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# Oregon's Death with Dignity Act: Data to Inform Policy & Research

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# OR Death with Dignity Act

- **Citizens' initiative:** passed 1994, 1997
- **Allows:** qualified terminally-ill patients to end their lives with legally-prescribed medications
- **Outlines:** process / requirements for patients; physicians; pharmacists; ***up to the point the prescription is written***
- **Requires:** Oregon Health Authority to monitor compliance; issue annual report

# Talk Overview

- Statutory requirements
- Data collection Process
  - Monitoring / reporting system
  - Compliance
  - Context: reasons for request, circumstances surrounding death
- 20 year experience
- Data issues for consideration

# Patient Requirements

- Oregon resident;  $\geq$  18 years old
- "Capable" - make / communicate health care decisions
- Terminal illness prognosis <6 mths
- Request voluntary

# Prescription Process

- 2 verbal requests: 15-day waiting period
- 1 written request: 2 witnesses
- Prescribing & consulting MDs
  - confirm diagnosis / prognosis
  - determine patient is "capable"
- Psych evaluation if appropriate
- Patient informed of alternatives

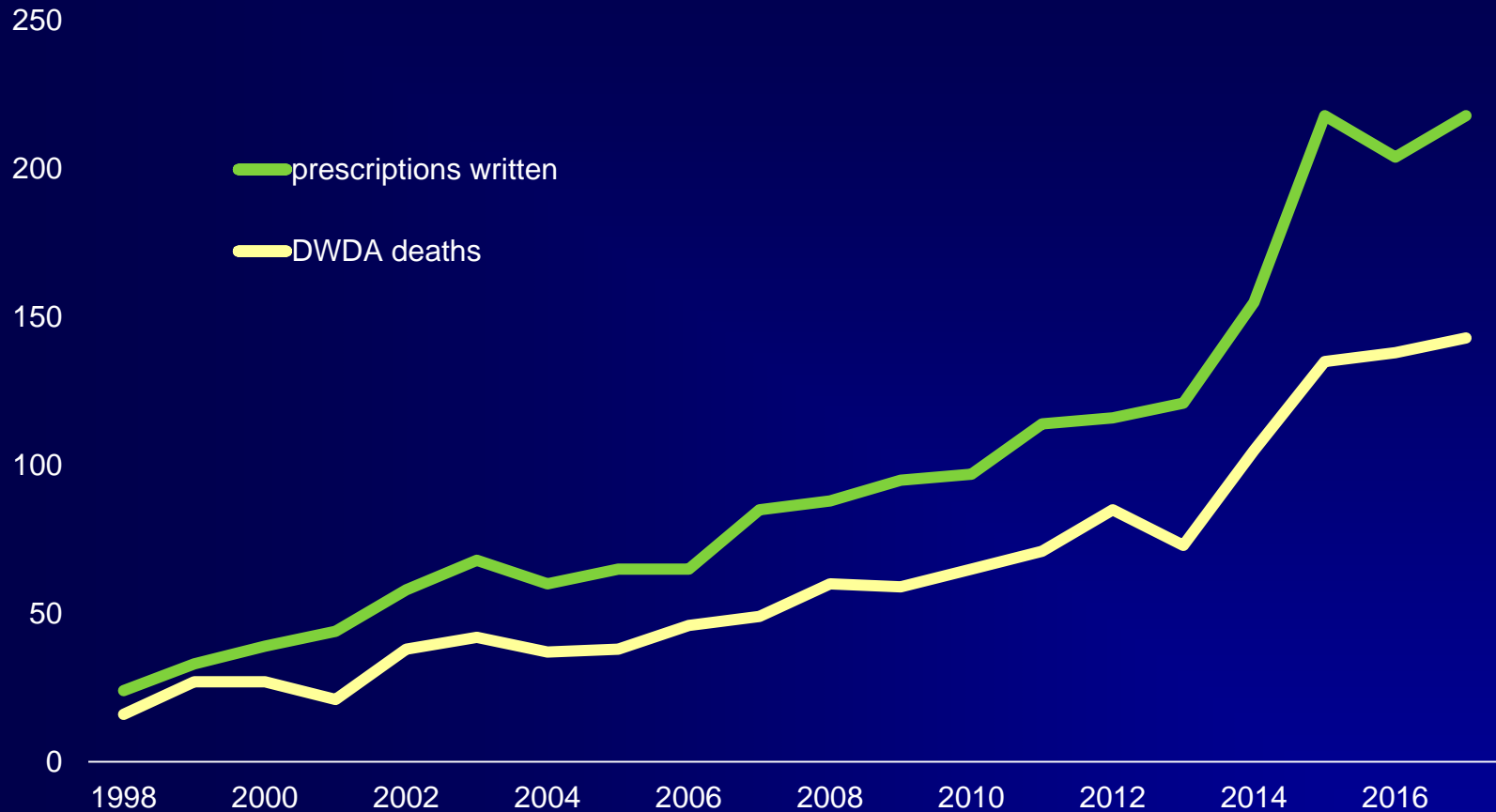
# Public Health Division: Monitoring and Compliance

