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Building an Evidence Base for Education on Advance Care Planning

Fall ADC Meeting, October 10, 2014

Baltimore, MD

Dementia is a Terminal Illness

- AD is 6th leading cause of death in the US, and 5th leading cause of death among those age 65+
- Dementia is under-recognized as a terminal illness & under-reported on death certificates
- Challenges for care providers:
 - Loss of decision making capacity is inevitable
 - Disease course includes prolonged disability
 - Treatment decisions can be anticipated

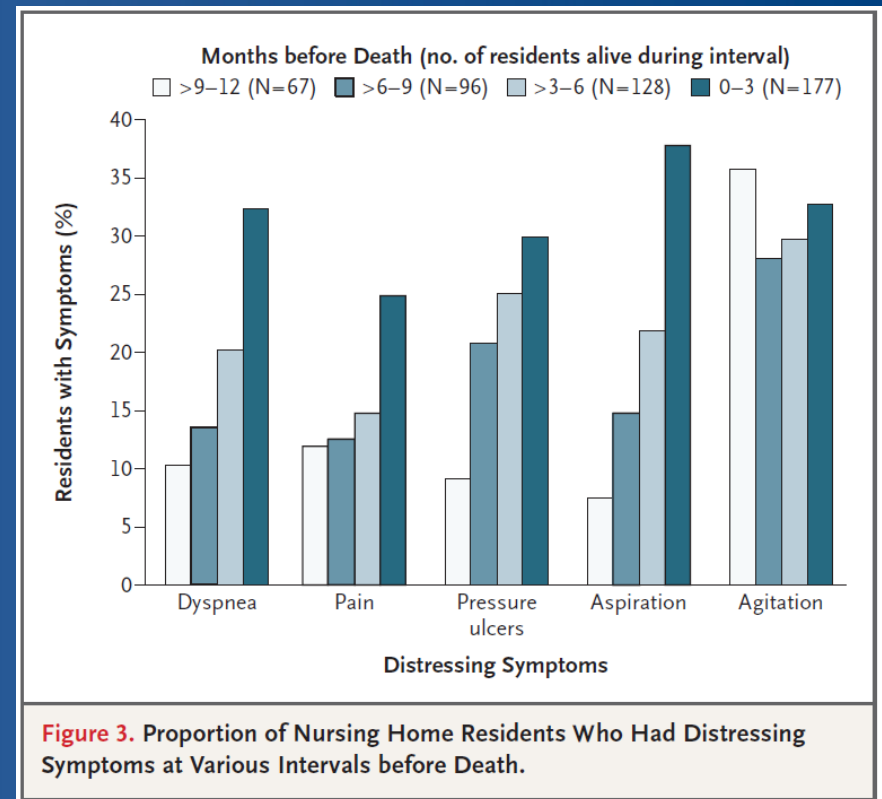
Advanced Dementia

Common complications:

- Pneumonia
- Febrile episodes
- Eating problems

Distressing symptoms:

- Dyspnea
- Pain
- Pressure ulcers
- Agitation
- Aspiration



Common Treatment Decisions near End of Life

- Hospital transfer
- Blood tests / diagnostic tests
- Tube feeding
- X-rays / scans
- Respirator / ventilator use
- Pneumonia / other infection treatment

Advanced Dementia

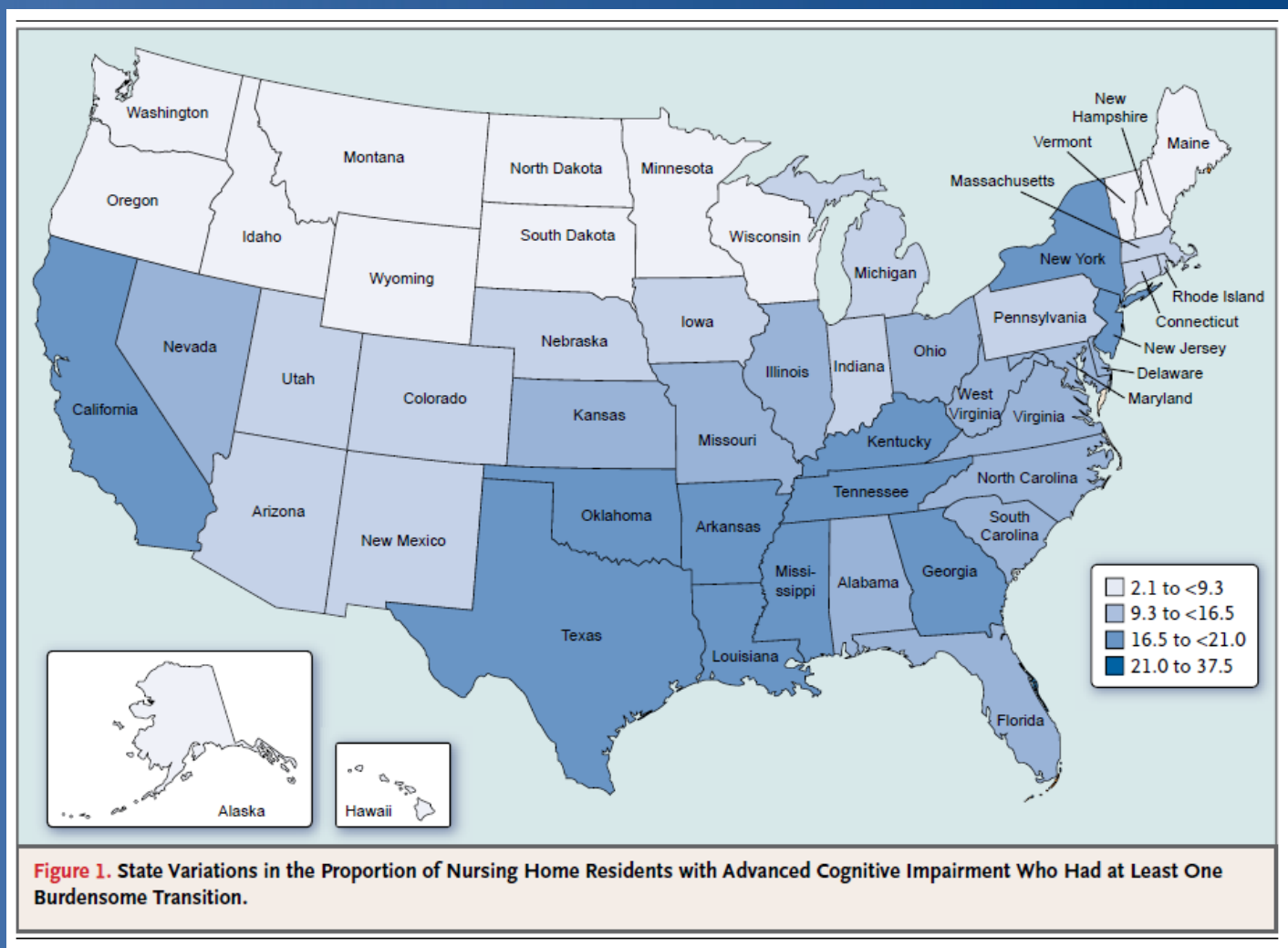
Burdensome Interventions:

