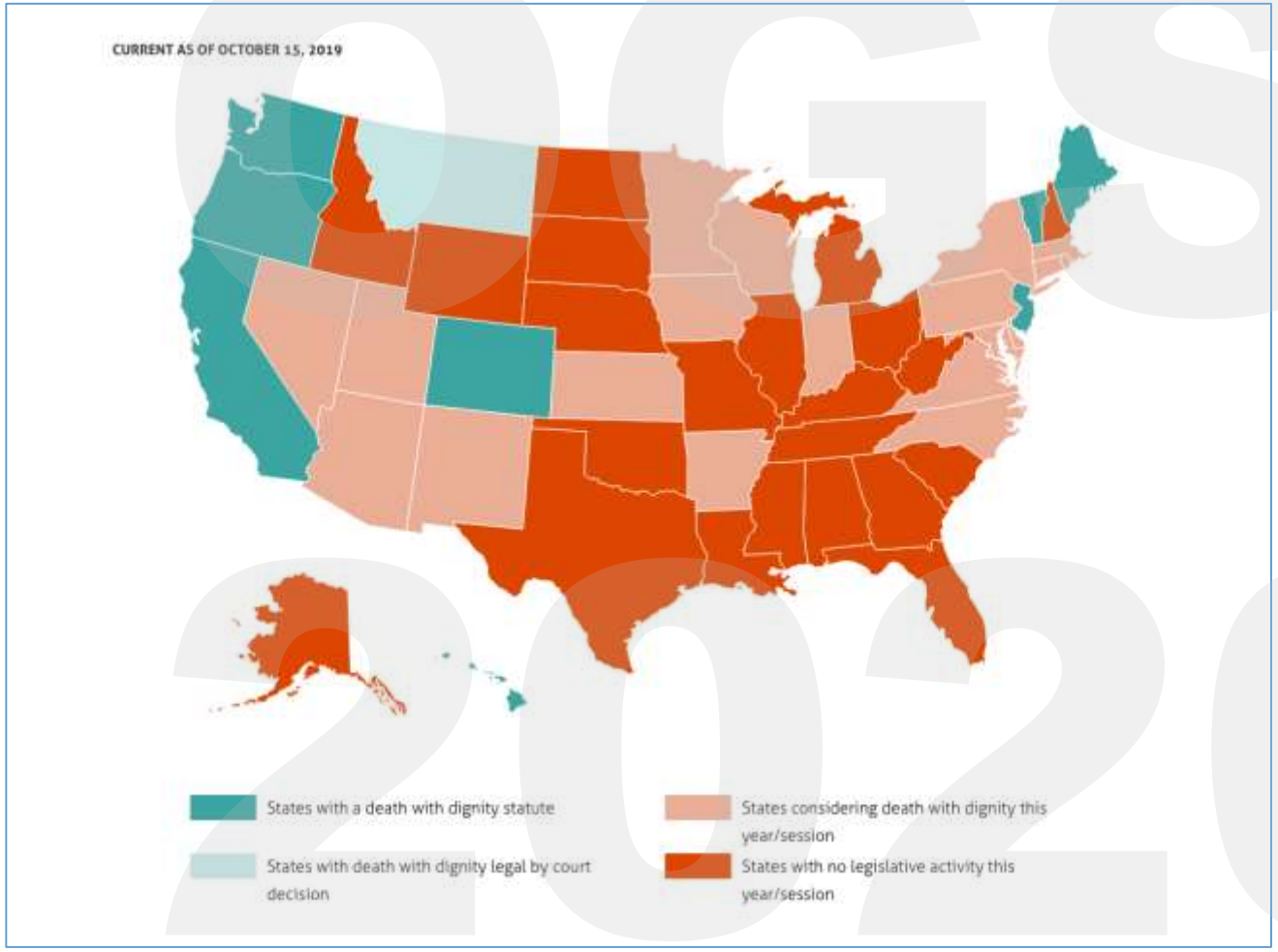
- 2004: Federal Appeals Court ruled Attorney General may not penalize doctors following state law
  - “Drug control is intended to halt drug traffickers, not regulate doctors or the practice of medicine”
  - Ashcroft retired
- 2005: US Supreme Court heard arguments *Gonzales v. Oregon*
- 2006: Court rules 6-3 to uphold Oregon’s law
- 2012: Poll showed *80%* Oregonians support DWD
- 2017: Potential appointment of anti-PAD Supreme Court Justice?

