A Day in the Life of Oscar the Cat
Dr. David Dosa
New England Journal of Medicine

Death cat?

“Oscar the Death Cat”
—Boston Globe
July 26, 2007
“If Oscar’s on your bed, you’re dead”
—London Times
July 26, 2007

“Oscar, de kat des doods”
(Oscar the Death Cat)
—German Translation
Nov. 19, 2007
Possible explanations

No one is certain if Oscar's behavior is scientifically significant; his behavior results from innate abilities or is the result of nearly his entire life in an end-stage medical facility when he was expected.

Dr. Joan Teno, a professor of community health at War
University in Providence who cares for Steere House re
basis, said: "It's not that the cat is consistently there for
make an appearance, and it always seems to be in the

Dr. Dosa (also affiliated with Alpert Medical School), who
essay in the July 26 issue of the NEJM, says that "Oscar
He seems to understand when patients are about to die
picking up on specific odors surrounding death." Dr. Te
Dementia is a terminal diagnosis
Oscar’s Lessons (cont’d.)

Nursing homes are often now the last place of care and site of death. They are “homes” not hospitals.

Oscar’s Lessons (cont’d.)

The opportunities to improve are sometimes daunting—Hospice has an important role:
• Advanced Care Planning
• Preventing hospitalizations

Oscar’s Lessons for Caregivers
• Be present
• Celebrate the small, but don’t forget the big picture
• The final act of love is letting go
Objectives

1. Recognize the clinical features of when consideration should be given to dementia as a terminal illness and appropriate referral made to hospice services.

2. Become familiar with current research that reports variation in the health care utilization and quality of care for persons with advanced dementia.

Oscar’s Lessons: Dementia as a Terminal Diagnosis

Epidemiology: Alzheimer’s
Epidemiology: Alzheimer’s (cont’d.)

Median survival from diagnosis: **3 to 6 years**

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2003: Causes of US Deaths > 65

<table>
<thead>
<tr>
<th>Cause</th>
<th>Deaths/100,100</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Diseases of heart</td>
<td>1571</td>
</tr>
<tr>
<td>2. Malignant neoplasms</td>
<td>1079</td>
</tr>
<tr>
<td>3. Cerebrovascular</td>
<td>385</td>
</tr>
<tr>
<td>4. Chronic lung disease</td>
<td>304</td>
</tr>
<tr>
<td>5. Alzheimer’s disease</td>
<td><strong>175</strong></td>
</tr>
</tbody>
</table>


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Trends of U.S. Deaths from Alzheimer’s Disease

<table>
<thead>
<tr>
<th>Year</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>15</td>
<td>16</td>
<td>17</td>
<td>20</td>
</tr>
</tbody>
</table>

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Disease Trajectory in Dementia

- Often terminal
- Trajectory of progressive decline to point of being bed bound with dysphagia
- Results in recurrent aspiration pneumonias and inability to maintain nutrition

Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life
CASCADE: Eligibility

- Age 65 and older
- At least 30 days length of stay in a nursing home
- Severe cognitive impairment—Global Deterioration Scale of 7
- Proxy

CASCADE: Aims

To establish a cohort of nursing home residents with advanced dementia and their proxies (families), follow repeatedly for 18 months:

1. Clinical Course
2. Decision-Making
3. Satisfaction with End-of-Life Care
4. Complicated Grief
Facilities

- 22 facilities
- Within 60 mile radius of Boston
- Over 60 Beds

Eligibility Criteria

- >60 years; length of stay > 30 days
- Dementia
- Global Deterioration Scale = 7
- Proxy available and communicates in English

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1728 residents met screening criteria

