



JOHNS HOPKINS
M E D I C I N E

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Building an Evidence Base for Education on Advance Care Planning

Fall ADC Meeting, October 14, 2016

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**
- **Issues Caregivers Can Anticipate:**
 - **Loss of decision making capacity is inevitable**
 - **Disease course includes prolonged disability**
 - **Treatment decisions can be anticipated**

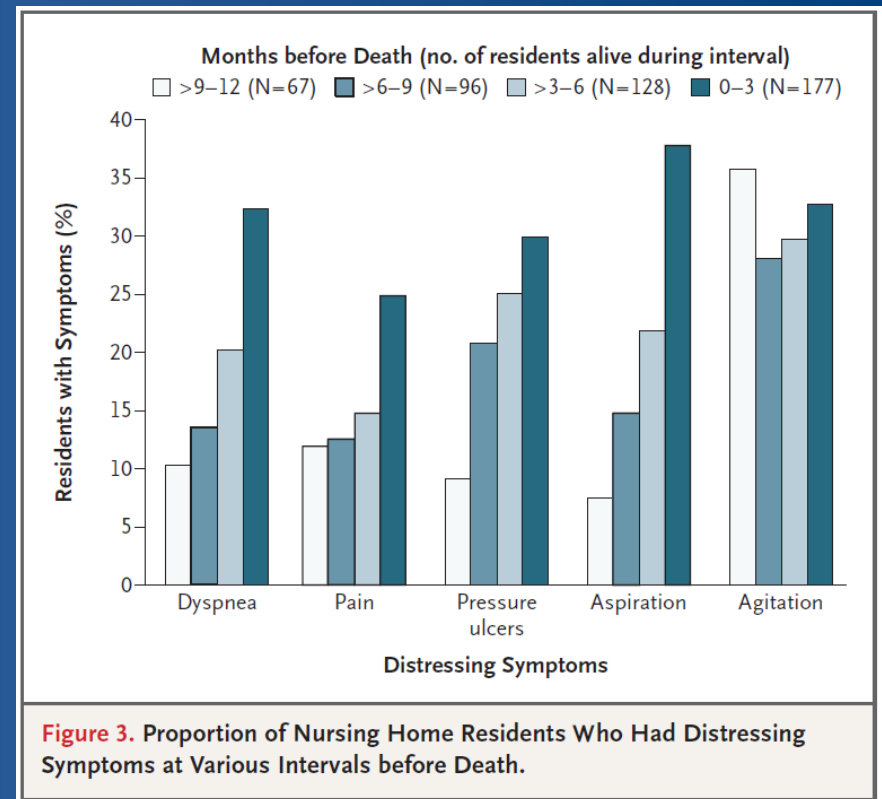
Advanced Dementia

Common complications:

- Eating problems
- Febrile episodes
- Pneumonia

Distressing symptoms:

