Barriers to Optimal End-of-Life Care for Patients with Advanced Dementia

Jensy Stafford, MD
Palliative Care
I have no relationships with any industry pertaining to this presentation
Objectives

- Recognize dementia as a terminal diagnosis
- Explore barriers to end-of-life care:
  - Clinician
  - Systems
  - Caregiver
- Identify how to optimize dementia care
Case Presentation: Bill

- 62 yo man
- Artist and teacher
- Short-term memory loss
- Word-finding difficulties
- Gets lost on subway
- Forgets appointments
1967
William
Utermohlen
Final Objective

- Recognize the individual experience of dementia using art
Prevalence of Dementia is Expected to Increase

<table>
<thead>
<tr>
<th>Year</th>
<th>United States</th>
<th>Worldwide</th>
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</thead>
<tbody>
<tr>
<td>2008</td>
<td>5 million</td>
<td>30 million</td>
</tr>
<tr>
<td>2050</td>
<td>13 million</td>
<td>100 million</td>
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</table>

National Center for Health Statistics. [www.cdc.gov](http://www.cdc.gov)
Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2008

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer's disease</td>
<td>+ 66%</td>
</tr>
<tr>
<td>Stroke</td>
<td>- 20%</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>- 8%</td>
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<tr>
<td>Breast cancer</td>
<td>- 3%</td>
</tr>
<tr>
<td>Heart disease</td>
<td>- 13%</td>
</tr>
<tr>
<td>HIV</td>
<td>- 29%</td>
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</tbody>
</table>
Trajectory of Dementia Differs from Cancer

'Cancer' Trajectory, Diagnosis to Death

- High
- Low
- Onset of incurable cancer
- Often a few years, but decline usually < 2 months
- Death
- Possible hospice enrolment

http://bestpractice.bmj.com/best-practice/monograph/1020.html
Trajectory of Dementia Differs from Organ System Failure

http://bestpractice.bmj.com/best-practice/monograph/1020.html
Trajectory of Dementia is Gradual and Less Predictable

![Dementia/Frailty Trajectory](http://bestpractice.bmj.com/best-practice/monograph/1020.html)

http://bestpractice.bmj.com/best-practice/monograph/1020.html
Objectives

- Recognize dementia as a terminal diagnosis
- Explore barriers to end-of-life care:
  - Clinician
  - Systems
  - Caregiver
- Identify how to optimize dementia care
Dementia is a Terminal Diagnosis

- CASCADE trial
  - 323 patients and HCPs
  - 18 month prospective study
  - 25% died by 6 mos
  - 55% died by 18 mos

Pneumonia: Known Complication of Dementia

Pneumonia = Increased Mortality

Fever and Dementia

Fever = Increased Mortality

Eating Problems are Common in Dementia

Eating Problem = Increased Mortality

Eating Problem = Increased Mortality

HCPs Favor Comfort but Lack Education

- 323 HCPs
  - 96% comfort was primary goal
  - 18% received prognostic information
- HCPs understanding prognosis, less likely to choose burdensome interventions

Dementia Patients Often Receive Invasive Interventions at End-of-Life

- In last 3 months 41% received:
  - Hospitalization
  - ER visit
  - Parenteral therapy
  - Tube feeding

Recap

- Life-limiting illness
- Known complications due to advanced dementia significantly affect prognosis
- HCPs favor comfort but patients still receive invasive interventions at end of life
Objectives

- Recognize dementia as a terminal diagnosis
- Explore barriers to end-of-life care:
  - Clinician
    - Prognostication
  - Systems
  - Caregiver
- Identify how to optimize dementia care
Clinicians Are Poor at Prognosticating

- Most variability about median survival
- Identified as main barrier to hospice enrollment

Functional Assessment Staging is Used for Dementia Staging

The FAST scale has seven stages:

1. Normal
2. Forgetful
3. MCI
4. Mild
5. Moderate
6. Moderately severe
7. Severe

A. Ability to speak limited to six words
B. Ability to speak limited to single word
C. Loss of ambulation
D. Inability to sit
E. Inability to smile
F. Inability to hold head up

FAST is the Inverse of Normal Childhood Development

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PC Consults Often Occur in Severe Dementia

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PC Consults Occur When Patients are Hospice Eligible

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# PC Should be Earlier in Disease Trajectory

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Hospice Eligibility Determined by Number of Factors

- 1 of 6 in past year:
  - A. PNA (aspiration)
  - B. Pyelonephritis/UTI
  - C. Septicemia
  - D. Stage 3-4 decubitus ulcer
  - E. Fever (on abx)
  - F. 10% weight loss (6 mos) or serum albumin <2.5 gm/dl
FAST is Imperfect

ADEPT is Alternative Method to Determine Prognosis

- Retrospective analysis
  - 2004 US NH residents
- Prospectively applied
  - 606 NH residents