- > 60 Years
- CPS Score = 5, 6
- Length of Stay > 30 Days

- Dementia
- GDS=7
- English-Speaking Health Care Proxy

570 eligible

246 HCP refused
1 physician refused

323 dyads recruited
Resident Characteristics

<table>
<thead>
<tr>
<th>Characteristic (N=323)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years) (mean ± SD)</td>
<td>85.3 ± 7.5</td>
</tr>
<tr>
<td>Female</td>
<td>85.4%</td>
</tr>
<tr>
<td>White</td>
<td>89.9%</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>72.4%</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>17.0%</td>
</tr>
<tr>
<td>Other dementia</td>
<td>12.7%</td>
</tr>
</tbody>
</table>

Survival

- N=177/323 (55%)
- Median = 478 days
- 6-months = 25%
- 93% die in Nursing Home

Pneumonia

- Probability of ≥1 pneumonia: 41% (N=132/323)
- 6-month mortality after pneumonia: 47%
Pneumonia

6-month mortality after pneumonia: 47%

Febrile Episodes

Probability of ≥ 1 febrile episode: 53% (N=171/323)

6-month mortality after febrile episode: 44.5%
Probability of eating problem: 86% (N=278/323)

6-month mortality after eating problem: 38.6%

Distressing Symptoms at the End-of-Life
Burdensome Interventions

<table>
<thead>
<tr>
<th>Decedents in last 3 months of life (N=177)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parenteral Therapy</td>
</tr>
<tr>
<td>Hospitalizations</td>
</tr>
<tr>
<td>Emergency room visits</td>
</tr>
<tr>
<td>Feeding tube</td>
</tr>
<tr>
<td>ANY</td>
</tr>
</tbody>
</table>

Proxy Preparedness: Association with Interventions

<table>
<thead>
<tr>
<th>HCP perceives...</th>
<th>All Decedents N=177 (%)</th>
<th>Burdensome interventions last 3 months of life* (%)</th>
<th>AOR (95% CI)**</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 6 months to live</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>26</td>
<td>30</td>
<td>0.3 (0.1-0.8)</td>
</tr>
<tr>
<td>No</td>
<td>74</td>
<td>44</td>
<td>referent</td>
</tr>
<tr>
<td>Understand complications</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>82</td>
<td>36</td>
<td>0.3 (0.2-0.6)</td>
</tr>
<tr>
<td>No</td>
<td>18</td>
<td>65</td>
<td>referent</td>
</tr>
<tr>
<td>Both</td>
<td>21</td>
<td>27</td>
<td>0.1 (0.04-0.4)</td>
</tr>
<tr>
<td>Either</td>
<td>67</td>
<td>39</td>
<td>0.2 (0.1-0.5)</td>
</tr>
<tr>
<td>Neither</td>
<td>12</td>
<td>73</td>
<td>referent</td>
</tr>
</tbody>
</table>

* Burdensome interventions: hospitalization, emergency room, parenteral therapy, feeding tube during last 3 months of life
** Adjusted for facility clustering and occurrence of clinical complications

What do we know about quality-of-care for persons with advanced dementia?
Increasingly, Nursing Homes are the last place of care. Key is the word “home”.

2001 Location of Death

Proportion of Deaths Occurring in Nursing Homes 1989

Less than 1 in 5 (18.6%)
Proportion of Deaths Occurring in Nursing Homes 1997

About 1 in 4 (24.1%)

Source: Brown University School of Medicine, Center for Gerontology & Health Services Research

2000 Mortality Follow-Back Survey (MFB)
Teno, JAMA 2005

2000 MFB Results

• 111 deaths representing 132,508 deaths from dementia in 2000
• 80% last place of care was Nursing Home, on average 25 in 30
• 1 in 3 in more than one place (majority hospital)
2000 MFB Results (cont’d.)

Unmet Needs and Concerns
Pain: 22%
Loved one not treated with respect: 32%
Dyspnea: 33%
Emotional support to family: 45%

Rate of Persistent Pain in U.S. Nursing Homes
Source: Brown University School of Medicine, Center for Gerontology & Health Services Research

Approximately 41% Nationwide (variation: 37–49.5%)
Oscar’s Lessons:
Important opportunities to improve quality of care—
How Can Hospice Help?