- Data from mandatory reporting:
  - Process in administrative rule
  - After the prescription is written
  - Met law requirements: dates of requests, diagnosis, prognosis
  - Medications prescribed
- Non-compliance reported to licensing board
- Data from death certificates
  - Demographics, education level, underlying illness

# Data for Policy / Research

- Data from post-death follow-up reports
- How many people die from medications?
- Reasons for requesting DWDA:
  - “existential”, end-of-life care access, pain control, financial concerns
- DWDA process:
  - time to death, complications

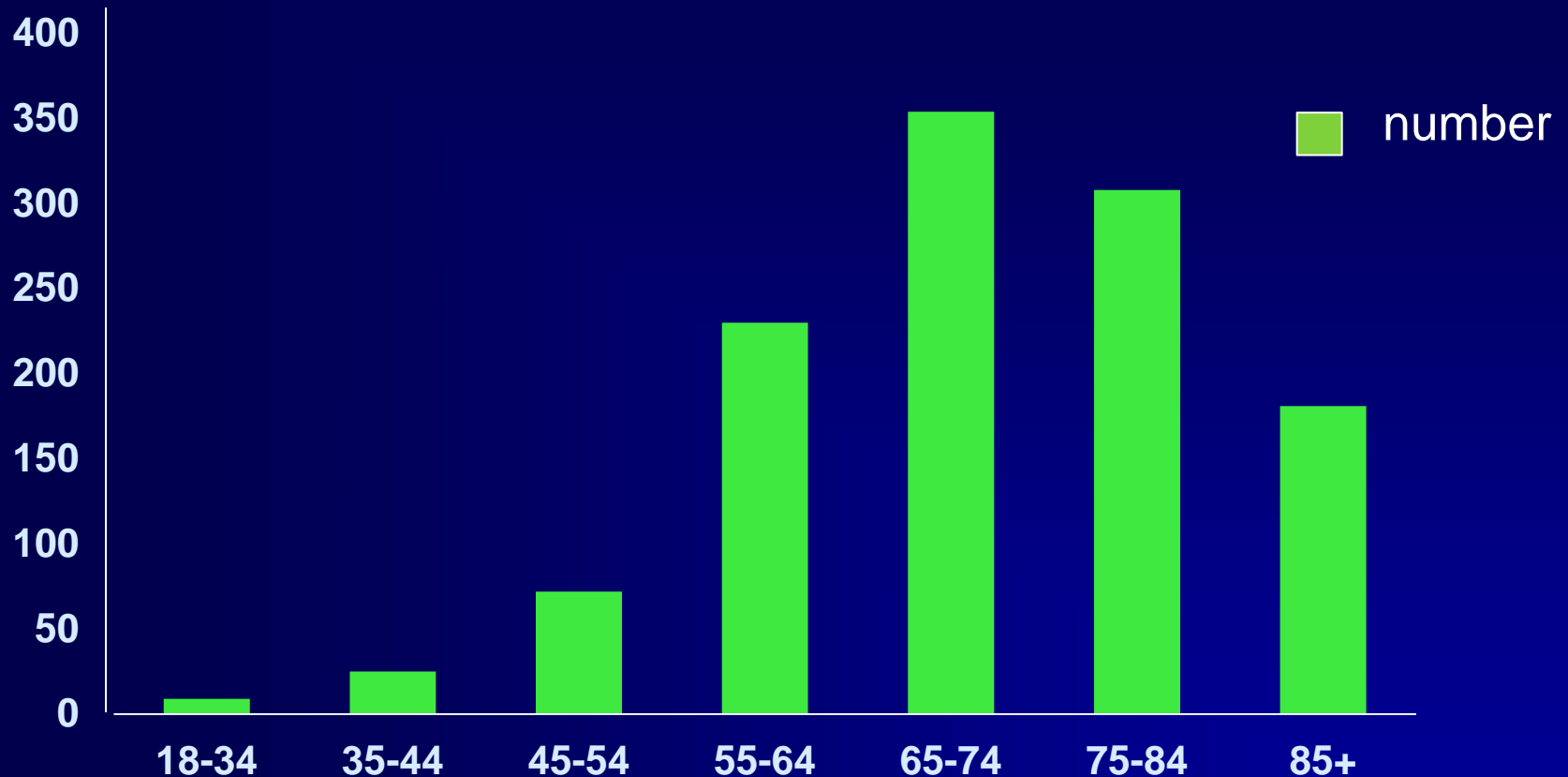
# Oregon's 20-year Experience



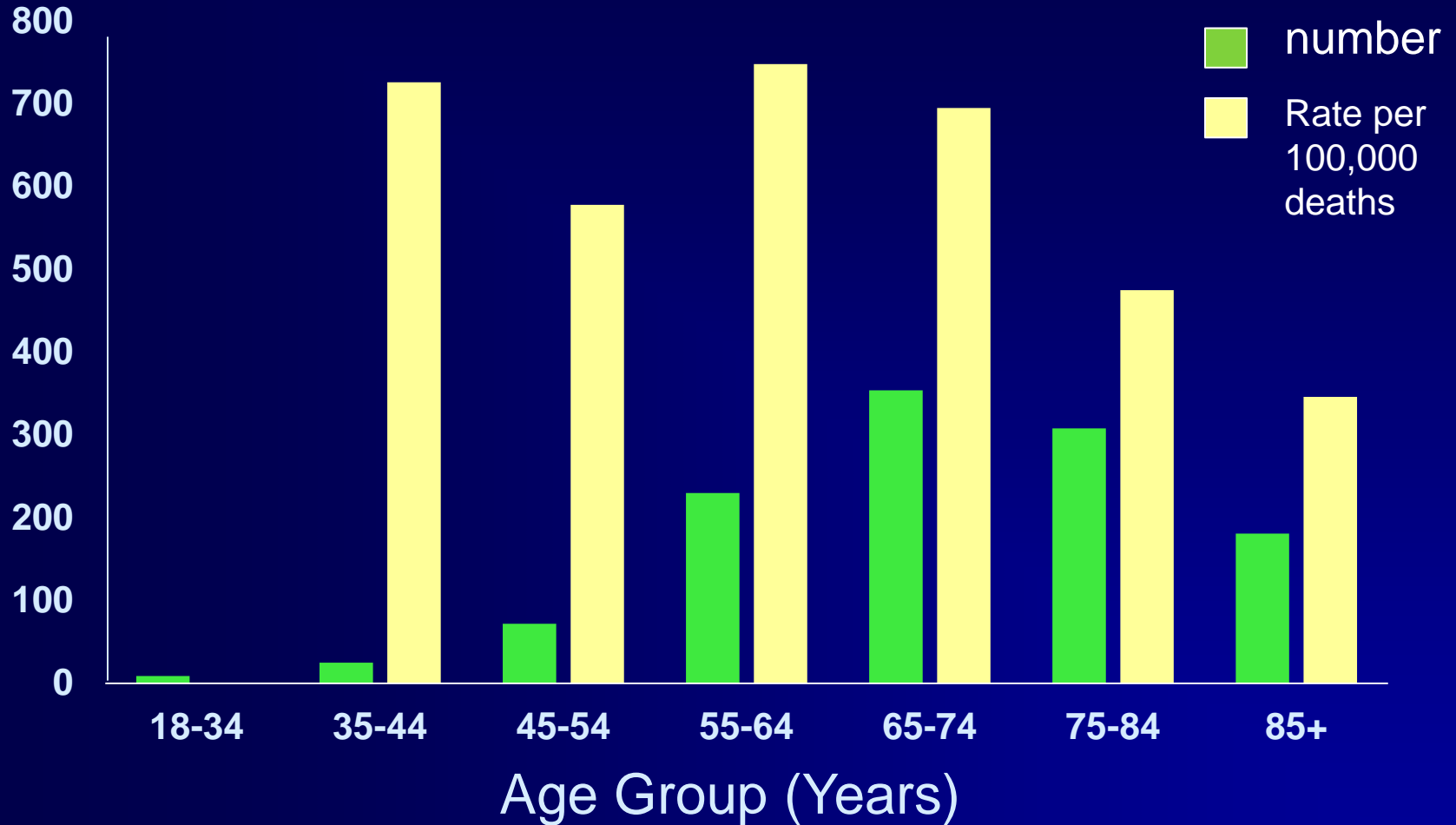


# DWDA Deaths by Age

Median = 72 yrs



# DWDA Deaths by Age



# DWDA by Education

<b>Education Level</b>	<b>DWDA Percent</b>	<b>Rate per 10,000 deaths</b>
< High school	6%	16.0
HS graduate	22%	28.5
Some college	26%	65.6
Bachelor's deg	24%	128.3
Graduate deg	22%	190.9

# Underlying Cause of Death

Underlying Dis	DWDA	Rate
Cancer	77%	65.5