Legislating MAID: Summary

- Patients do not have a constitutional right to MAID
- The federal government cannot prevent states from making MAID legal *through regulation of prescriptions*
- The legality of MAID continues to be decided at the state level
  - 26 states have been considering recently

Spence, JOP 2017

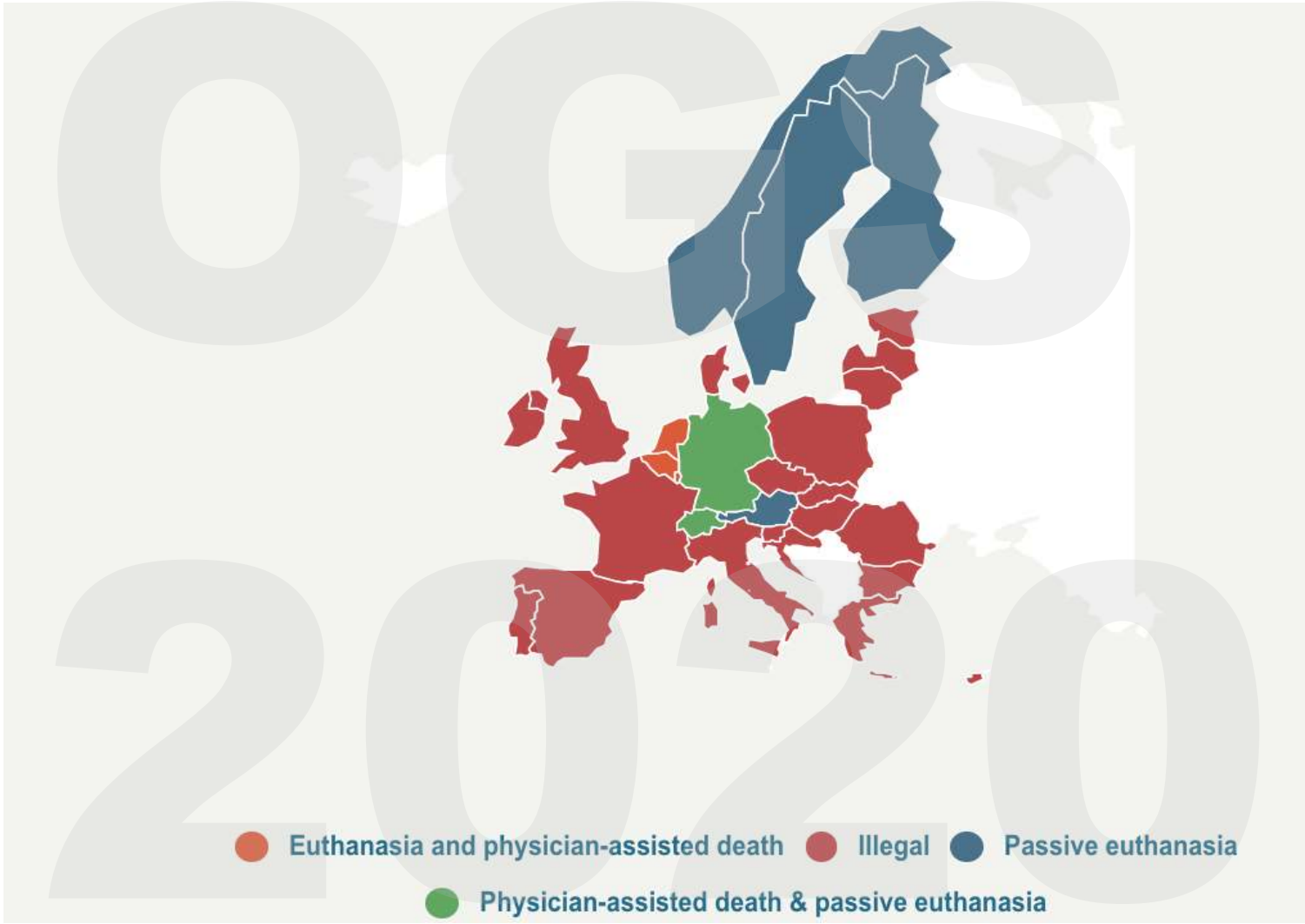
Other US MAID Implementation



*Briefly legal in parts of New Mexico

Adapted https://bit.ly/31iPSYh
Accessed 9/21/20

MAID and Euthanasia in Europe



https://bit.ly/2qiOEhD Accessed 9/21/20

OR Death with Dignity Rules and Regulations

- Oregon residency
- Life expectancy of ≤6 months (exception for imminently dying)
- Prescriber must be MD or DO *and* licensed in Oregon
- Patient must be capable of *making* and *communicating* health care decisions for himself/herself

OR DWD Rules and Regulations (cont.)