- Hospice improves the quality of care
- Hospice prevents health care transitions
- **Education:** Limited role of feeding tubes in end-stage dementia

Existing Evidence:
Feeding Tubes in Persons with Dementia
Findings: Structured Literature Review

Observational studies found that feeding tubes were not associated with:

- Improved survival
- Healing of pressure sores
- Prevention of aspiration pneumonia
- Improved quality of life

Finucane, JAMA1999

Facility Predictors of a Feeding Tube

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>For Profit</td>
<td>1.09 (1.05-1.12)</td>
</tr>
<tr>
<td>Urban Location</td>
<td>1.14 (1.11-1.16)</td>
</tr>
<tr>
<td>Residents with DNR order</td>
<td></td>
</tr>
<tr>
<td>&lt;.10</td>
<td>1.67 (1.54-1.80)</td>
</tr>
<tr>
<td>21-40</td>
<td>1.54 (1.44-1.65)</td>
</tr>
<tr>
<td>61-80</td>
<td>1.22 (1.13-1.30)</td>
</tr>
<tr>
<td>&gt;80</td>
<td>1.0</td>
</tr>
</tbody>
</table>

Feeding Tube Use Among Persons With Renal Cognitive Impairment

- 0.0%-7.7%
- 7.8%-13.1%
- 13.2%-21.6%
- 21.7%-26.7%
- 26.8%-44.6%
Study of Feeding Tubes in Persons with:
Advanced Cognitive Impairment

Study Findings

• National Minimum Data Set (MDS) data repository

• Medicare Denominator, Part A & Part B data

• Merged to examine the incidence use of feeding tubes and characterize health care markets that vary in feeding tube incidence

New Work

Examining incidence feeding tube insertion among 97241 nursing home residents (74% female, mean age 84.8 years) with Cognitive Performance Score of 4, 5 and 6.
### Incidence of Feeding Tube

<table>
<thead>
<tr>
<th>Low States</th>
<th>High States</th>
</tr>
</thead>
<tbody>
<tr>
<td>HI</td>
<td>MS 108/1000</td>
</tr>
<tr>
<td>ND</td>
<td>AL 100/1000</td>
</tr>
<tr>
<td>SD</td>
<td>Rhode Island</td>
</tr>
<tr>
<td>UT</td>
<td>20/1000</td>
</tr>
<tr>
<td>Iowa</td>
<td>Less than 5/1000</td>
</tr>
</tbody>
</table>

### Key Questions

1. **Are feeding tube inserted in an Acute Care Hospital stay or in Nursing Home?**
   - **✓ 68% are inserted during an acute hospital stay**

2. **How long do persons survive after a feeding tube insertion?**
   - **✓ 64% die within one year of feeding tube insertion**
Rate of Health Care Transitions in the Last Six Months of Life Among Nursing Home Residents (Adjusted for age, gender, disease duration)

Incidence of Feeding Tube Insertion
Table 1

Risk of Feeding Tube Insertion Among Nursing Home Residents with Advanced Cognitive Impairment Residing in Regions Varying on Rate of Health Care Transitions

<table>
<thead>
<tr>
<th>Quintile of Health Care Transition</th>
<th>Mean Rate of Health Care Transitions per 100 decedents</th>
<th>Adjusted Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Quintile</td>
<td>264.6</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>2nd Quintile</td>
<td>302.7</td>
<td>1.3</td>
<td>0.97-1.7</td>
</tr>
<tr>
<td>3rd Quintile</td>
<td>330.0</td>
<td>2.3</td>
<td>1.7-3.0</td>
</tr>
<tr>
<td>4th Quintile</td>
<td>395.6</td>
<td>1.9</td>
<td>1.5-2.4</td>
</tr>
<tr>
<td>5th Quintile</td>
<td>401.5</td>
<td>2.5</td>
<td>2.0-3.2</td>
</tr>
</tbody>
</table>
Highlights

• 12% of the Hospitals—NO feeding tube insertion over 8 years
• 25% hospitals you one in ten chance of getting a feeding tube insertion
• Among the highest, one in three Nursing Home residents with advanced dementia had a feeding tube inserted.

