University of Wyoming

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Approaching Death in Dementia

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WYCoA ECHO

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Dementia and mortality

- Dementia increases mortality by a factor of ~ 2.6
- About 24% of deaths among people 70+ years old are attributable to cognitive impairment (dementia + milder degrees of impairment)
- Death certificates underestimate contribution of cognitive impairment in deaths by 2.7 times
- Relative contribution of cognitive impairment to death varies by age, race, ethnicity, gender, health status, and geographic region

Stokes AC et al. JAMA Neurology online Aug 24, 2020

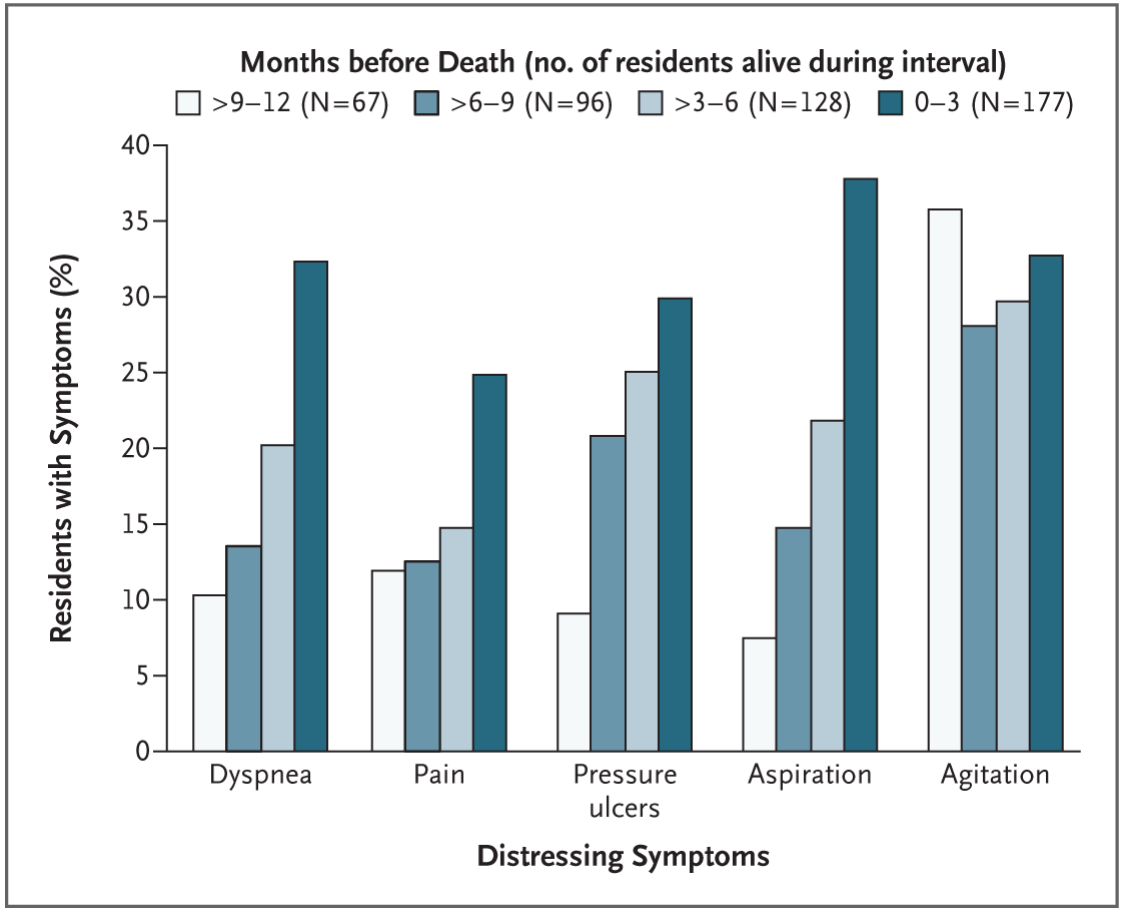
Predicting death

- We're 100% accurate but bad at predicting *when* or *how soon*
  - Many old people bounce back against the odds
  - Dementia patients often leave hospice because they improve
- But as caregivers we have to think about it and plan for it
- The "Surprise" question – just something to think about
  - "Is this person sick enough that it would be no surprise for the person to die within the next 6 months, or a year?" – Joanne Lynn MD
    - Widely used but predictive accuracy varies a lot
    - Better in cancer (where survival is more predictable) than other clinical conditions; better with more experienced clinicians

Can we predict death in people with dementia?