- Physician must inform patient of alternatives including comfort care, hospice, and adequate pain control
- Patient must make 3 separate requests for lethal medication
- Patient must be mentally competent *when script is written*
- No one may administer a lethal iv injection to another person

OR DWD Rules and Regulations: Greyish Areas

- Preparation (not really)
- Mental competence *at time of administration*
- Self-administration of oral versus parenteral formulations
  - Language requiring former only comes up in insurance clause: “ingestion”
- Advance directives (not really)

Records

- Oregon Health Authority requires timely collection of information about participating patients and physicians

- Includes demographics and number prescriptions written/taken
  - Above listed information + special requests publicly available

- Patient confidentiality is maintained
  - So is physician's

SEND A COPY OF THIS FORM TO THE OREGON STATE PUBLIC HEALTH DIVISION

ATTENDING PHYSICIAN'S COMPLIANCE FORM

ORS 127.800 - ORS 127.897

MAIL FORM TO: Oregon State Public Health Division, Center for Health Statistics, P.O. Box 14050, Portland, OR 97293-0050

PLEASE PRINT

A PATIENT INFORMATION

PATIENT'S NAME (LAST, FIRST, M.I.) | DATE OF BIRTH:

MEDICAL DIAGNOSIS

B PHYSICIAN INFORMATION

NAME (LAST, FIRST, M.I.) | TELEPHONE NUMBER

MAILING ADDRESS

CITY, STATE AND ZIP CODE

C ACTION TAKEN TO COMPLY WITH LAW

1. FIRST ORAL REQUEST FOR MEDICATION

Indicate compliance by checking the boxes | DATE

- ☐ 1. Determination that the patient has a terminal disease
- ☐ 2. Determination the patient has six months or less to live (If less than 15 days, check here: ☐ - see footnote 3.)
- ☐ 3. Determination that patient is capable[1]
- ☐ 4. Determination that patient is an Oregon resident[2]
- ☐ 5. Determination that patient is acting voluntarily
- ☐ 6. Determination that patient has made his/her decision after being fully informed of:
  - a) His or her medical diagnosis
  - b) His or her prognosis
  - c) The potential risks associated with taking the medication to be prescribed
  - d) The potential result of taking the medication to be prescribed
  - e) The feasible alternatives, including, but not limited to, comfort care, hospice care and pain control

Indicate compliance by checking the boxes. | DATE:

- ☐ 1. Patient informed of his or her right to rescind the request at any time
- ☐ 2. Patient recommended to inform next of kin
- ☐ 3. Patient counseled about the importance of having another person present when the patient takes the medication(s)
- ☐ 4. Patient counseled about the importance of not taking the medication in a public place

Comments:

2. SECOND ORAL REQUEST FOR MEDICATION

*Must be **15 days** or more after the first oral request unless patient is exempt[3]* | DATE:

Indicate compliance by checking the boxes.

- ☐ 1. Patient made second oral request for medication to end life
- ☐ 2. Patient informed of the right to rescind the request at any time

Comments:

Other Tidbits

- OR DWDA offers good faith protection against civil and criminal liability
- Cannot give script directly to patient
- Cause of death not suicide
  - Originally “drug overdose, legally prescribed”
  - Now underlying terminal illness
  - Insurance companies forbidden from denying benefits

Comparison: Canada

- 241(b) of the Canadian *Criminal Code* provided that aiding a person in committing suicide is an indictable offence, and s.14 stated that no person may consent to death being inflicted on them

- Carter v. Canada: Brought on behalf Carter (degenerative spinal stenosis) and Taylor (ALS)

- Carter premise: Prohibiting assisted suicide violates Canadian Charter of Rights and Freedom

Carter (cont.)

"In a unanimous decision on February 6, 2015, the Court struck down the provision in the Criminal Code, giving Canadian adults who are mentally competent and suffering intolerably and enduringly the right to a doctor's help in dying"

Carter Safeguards

Individuals who meet rigorous criteria should be able to avail themselves of assistance in dying:

- *Be a competent adult*
- *Clearly consent to the hastening of death*
- *Have a grievous and irremediable medical condition (including an illness, disease or disability), and*
- *Be suffering intolerably*
- Under discussion: mental incompetence; suffering minors

How is Carter Different from US Laws?