Higher Insertion Rates

Factors

• For-Profit: Adjusted Odds Ratio (AOR) 1.33
• Larger Hospitals: AOR 1.48
Higher Insertion Rates

Hospitals with more aggressive care:  
AOR 2.6

Feeding Tube Decision-Making

5-State Survey
• Half said conversations were under 15 mins  
• One-third said they did not discuss risks  
• Half said doctor was strongly in favor  
• 13% felt pressured by doctor to insert  
• 1 in 4 family members regretted the decision

Our Conclusion

Our results suggest that decision to insert a feeding tube in nursing home residents with advanced dementia is more about which hospitals you go to than a decision making process that elicits and supports patient choice.
Does Hospice Improve…

**Quality of Care & Quality of Dying?**
- Simple answer = YES
- Of 538 respondents, 73.0% (n=393) were in a nursing home at the time of death and 48.3% (n=260) received hospice services…

### Table 2

**Quality of Care and Quality of Dying Among Persons With and Without Hospice**

*Adjusted results are persons receiving hospice compared to those who did not receive hospice services after adjusting for age, gender, race, respondent relationship, and years of education.*
Table 2

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Non-Hospice (n=252)</th>
<th>Hospice (n=100)</th>
<th>Hospice, too late (n=32)</th>
<th>Adjusted Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Problem Score</td>
<td>1.2</td>
<td>0.8</td>
<td>2.7</td>
<td>0.57 (95% CI, 0.42-0.78)</td>
</tr>
<tr>
<td>(Mean, 95% CI)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ratings of Quality of Care</td>
<td>31.8</td>
<td>33.8</td>
<td>25.2</td>
<td>0.57 (95% CI, 0.42-0.78)</td>
</tr>
<tr>
<td>(Mean, 95% CI)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peacefulness of Dying</td>
<td>1.8</td>
<td>1.2</td>
<td>2.4</td>
<td>0.57 (95% CI, 0.42-0.78)</td>
</tr>
<tr>
<td>(Mean, 95% CI, 0=peaceful)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Dying</td>
<td>8.4</td>
<td>8.8</td>
<td>7.5</td>
<td>1.6 (95% CI, 1.2-2.2)</td>
</tr>
<tr>
<td>(Mean, 95% CI, 10=very good)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Hospice & Nursing Home Transitions

• Hospice patients were less likely than non-hospice residents to be hospitalized (OR 0.56; 95 percent CI: 0.53-0.61).

• Translation: 47% reduction in the rate of hospitalization among NH residents using hospice services in the last month of life!

—Gozalo and Miller Health Services Research, April 2007

Summary

• Dementia is a common cause of death

• 70% die in nursing homes. Thus, nursing home is main site of terminal care
Summary (cont’d.)

Under-recognition of dementia as a terminal disease
• Pain is often untreated
• Lack of advance care planning
• Under-utilization of hospice

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Summary (cont’d.)

Natural history/clinical course
• Functional Status: Severely impaired throughout the last year
• Eating problem: 40% → 85% prior to death
• Pneumonia: 10% → 50% prior to death

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Summary (cont’d.)

Natural history/clinical course: Most common decisions
• Treatment of dysphagia and infections
• Hospitalization
Implications

• Even with newer pharmacological treatment, dementia remains a leading cause of death
• Important opportunities to improve

Implications (cont’d.)

• Hospice plays an important role in the Nursing Home setting through Advance Care Planning and helping prevent unnecessary transitions in the last month of life
• Hospice Improves quality of care and quality of dying

So What are the Real Lessons from Oscar the Cat for Caregivers?
Caregivers Lessons: Mary & David

1. Be present
2. Celebrate the small, but don’t forget the big picture
3. The final act of love is letting go

For more information or questions on this presentation, contact:

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