- Shortness of breath
- Pressure ulcers
- Aspiration
- Pain
- Agitation



Common Treatment Decisions near End of Life

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

Advanced Dementia

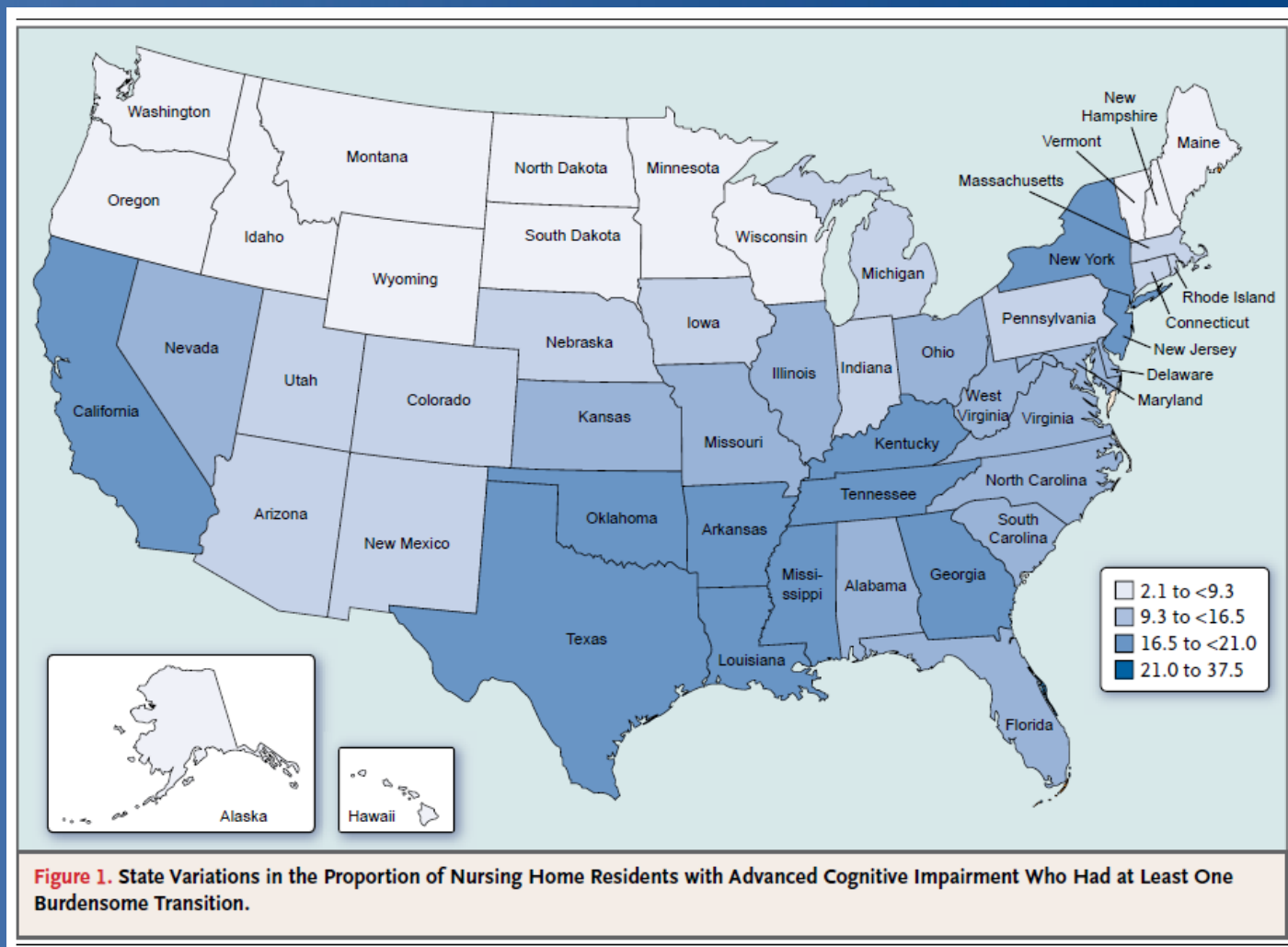
Burdensome Interventions:

Not associated with improved outcomes

- **Emergency room visits**
- **Hospitalizations**
- **Intravenous nutritional therapy**
- **Tube feeding**

Burdensome Transitions Vary by Regions

Gozalo et al., *NEJM*, 2011



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**
- **nurse practitioners on-site in NHs**
- **residence in a special care dementia unit**
- **use of hospice**

Advance Care Planning Needs

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 Project

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

Study Aims:

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

Advance Care Planning Project

Sample Characteristics:

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

- **complete survey ~ 40 English speaking study partners of dementia patients per ADC**
- **seek sample of ~ 70% white & 30% non-white study partners**

Advance Care Planning Project

Participating ADCs:

- * **Ask study partner of dementia patient enrolled in their ADC to complete the survey during: (1) an in-person visit or (2) a telephone follow-up visit or (3) by mail**
- * **Receive \$25 for each completed survey (NB: the Alzheimer's Association is funding this project)**
- * **Try to complete a target number of surveys for each racial group based on the NACC racial profile for their ADC**

Advance Care Planning Survey

Survey Content Areas (~20 minutes):

- 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 at EOL
- 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

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Current Status:

- **Number of completed surveys = 250**
- **Number of participating ADCs = 12**
- **Survey generally well received by study partners and seen by ADCs as helpful for expanding links with caregivers of dementia patients they are following**
- **Some sites still in the process of getting IRB approval**

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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 Project

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