- Allows practitioner to *administer* lethal substance
  - Can be IV formulation
- Allows *nurse practitioners* to prescribe
- Natural death is “reasonably foreseeable” but a *specific prognosis need not be stated*
  - Grievous suffering counts
- Patients with dementia may qualify, but it’s complicated!

Carter Results*

Description	Data
Total number of medically assisted deaths (2018)	6,749
-Self-administered*	0.4%
In-hospital*	~48%
Cancer as cause*	70%
Urban setting*	65%
NW Territories, Yukon, Nunavut	NOYB

*varying denominators

https://bit.ly/3kByhDp accessed Sep 21, 2020

Comparison: Netherlands

- MAID/euthanasia if “only escape from unbearable suffering” (i.e., no prospect of improvement)
- IV meds (with a paralytic) are acceptable
- Patients age >12 may request
- Parents may request for very young infants
- Doctor must be present

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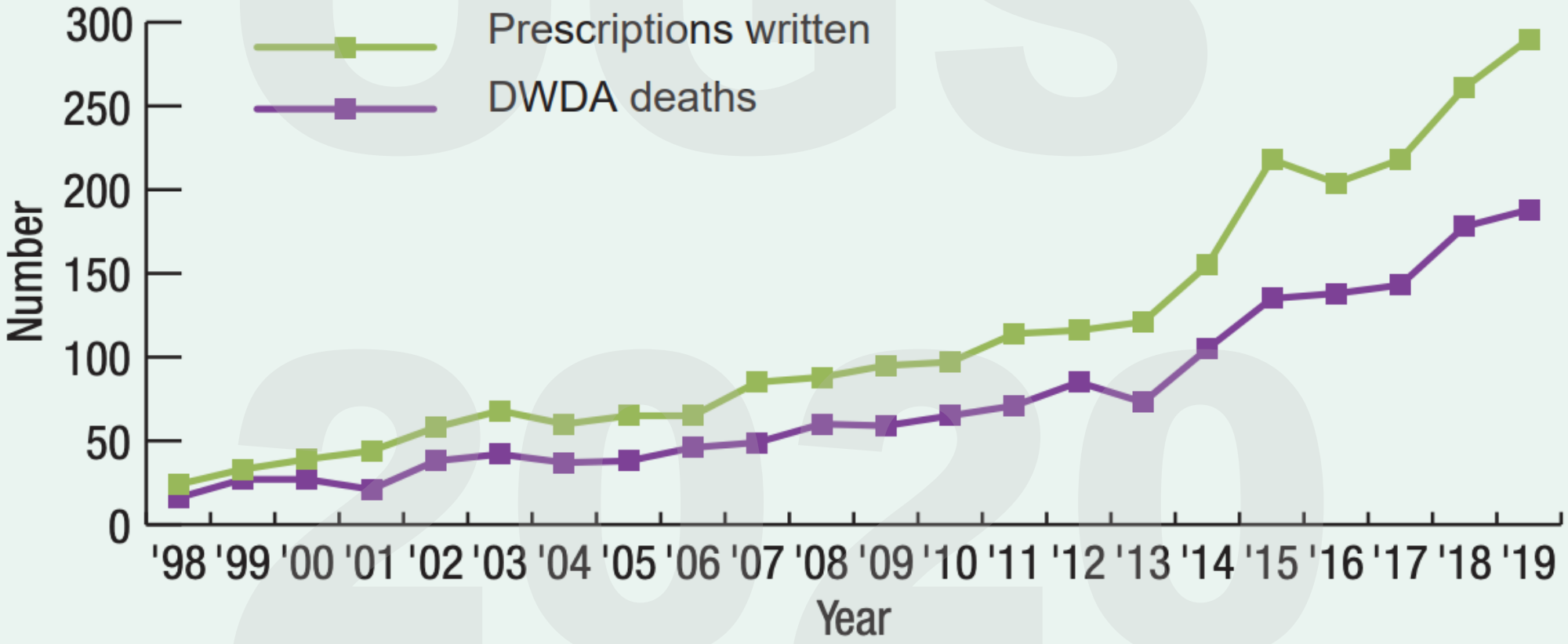
Oregon MAID General Results: 1998-2019

