

# End of Life Care: Why Community Matters

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# Objectives

- » Provide a history of physician aid in dying
- » Lay out arguments on both sides
- » Offer an alternative

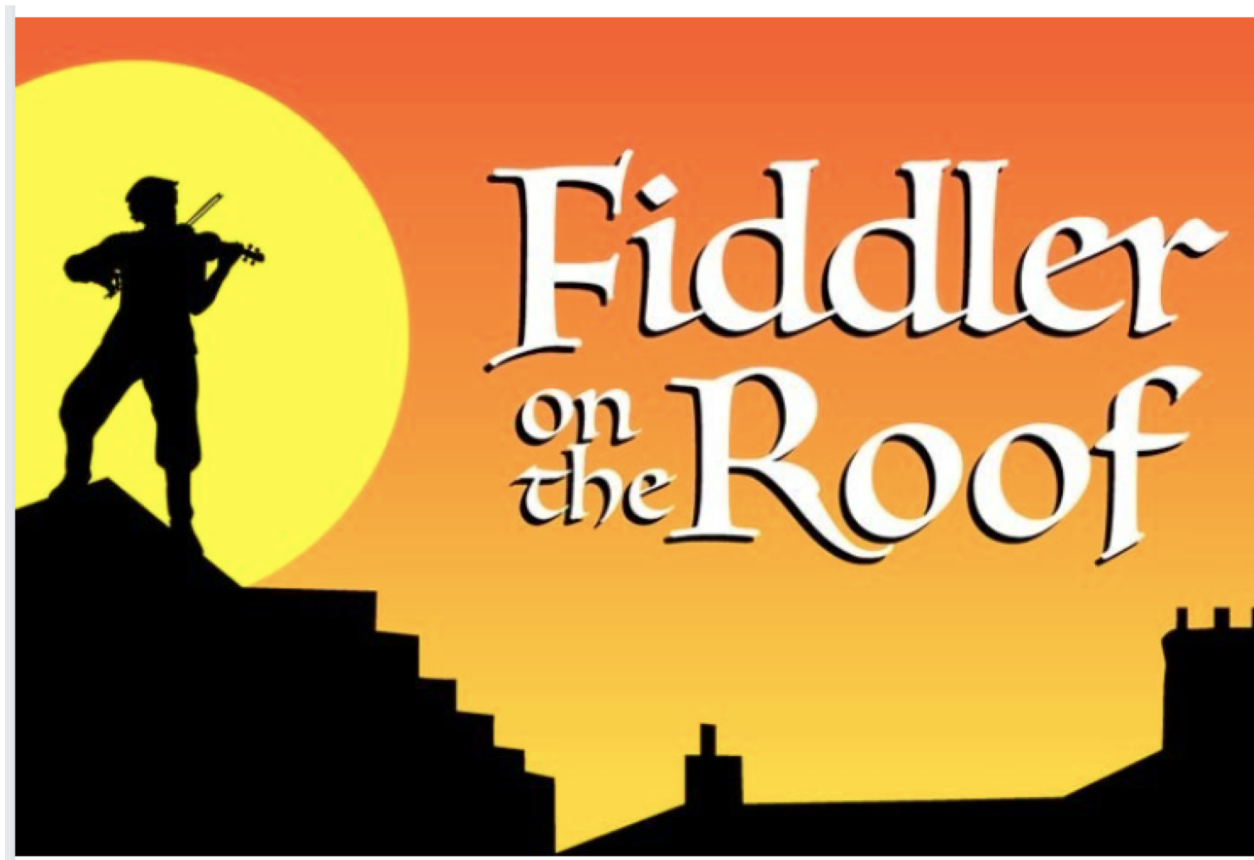


# Methods

- » Theater
- » Language
- » History
- » Law
- » Narrative
- » Proposal



# Fiddler on the Roof



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# Tradition



Steven Skybell and ensemble (Victor Nechay / ProperPix)



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# Physician Aid in Dying



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# Brittany

- » Dx'd with astrocytoma Jan. 1, 2014
- » s/p resection
- » Recurrent April 2014 – given 6 mos prognosis
- » Decided to move to Oregon
- » Oregon's Death with Dignity Law



# Physician Aid in Dying

- » Medical help with a patient's intentional act to end his or her own life
- » Lethal dose of medication prescribed by physician
- » Ethically, legally, clinically different from:
  - ~ Withholding or withdrawal
  - ~ Euthanasia