ADEPT is Only Slightly Better at Prognosticating

- Higher score = higher sensitivity/specificity
- Not significantly different from current hospice eligibility guidelines

Recap

- Clinicians are poor at prognosticating
- FAST
  - Hospice: Stage 7 (c) → loss of ambulation
  - Palliative Care: Stages 3-4
- ADEPT is a slightly better alternative to determine 6 and 12 month mortality
Objectives

- Recognize dementia as a terminal diagnosis
- Explore barriers to end-of-life care:
  - Clinician
  - Systems
    - Transitions
  - Caregiver
- Identify how to optimize dementia care
Increased staff requirements → Hospitalization → Acute Illness → Decline in function & cognition → Return to NH
End-of-Life Transitions among Nursing Home Residents with Cognitive Issues

- Retrospective review
  - 474,829 NH residents
- Transitions in last 120 days

Potentially Burdensome Transitions

- Transfer: last 3 days
- NH discontinuity: last 3 months
- Multiple hospitalizations: last 3 months
  - >2 (any reason) or
  - >1 (PNA, UTI, dehydration, sepsis)

Transitions are Common at End-of-Life in Patients with Dementia

- 19% had ≥ one burdensome transition
- Highest risk
  - Hispanic
  - African-American
  - Male
  - No advance directive
  - Residence in certain states

Certain States Have Higher Rates of Burdensome Transitions

Transitions are Markers of Poor End-of-Life Care

- More likely to have feeding tube
- ICU in last 30 days of life
- Stage IV decubitus ulcer
- Late hospice enrollment

NH vs. Hospital-Level of Care: Similar Mortality

- NH residents
  - Pneumonia
  - Randomized: clinical pathway or “usual care”

<table>
<thead>
<tr>
<th></th>
<th>Pathway</th>
<th>Usual Care</th>
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</thead>
<tbody>
<tr>
<td>Hospitalization</td>
<td>10%</td>
<td>22%</td>
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<tr>
<td>Mortality</td>
<td>8%</td>
<td>9%</td>
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Hospice is Underutilized in Dementia

- Hospice improves care for patients with dementia and their families
- Dementia and hospice:
  - 2001: 7%
  - 2008: 11%
  - 1:10 of those dying with advanced dementia

National Hospice and Palliative Care Organization. www.nhpco.org
Recap

- End-of-life transitions
  - Common
  - Poor end-of-life care
- No significant difference between NH and hospital level of care for PNA
- Hospice is underutilized
Objectives

- Recognize dementia as a terminal diagnosis
- Explore barriers to end-of-life care:
  - Clinician
  - Systems
  - Caregiver
    - Caregiver burden
- Identify how to optimize dementia care
More than Half of Caregivers are 55 years or Older

Prevalence and Impact of Caregiving: Detailed Comparison Between Dementia and Nondementia Caregivers

- 1,509 caregivers
- Unpaid caregiving in last year
- Did not necessarily live with patient
- Questionnaire

Ory MG, et al. Gerontologist. 1999
Caregiving in Dementia Causes More Strain than in Nondementia

- More time
- Employment problems
- Physical strain
- Emotional strain
- Financial strain

Ory MG, et al. Gerontologist. 1999
http://www.msnbc.msn.com/id/47314169/ns/health-alzheimers_disease/t/when-illness-makes-spouse-stranger/
...the physical demands on her became daunting. Streets she had thought flat revealed themselves to be hills... Potholes yawned like chasms...She injured her wrist, developed a stomach ulcer and lost so much weight that people worried about her...She would sometimes wake up in a pool of his urine...She had hoped to keep him home until the end...

“This thing is going to kill both of us, and I don’t know who’s going first.”
Recap

- Caregiving in dementia poses unique challenges
- Caregivers experience more physical, emotional, and financial strain
Objectives

- Recognize dementia as a terminal diagnosis
- Explore barriers to end-of-life care:
  - Clinician
  - Systems
  - Caregiver
    - Caregiver burden
- Identify how to optimize dementia care
Overcoming Clinician Barriers

- Early palliative care
  - Triggers
- Refer to hospice
- Collaboration
- Research
Overcoming Systems Barriers

- Avoid transitions
  - Discuss trajectory
  - Not just code status
- PC at home/NH
- Health policy change
  - Broaden access to hospice
  - Change financial structure
Overcoming Caregiver Barrier

- Support
- Educate
- Early PC
- Early hospice
- Respite
- Interdisciplinary team
Summary

- Life-limiting illness with increasing prevalence
- Use existing tools to prognosticate
  - FAST as framework/hospice eligibility
  - ADEPT for 6 and 12 month mortality
- Avoid transitions when possible
  - Poor quality of care
  - Similar mortality
- Dementia caregivers have more strain
  - Support and educate
2000

William Utermohlen
1933-2007