- 2,518 total patients had MAID prescriptions written
- 1,657 patients (66%) died from ingesting legally prescribed medication
- 374 Oregon physicians wrote DWD prescriptions through 2015
  - 91% wrote <5 prescriptions (range 1-85); 62% one
  - Max written 2019: 33 (45)

JAMA Netw Open. 2019;2(8):e198648
Ann Intern Med 2017
http://bit.ly/2IaKtss

Oregon Prescriptions Written v. Deaths



Courtesy OHA

Results: Process

	%
Referred for psychiatric consultation (2019)	0.34
Patient informed family of decision	95
Prescribing physician present when patient died	18
Patient died at home (%)	93

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More on Psychiatric Referrals

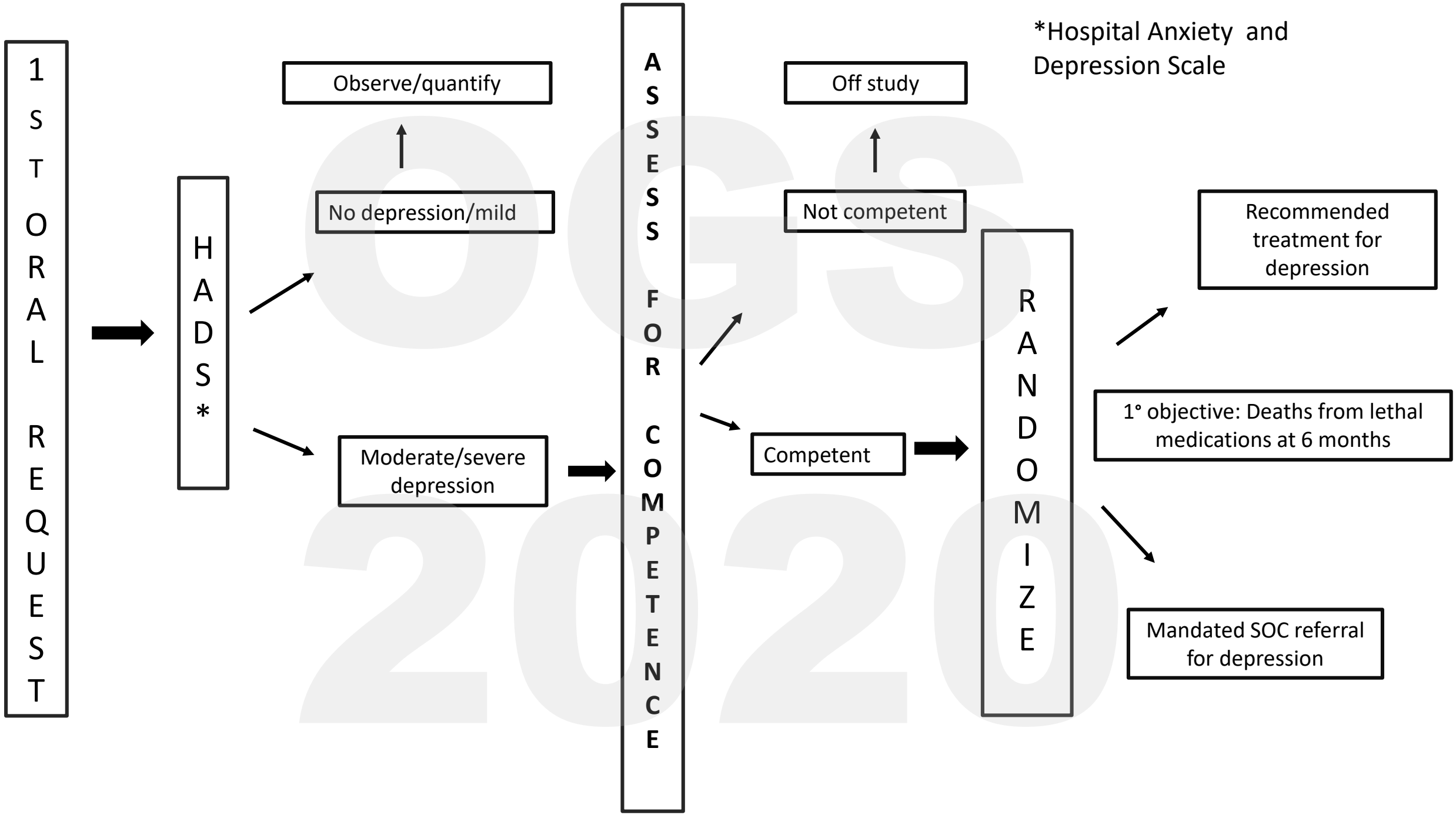
- No guidelines or (recent) court cases define decisional competency (=capability)
- Terminal patients in general tend to have sad mood but do they suffer from formal depression?
  - True incidence 25-77%

    and
  - 58% psychiatrists feel major depression renders patient incompetent
    - 38% feel dysthymia is sufficient to exclude