# Language

- » Physician assisted suicide
- » Physician assisted death
- » Physician hastened death
- » Physician aid in dying
- » Medical aid in dying



# IOM 1997 Approaching Death: Improving Care at the End of Life

» Emphasis on intervention and cure sometimes comes at the expense of good end of life care



# IOM 2014 Dying in America

- » Principles and practice of hospice & PM not fully realized
  - ~ Access to care
  - ~ Communication barriers
  - ~ Time pressures
  - ~ Care coordination
  - ~ Inadequate reimbursement



# Palliative Medicine

- » 90% US adults do not know what PM is
- » When told the definition, >90% said they would want it



# Goal of PM

» Help you live as well as possible for as long as possible (as defined by the patient)

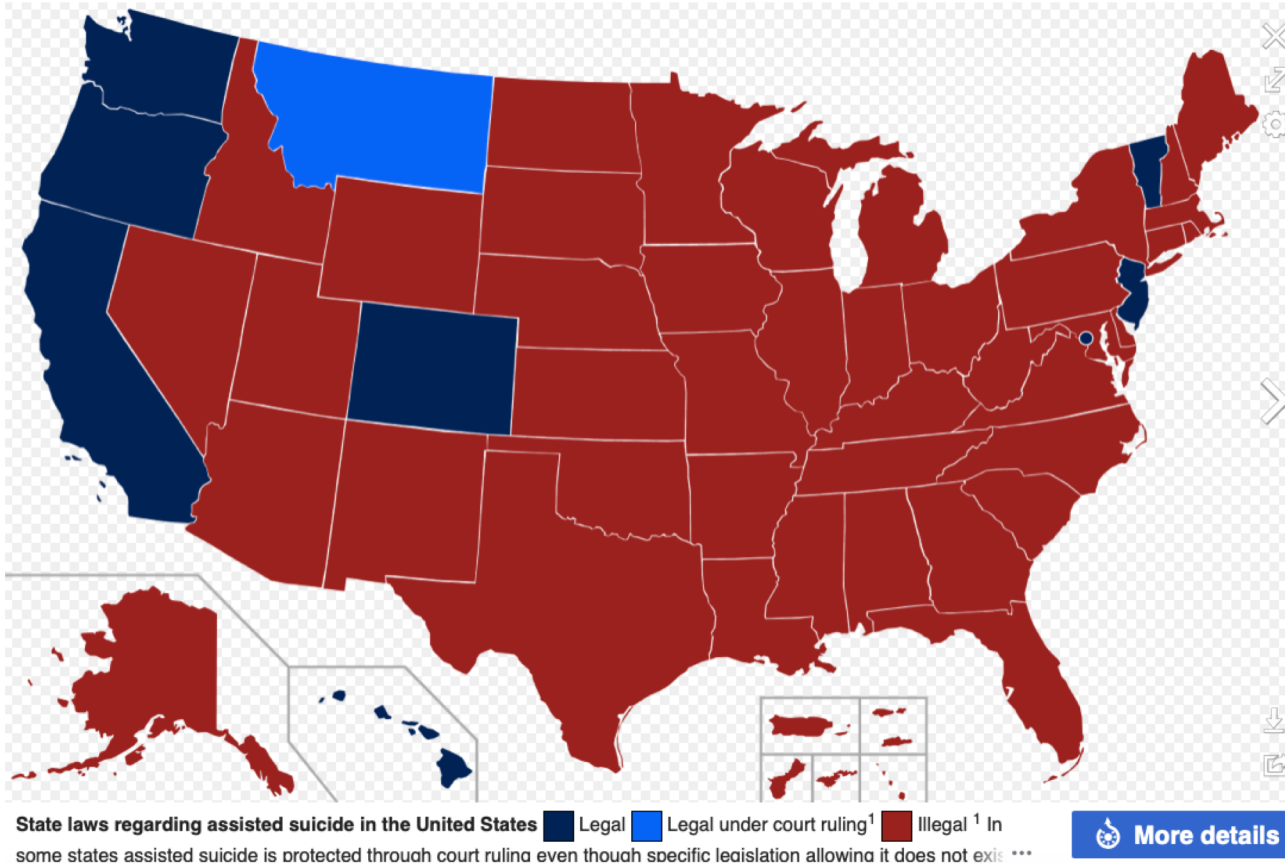


# LLU Grad

» “Is it possible for him to meet the palliative care team and/or explore what other resources we have to support him at home since his goals may not align with the palliative care team as he still hopes to pursue surgery?”