Not associated with improved outcomes

- Hospitalizations
- Emergency room visits
- Parenteral therapy
- Tube feeding

Burdensome Transitions Vary by Regions

Gozalo et al., *NEJM*, 2011



Disparities in Advanced Dementia Care

Non-white race is the most consistent risk factor associated with outcomes that are markers of poor-quality end-of-life care:

- lack of advanced directives
- terminal hospitalizations
- increased use of tube feeding

Strategies to Improve Care

Hospice helps, but is under-utilized

Dementia patients receiving hospice care have...

- better symptom management
- fewer terminal hospitalizations
- greater family satisfaction with care

Strategies to Improve Care

Modifiable factors associated with better outcomes for patients with advanced dementia:

- *presence of advance directives*
- better counseling of health care proxies
- residence in a special care dementia unit
- nurse practitioners on-site in NHs
- use of hospice

Advance Care Planning (ACP)

Need for ACP in dementia is clear:

- Loss of decision-making capacity is inevitable
- Disease course includes prolonged severe disability
- Common complications & distressing symptoms
- Treatment decisions can be anticipated
- EOL care should be based on patient preferences

It is critical to understand how, when & with whom ACP should be conducted.

Advance Care Planning Survey

Goals:

- To gain a better understanding of the status of advance care planning (ACP) among patients with dementia
- To examine how ACP differs by race & disease stage

Proposal:

- Conduct a cross-sectional survey on ACP
- Include a geographically & racially diverse sample of *study partners* of patients with mild, moderate and severe AD followed in ADCs

Advance Care Planning Survey

Aim:

Survey study partners of ~ 400 patients with mild, moderate & severe AD dementia (based on power analyses)

- recruit ~ 40 English speaking study partners at each of 10 willing ADCs
- seek sample of ~ 70% white & 30% non-white study partners

Advance Care Planning Survey

Willing ADCs would...

- * Complete a target number of surveys for each racial group based on their NACC racial profile
- * Exclude study partners of patients being seen for the first time at the ADC
- * Ask study partner volunteers to complete the survey during an in-person visit or during a telephone follow-up visit
- * Receive \$25 for each completed survey, within a 1 year period (NOTE: the Alzheimer's Association has agreed to fund this effort, given this time frame)

Advance Care Planning Survey

Survey Content Areas:

- Knowledge of dementia & dementia stages
- Perspectives on the patient's dementia status
- Knowledge of any ACP by the patient
- Perspectives on the patient's preferences for level of medical care
- Opinions on the family's openness to discussing EOL care
- Religious/spiritual affiliations & impact on EOL care preferences
- Knowledge of hospice
- Comfort level with survey topics
- Interest in obtaining information on stages of dementia, health care decision-making, treatment options or EOL care

Advance Care Planning Survey

Potential Impact of the Survey:

- Will be the first large survey on ACP among a well-characterized cohort of racially & geographically diverse patients across the dementia stages
- Will provide novel data on the need, preparedness & willingness of study partners to engage in ACP
- Will further our understanding of reasons for disparities in the quality of EOL care that patients receive
- Will lay the groundwork for a larger prospective study on factors to improve earlier ACP & for designing educational programs to improve ACP

Advance Care Planning Survey

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Advance Care Planning Survey

Discussion questions:

- Is the overall study design feasible for the ADCs ?
- Does the survey cover appropriate topics ?
- Would study partners be receptive to completing the survey ?
- Other questions / comments / suggestions ?

Advance Care Planning Survey

Thank you!

Advance Care Planning Survey

Hypotheses:

1. A lower proportion of non-white (vs. white) study partners will report the patient has completed advance directives or engaged in ACP discussions
2. A lower proportion of non-white (vs. white) study partners will report the patient would prefer comfort care as the primary goal of care
3. The majority of study partners (i.e., >50%) will report a desire for information about the future clinical course of dementia and to engage in ACP; this proportion will not differ by race

Prior Research on ACP in Cognitively Impaired Elders

Formal ACP * Univ. of Pittsburgh ADRC	MCI or Early AD (n=369)	Moderate or Severe AD (n=292)
Durable Power of Attorney	65%	67%
Living Will	56%	54%

Lingler et al., *Am J Geriatric Psychiatry*, 2008

* ACP most likely among whites, older adults & college graduates.