Am J Psych 2000

More on Psychiatric Referrals

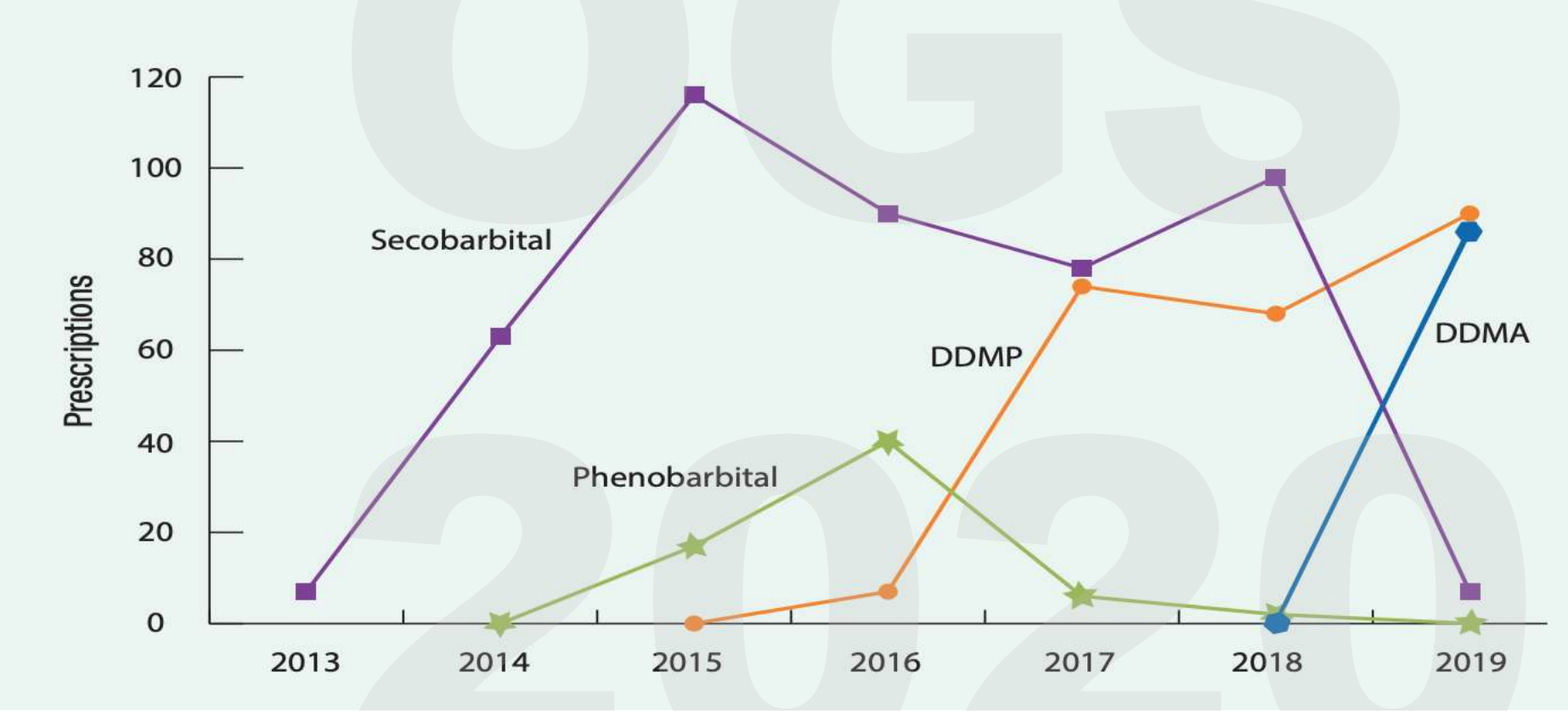
- 25% had clinical depression
- 22% suffered from anxiety
- Authors concluded DWDA may not protect pts with mental illness
  - They allowed depression *might* not influence judgment
    - *But,* quoted trial in which only 6% of OR psychiatrists are confident they can determine that in limited consultation
- "More research is needed"