# Legal in....



# 2017

» PAD bills rejected in 27 states



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# Worldwide

- » UK, Australia – rejected
- » The Netherlands, Belgium, Luxembourg, Canada (2015)  
– both MAID and euthanasia legal



# At His Own Wake...



Credit Leslye Davis/The New York Times

**At His Own Wake, Celebrating Life and the Gift of Death**



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# Arguments for...

- » Respect for autonomy
- » Physician's duty to relieve suffering



# Respect for autonomy

- » Based in negative rights
- » Can't demand bad medicine
- » Medicine has limits



# Must relieve suffering

- » Tremendous number of interventions
- » Don't eliminate the sufferer



# Suffering

- » Is it reasonable to ask medicine to relieve all human suffering?
- » It cannot eliminate death



# Arguments against...

- » Duty of physicians to heal
- » Patient-physician relationship
- » Protection for the vulnerable
- » Difference between "killing" and "allowing to die"
- » Sanctity of life



# Supreme Court

- » No constitutional right to PAD
- » Overruled two lower courts





# Supreme Court

- » *Compassion in Dying v. Washington*
- » Court of Appeals for the Ninth Circuit
- » Persons have a right to choose how and when they die
- » Ban on PAD found unconstitutional as a violation of Due Process Clause of the 14th amendment
- » A state may not “deprive any person of life, liberty, or property without due process of law”



# Supreme Court

- » *Quill v. Vacco*
- » Court of Appeals for the Second Circuit
- » Declined to “identify a new fundamental right”
- » Violation of the Equal Protection Clause of the 14<sup>th</sup> amendment
- » Patients at end of life being treated differently
- » No state shall “deny to any person within its jurisdiction the equal protection of the laws”



# Supreme Court

» Justice Sandra Day O'Connor

» "...a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death."



# The Other Opioid Crisis



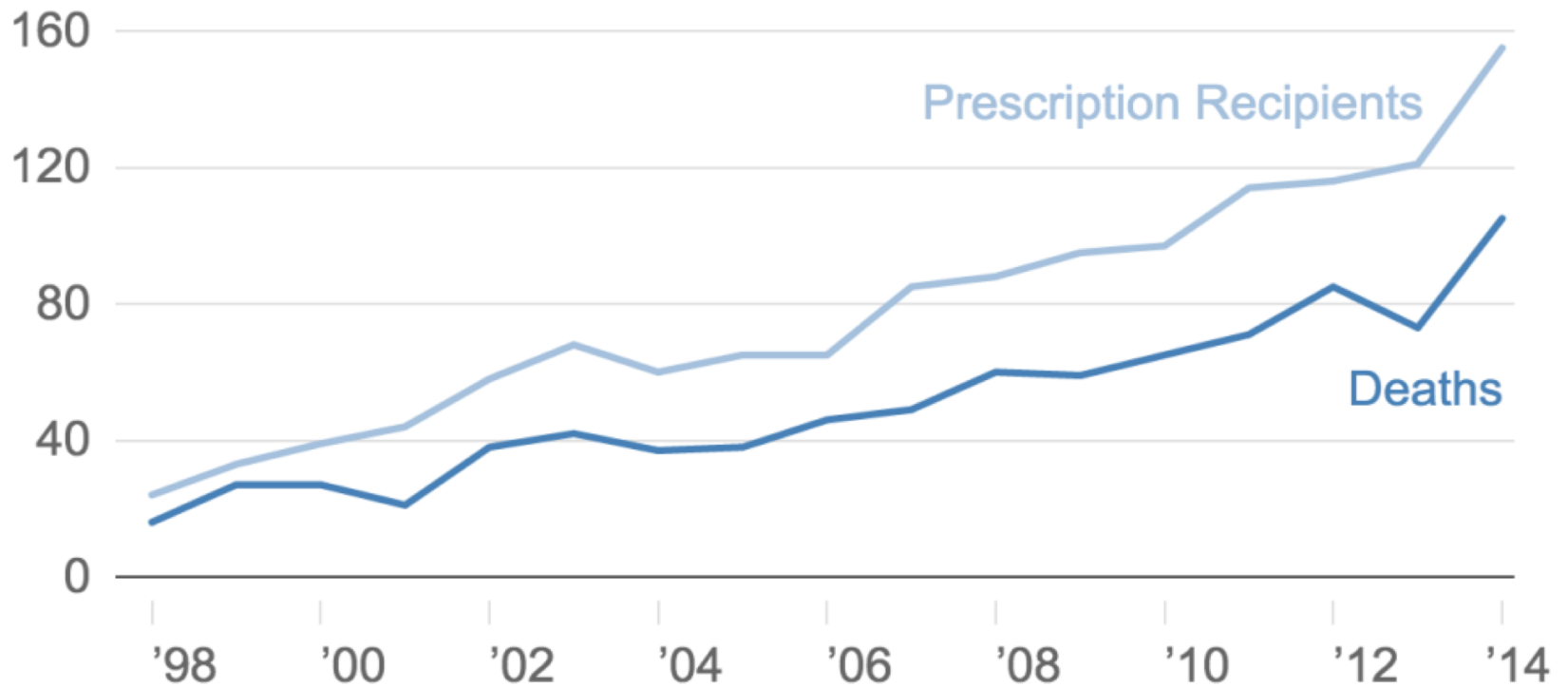
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# What Does Data Show?