- People can die *with* dementia – or *of* it.
- Dying *with* dementia – other conditions are terminal, but dementia can increase risk
  - Dementia, diseases and disabilities accumulate with aging
  - Dementia can be an indicator of other advanced illness - heart, lung, kidney, liver; cancer
  - Dementia decreases fitness, mobility, nutritional status and increases risk of injury, aspiration, and other accelerators of decline
- Dying *of* advanced dementia is different

Dying of Advanced Dementia: Symptoms and Problems As Death Approaches
- 323 patients in 22 nursing homes

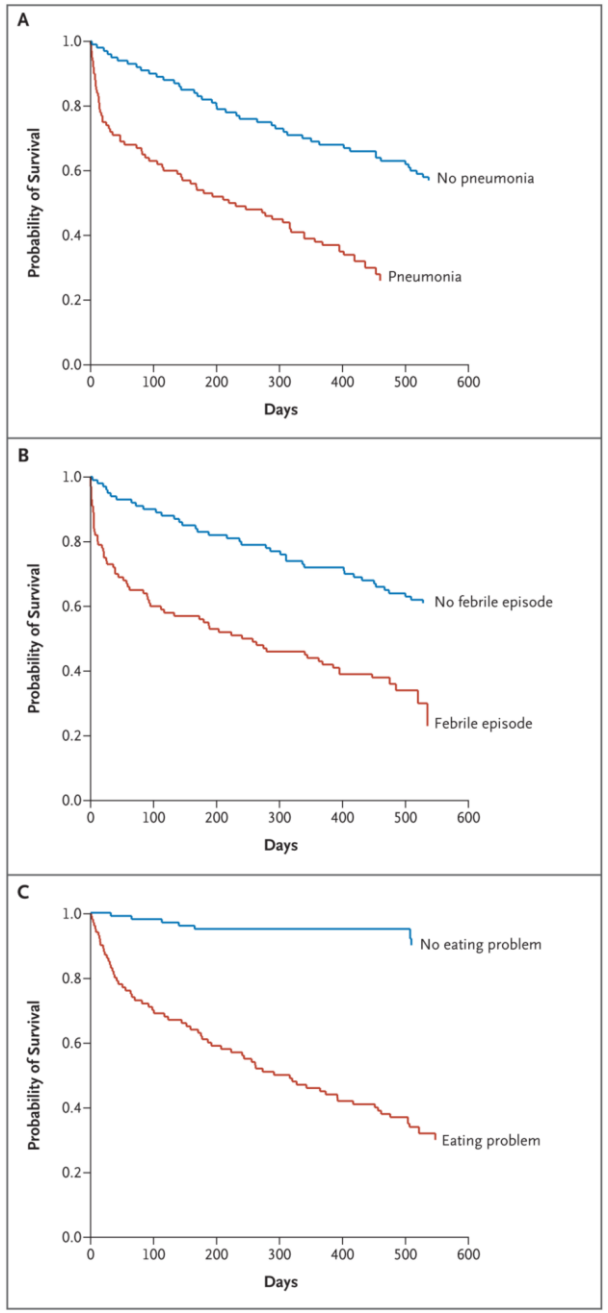


- 323 patients in 22 nursing homes
- MDS/CPS stage 5-6 (MMSE 0-5)
- GDS stage 7 (total dependence, little to no speech, unable to recognize family)

Mitchell SL et al. NEJM 2009

Probability of survival after first

- Pneumonia
- Fever
- Eating problem



- 41% had pneumonia
- 53% had fever
- 39% had problems eating
- 54.8% died over 18 months

Mitchell SL et al. NEJM 2009

What Matters Most

Measuring Quality of Life in Advanced Dementia

- Many tools – some for QoL, some for quality of care
- No perfect measure of either construct – emerging field
- QUALID (Quality of Life in Late Stage Dementia) – most used
  - Observational scale completed by everyday caregivers
  - Relies on frequent contact
  - Effect of interventions not clear
  - Makes clinical sense
  - Helps communicate with family and friends

Zimmerman S et al. J Pain Sympt Management April 2015
Weiner M et al. 2000 (QUALID)

QUALID: Sample content

- Positive vs negative facial expressions
- Response to eating
- Apparent comfort vs discomfort
- Reaction to being touched
- Response to being with people…

See sample distributed with these slides

When to withdraw treatment, and what treatment to withdraw?

- Answers depend on who's asking, and why
- No fixed answers!
- For health care payment and systems administration, continuing clinically futile interventions is wasteful (e.g. cholinesterase inhibitors, statins, feeding tubes - in advanced dementia)
- For individual patient care, process is more important than what's actually decided

See helpful guide from the Alzheimer's Association, distributed with these slides.