1ST ORAL REQUEST
HADS*
Observe/quantify
No depression/mild
Moderate/severe depression
ASSESS FOR COMPETENCE
Off study
Not competent
Competent
RANDOMIZE
Recommended treatment for depression
1° objective: Deaths from lethal medications at 6 months
Mandated SOC referral for depression
*Hospital Anxiety and Depression Scale

MAID: Effectiveness and Complications

Median time to coma, minutes (range)	5 (1-240)
Median time to death, minutes (range)	30 (1-6,240)
Complications (%)	N= 1.8; Sz = 0.12
Regained consciousness #(%)	8 (0.48%)

Medications Used in DWD



- 2020: D-DMAPh

Source: OHA

Location of Practice, MAID Prescribers (2019)

Region	%
Metro	43
NW Oregon	33
Southern Oregon	16
Central Oregon/Gorge	6
Eastern Oregon	3
Unknown	2

Characteristics of Patients Who Have Died: Gender, Race, and Age

Gender	**(%)**
Male	53
Female	47
Race	**(%)**
White	96
Other	4
Unknown	0.3
Age median; range	72; 25-102 years

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Other Patient Characteristics

	%
Education ≥college	74
Enrolled in hospice OR	90.2
Medical insurance OR	98.8

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Underlying Terminal Illness

	%
Cancer	75
Neurologic	11
Lung disease	5
Heart disease	5
Endocrine disease	1

Reasons Underlying DWD Request

	%
Loss of autonomy	74
Cannot participate in enjoyable activities	89
Loss of dignity	47
Poor pain control	27
Cost of therapy	4

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Social Issues: Patient Homeless

- Patient clearly an Oregon resident
- Otherwise qualifies
- Literally nowhere private to take lethal meds
  - All in-patient hospices declined
- Asked me to come to cheap motel
  - I wanted motel to give permission, but that demand violates privacy
- Patient told motel anyway
  - I had to later tell a 22 year old assistant manager fresh out of hotel school there was a deceased person in room 316

Other Challenging Situations

- **Patient in any otherwise eligible situation is child**
  - Must be ≥18 for MAID
  - But, some want it available for children
    - Euthanasia situation Belgium *really* makes people uncomfortable
  - Hard to see it happening in US

- **Patient has to choose between hospice and MAID**
  - Hospice sometimes opposes (religion, etc.)
  - Hospice will not pay for meds or consults

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Other Random Problems

- Family members strongly oppose MAID
- Non-family member seems to be pushing agenda
  - Often seems to be for financial reasons
- No written advance directive
  - Neighbors called 911. Paramedics obliged to try to revive person who just took lethal med

Other Random Problems: Patient moving to non-MAID State

- Legal to bring meds? Yes (prescriber OK)
- Legal to take meds?
  - Family might not be protected
- Concerns about insurance death payment?

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Other Random Problems (cont.): Deriving New Formulations

- Secobarbital effective but $$$$$
- Triple cocktail (chloral hydrate) burns like wildfire
- :DDMX (digoxin, diazepam, morphine, other
  - July 2018: digoxin 20 minutes earlier
  - Mar 2019: X = a = amitriptyline
    - Phenobarb added several months ago = D-DMAPh
    - Burns like wildfire!

Deriving New Formulations: DDMP-2

- Empirically derived by cardiologist
- No animal data or “reverse” phase I trials
- Might be OK, or might just cause horrible dig toxicity
- No phase III comparison
- No one regulates off-label use of lethal meds
- When to adopt, if ever……..

New Concerns

- I have now been consulted by several attorneys representing condemned prisoners
  - Lethal injection fails 7% of time
  - DWD meds work 99.4% of time
- Some advocates want broader eligibility
  - No time period for terminal illness
  - IV administration (still by self)
  - Advance directive, to help those with early dementia
- Some advocates fear change will have nationwide backlash

Conclusions

- ~2/3rds of those given prescriptions for lethal medication fill the prescription and ingest the drug

- The medications are highly lethal and relatively fast-acting
  - Other complications are rare

- While the number of prescriptions written annually has generally increased, MAID deaths make up a very small fraction of overall resident mortality