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## Oregon Death With Dignity Participants



Lindsay Cook for HSN&WB. Source: Oregon Public Health Division

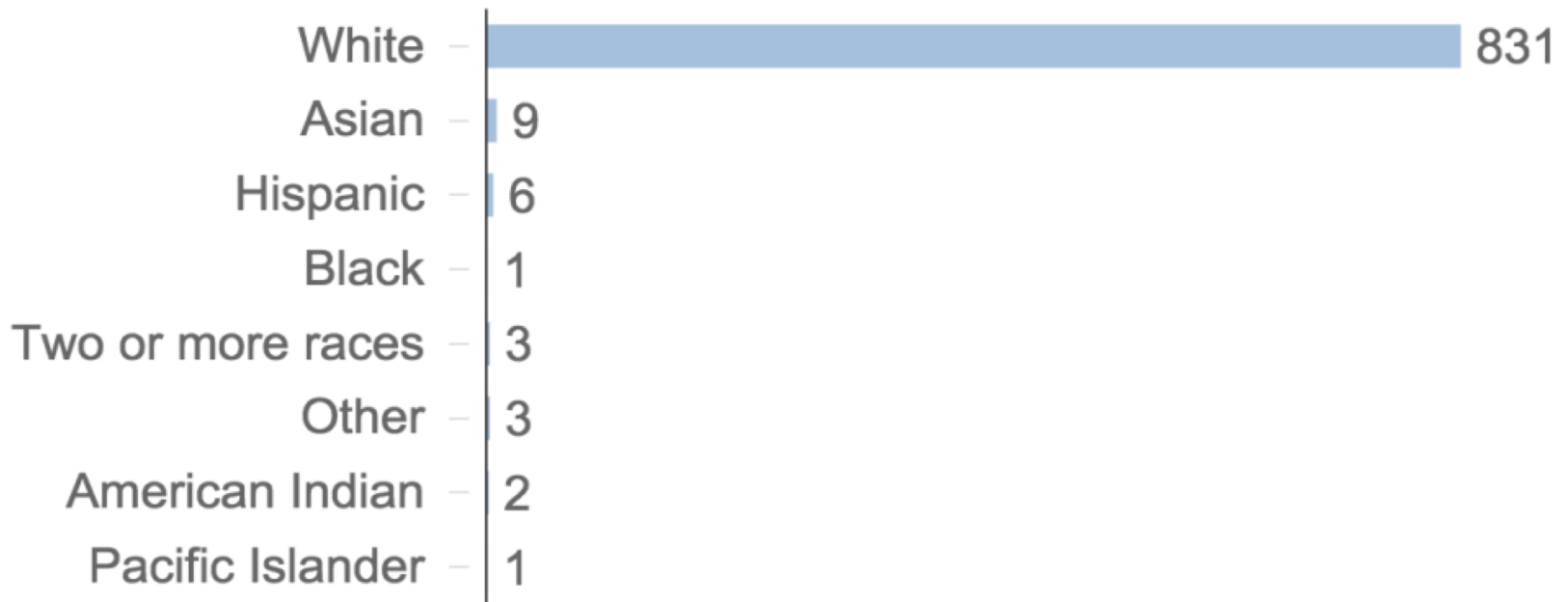
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## Oregon Patients Who Died From Lethal Dose, by Race (1998 - 2014)