ALS	8%	439.3
Respiratory Dz	5%	14.4
Heart Disease	2%	7.9
HIV/ AIDS	1%	141.4

# Physician Participation

- 2000\*-2017:
  - 374 physicians wrote prescriptions (range: 1-85)
- 1997-2017
  - 22 physicians reported to Oregon Medical Board
  - Reasons: Incorrect documentation; incomplete written consent; lack of two witnesses; not complying with waiting periods
  - OMB response: Found all MD's to be acting in "good faith compliance" with law

\*first year data tracked

# DWDA Process

Referred for psych eval	59 (5%)
Hospice	976 (88%)
Location of death	
home	1093 (93%)
assisted living	53 (5%)
Ingestion to death	
median (range)	25 min (1 min-104 hrs)

⇒ Seven people regained consciousness

# End-of-Life Concerns

- Losing autonomy 1070 (91%)
- Unable to participate 1054 (89%)
- Loss of dignity\* 802 (68%)
- Loss bodily control 546 (46%)
- Burden on family 503 (43%)
- Inadequate pain control 308 (26%)
- Financial concerns 41 (3.5%)

\* After 2003

# Data Collection Issues

- Reason for data
  - Monitoring, compliance, research
- Data collection method
  - Required reports, death certificates, special studies
- Source of Information
  - Providers, families, volunteers (secondary sources)
  - Patients (primary source)
- Balance
  - Confidentiality, transparency, regulatory



# Elements Not Included in DWDA

- Patient evaluation:
  - Reasons for request denial; depression evaluation; psychological autopsy
- Process between written prescription and death
  - Decision-making; re-evaluation of patient competency
- At time of death:
  - Who needs to be present at death; reporting of circumstances and complications
- After death: No required patient follow up

# Improvements in Data

- Role of government
  - Monitoring, compliance
  - Role of external stakeholders: Task Force to Improve Care of Terminally-ill Oregonians
  - Barriers to access/ reporting
- Role of academia / researchers
  - Why differences in SES of patients who participate
  - End-of-life care research; range of practices; shared decision-making; needed family supports
  - Medical ethics; doctor-patient relationship

# Questions?