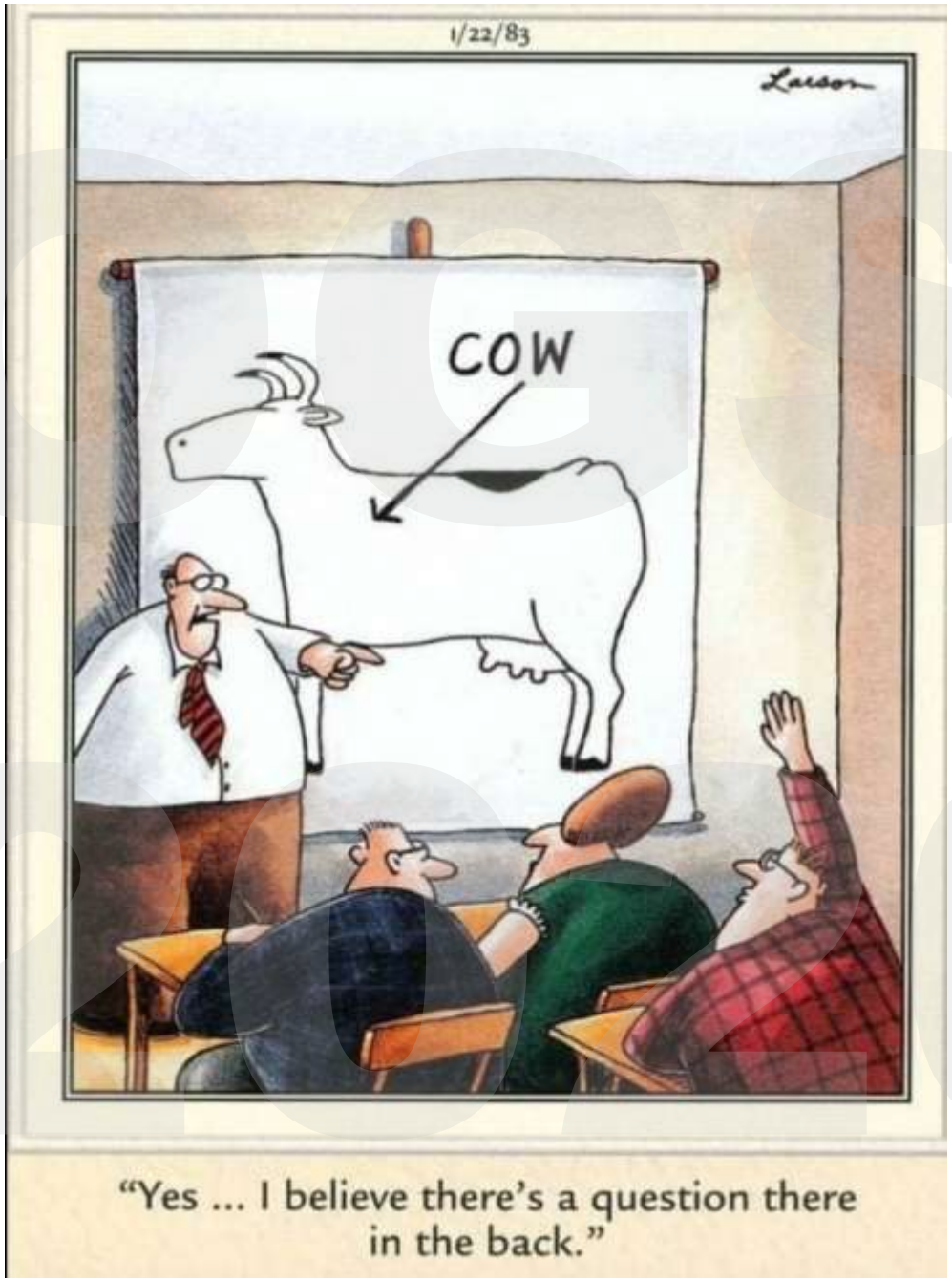
Conclusions (cont.)

- Patients are predominantly elderly, white and well educated; Gender is split evenly
- Almost all users take the medication at home
- Approximately 80% of patients have an underlying oncologic diagnosis
  - But 8-10% have neuro issues

Conclusions (cont.)

- The major end of life concerns prompting physician-aided dying in the Pacific NW are loss of autonomy, inability to enjoy life, and loss of dignity

- Research is hard to do, but is needed to understand:
  - Why one-third of patients do not take the lethal medication
  - Factors contributing to prolonged coma
  - How we can better palliate end-of-life concerns not related to pain
  - Whether treating depression affects DWD desire


1/22/83
Larson
COW
"Yes ... I believe there's a question there in the back."