### Race and Ethnicity



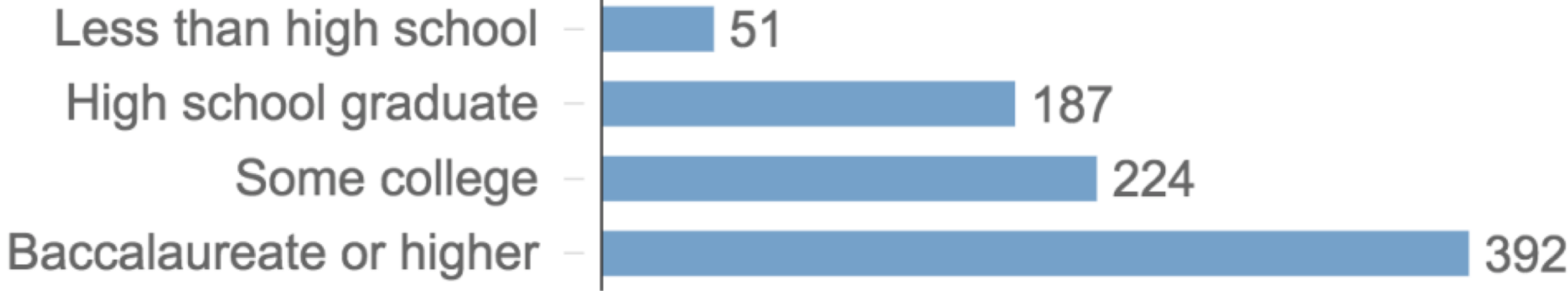
Lindsey Cook for USN&WR; Source: Oregon Public Health Division



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# Oregon Patients Who Died From Lethal Dose (1998 - 2014)

## Education Level

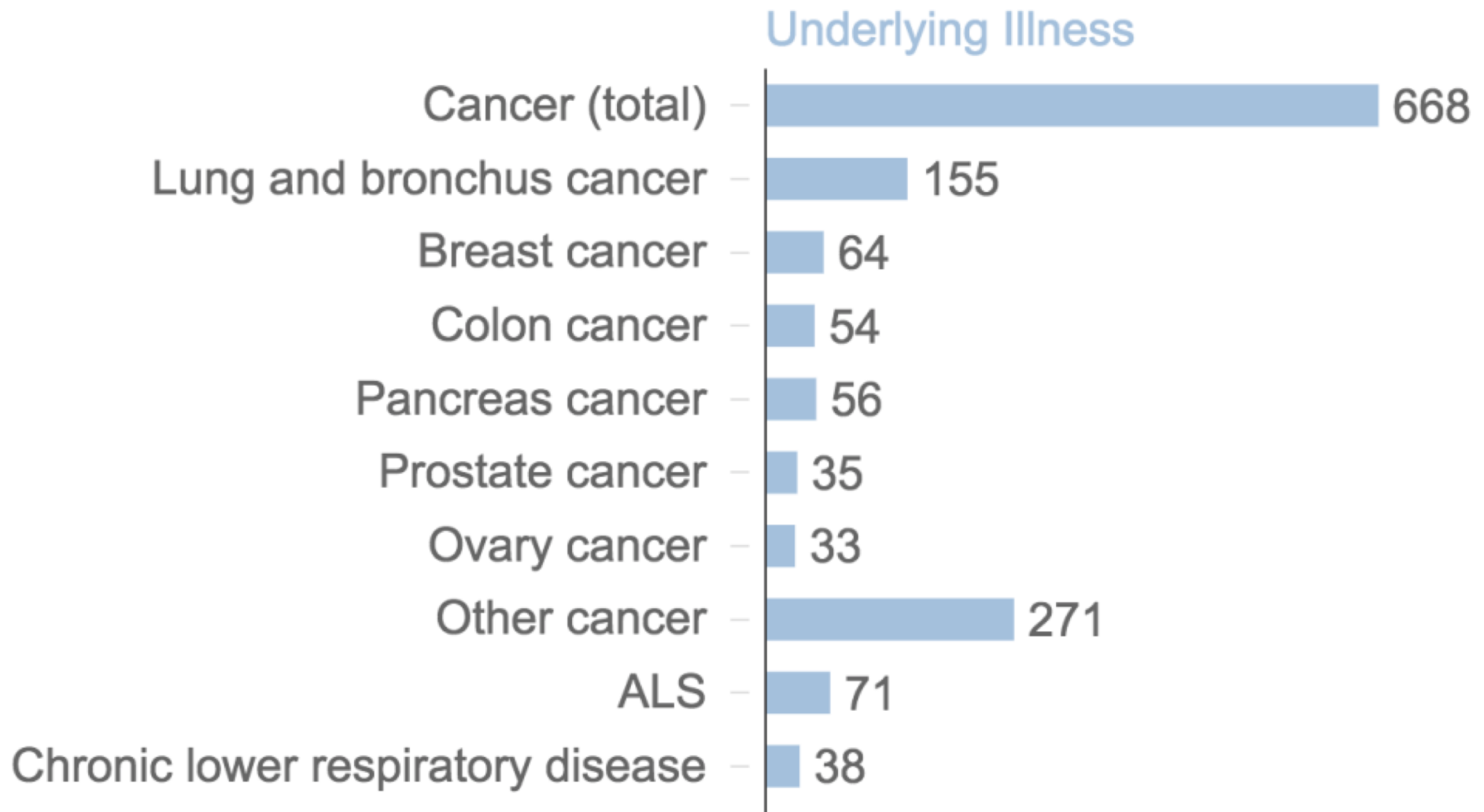


Lindsey Cook for USN&WR; Source: Oregon Public Health Division

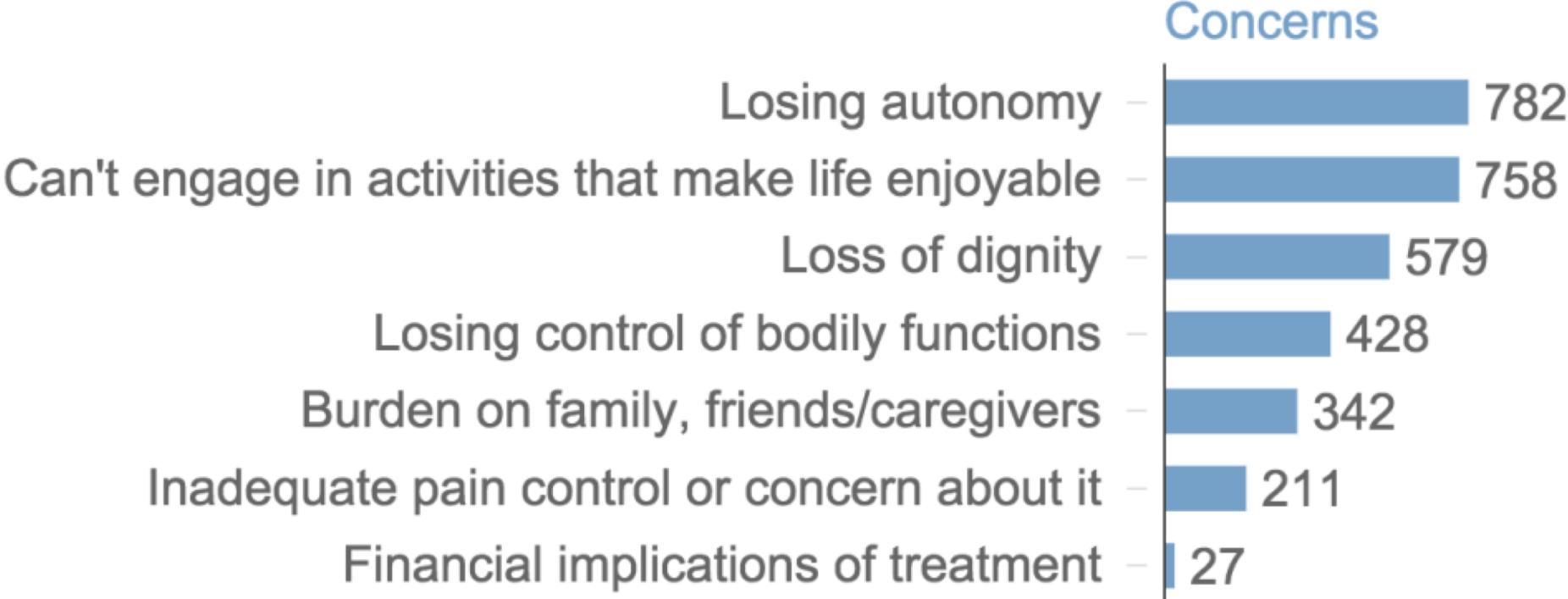




# Oregon Patients Who Died From Lethal Dose, by Illness (1998 - 2014)



# End-of-Life Concerns for Oregon Patients (1998 - 2014)

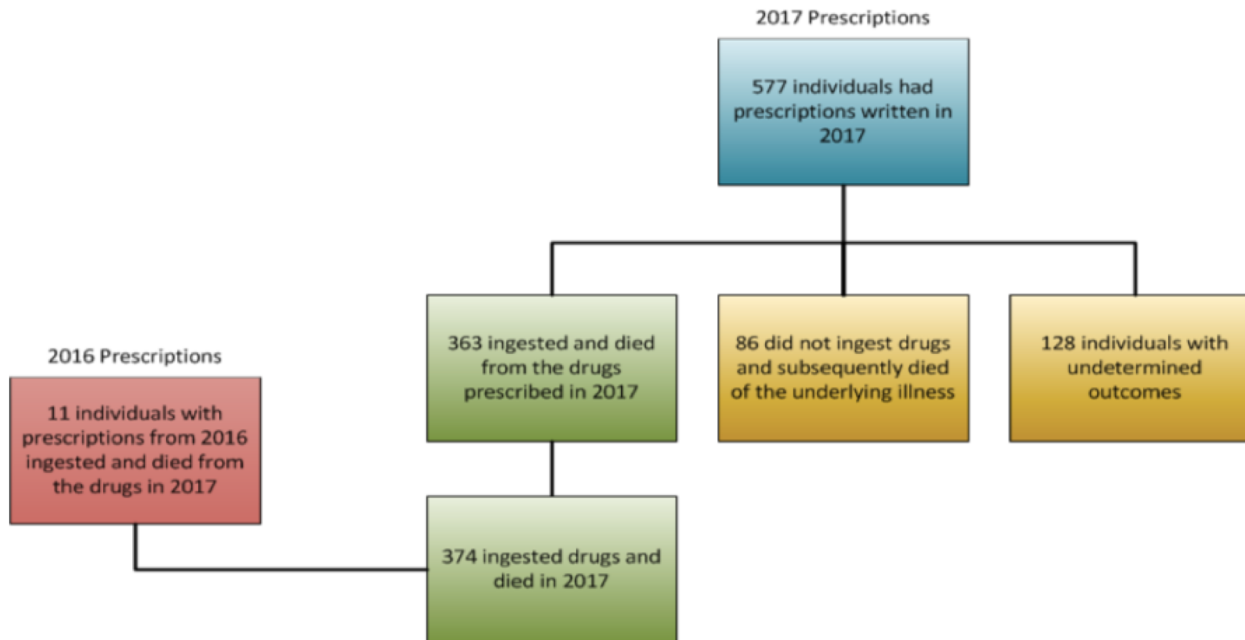


Lindsey Cook for USN&WR; Source: Oregon Public Health Division



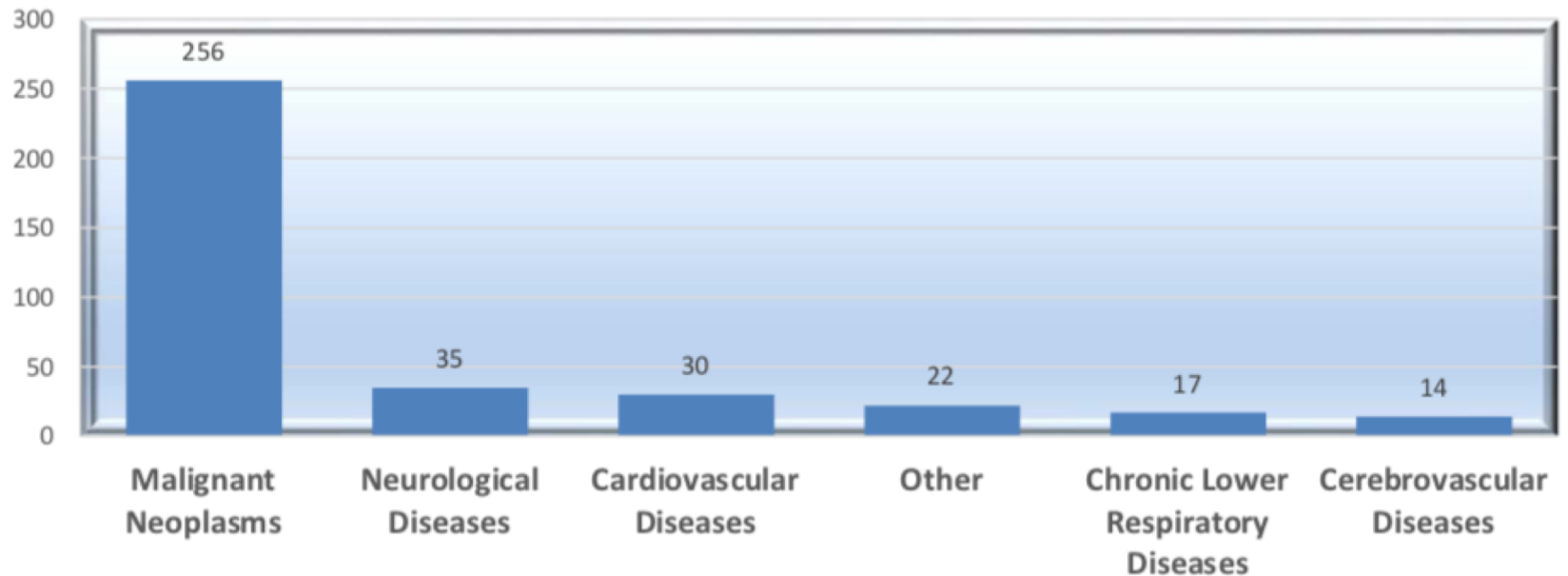
# California EOLOA

Figure 1: Summary of EOLOA Prescriptions Written in 2017



# California EOLOA

Figure 2: Major Illness Categories for EOLA Individuals in 2017



# California EOLOA

**Table 1. Characteristics of the End of Life Option Act individuals who died following ingestion of aid-in-dying drug**

| Characteristics  | 2017         |          |
|--|--------------|----------|
|  | (N=374)      |          |
| <b>Age</b>   | <b>N (%)</b> |          |
| Under 60   | 36           | (9.6)    |
| 60-69  | 88           | (23.5)   |
| 70-79  | 93           | (24.9)   |
| 80-89  | 107          | (28.6)   |
| 90 and Over  | 50           | (13.4)   |
| Median Year (range)                                    | 74           | (31-106) |
| <b>Gender</b>  | <b>N (%)</b> |          |
| Female   | 190          | (50.8)   |
| Male   | 176          | (47.1)   |
| Unknown  | 8            | (2.1)    |
| <b>Education</b>                                       | <b>N (%)</b> |          |
| No High School Diploma                                 | 13           | (3.5)    |
| High School Diploma or General Educational Development | 80           | (21.4)   |
| Some College no Degree                                 | 67           | (17.9)   |
| Associate, Bachelor or Master Degree                   | 183          | (48.9)   |
| Doctorate or Professional Degree                       | 22           | (5.9)    |
| Unknown  | 9            | (2.4)    |



# California EOLOA

| <b>Race/Ethnicity</b>                  | <b>N = 389<sup>3</sup><br/>(%)</b> |        |
|--|------------------------------------|--------|
| White                                  | 346                                | (88.9) |
| Asian/Native American/Pacific Islander | 20                                 | (5.1)  |
| Hispanic                               | 15                                 | (3.9)  |
| Unknown                                | 8                                  | (2.1)  |
| Black                                  | 0                                  | (0.0)  |
| <b>End of Life Care</b>                | <b>N (%)</b>                       |        |
| Hospice and/or Palliative Care         |                                    |        |
| Enrolled                               | 312                                | (83.4) |
| Not Enrolled                           | 42                                 | (11.2) |
| Unknown                                | 20                                 | (5.4)  |





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# The Church

- » Opposed to PAD
- » What are we for?



# What do we advocate for?

- » Provide access for all
- » Hold medical schools, residencies accountable for PM education
- » Lift restrictions on the MediCare Hospice benefit
- » Cover SNF placement with hospice
- » Provide home health aids so patients can stay at home
- » Automate PM consults for the seriously ill
- » Make symptom mgmt. drills routine
- » Become community



# Hope

» Only for cures?



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# Hope...in the Face of Death

- » Hope to die at home
- » Hope to die comfortably
- » Hope to die surrounded by loved ones
- » Hope that family will be ok
- » Hope to see Jesus



# Atul Gawande

» “But we damage entire societies if we let providing this capability divert us from improving the lives of the ill. Assisted living is far harder than assisted death, but its possibilities are far greater, as well.”



# Paul Kalanithi

» “The angst of facing mortality has no remedy in probability... The physicians’s duty is not to stave off death or return patients to their old lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence.”





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