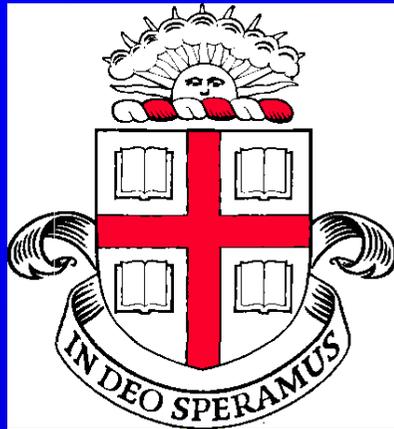


Does Hospice Improve the Quality of Care for Persons Dying with Dementia?



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Redefining Dementia as a Terminal Illness

By CATHERINE ELTON Wednesday, Oct. 14, 2009

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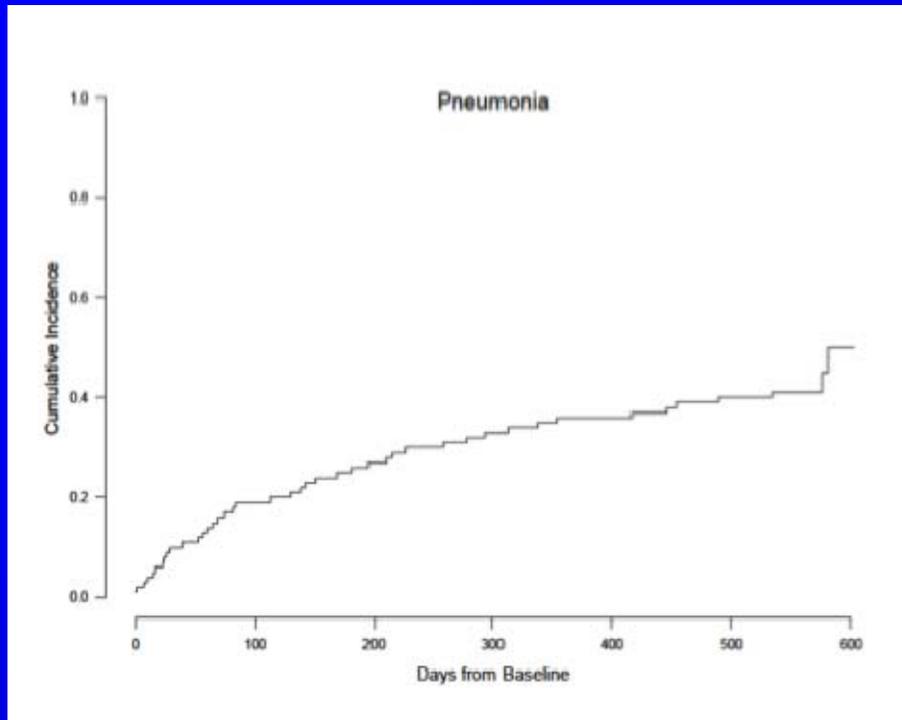
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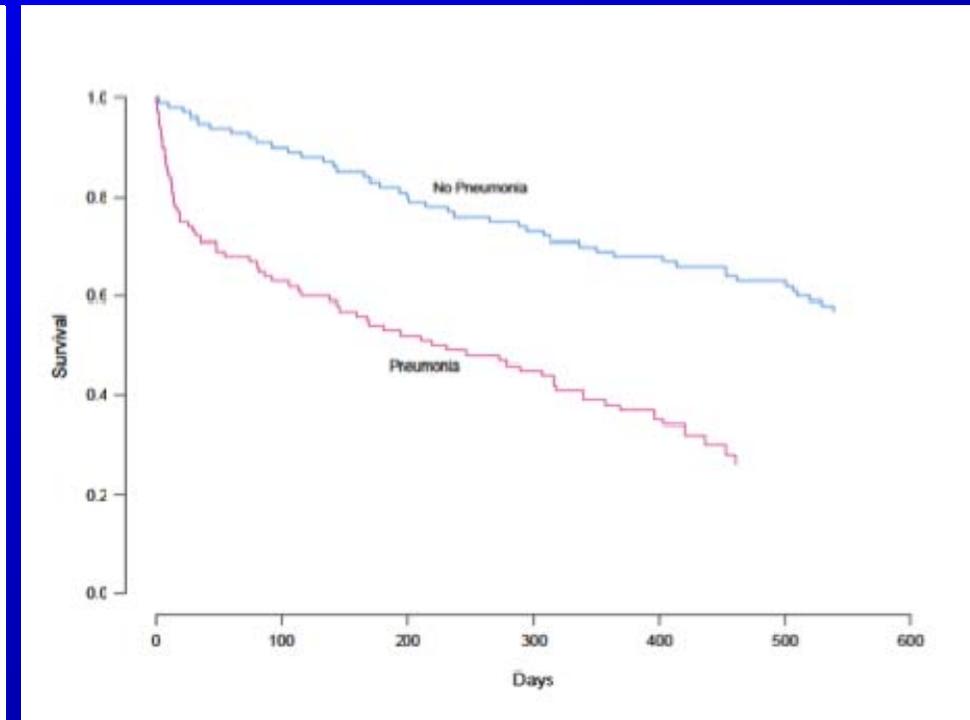
Dementia is most often thought of as a memory disorder, an illness of the aging mind. In its initial stages, that's true — memory loss is an early hallmark of dementia. But experts in the field say dementia is more accurately defined as fatal brain failure: a terminal disease, like cancer, that physically kills patients, not simply a mental ailment that accompanies older age.
 (See the top 10 medical breakthroughs of 2008.)

**Choices,
 Attitudes, and
 Strategies for
 Care of
 Advanced
 Dementia at
 the End-of-Life**

Pneumonia



Probability of ≥ 1 pneumonia:
41% (N=132/323)



6-month mortality after pneumonia:
47%

Recently, the US Federal Government has questioned the costs and benefits of hospice services for persons in nursing homes, mainly persons with non- cancer diagnosis such as dementia.

**TABLE
2E-4**

The volume of hospice use has increased substantially

| Category | 2000 | 2007 | 2008 | Average annual percent change 2000-2007 | Percent change 2007-2008 |
|--|-------------|-------------|-------------|--|---------------------------------|
| Number of hospice users | 513,000 | 1,000,000 | 1,055,000 | 10.0% | 5.5% |
| Total spending (in billions) | \$2.9 | \$10.3 | \$11.2 | 19.8 | 8.7 |
| Average length of stay among decedents (in days) | 54 | 80 | 83 | 5.8 | 3.8 |

Note: Length of stay reflects the total number of days the decedent hospice user was enrolled in the Medicare hospice benefit during his/her lifetime.

Source: MedPAC analysis of the denominator file, the Medicare Beneficiary Database from CMS, and the 100 percent hospice claims standard analytical file from CMS.

Objective

- To examine the outcomes of hospice services for patients with dementia from the perspective of bereaved family members.

Methods - Sample

- Mortality follow back survey of decedents with listed cause of death as dementia
- Death certificates were sampled from 5 states that varied in prevalence of feeding tubes (AL, FL, TX, MA, MN)
- A total of 1111 death certificates were sampled. Sixty-four persons were contacted and excluded based on a screening questions that found the decedent did not need assistance in eating and 50 decedents did not have a knowledgeable next of kin or that person did not speak English or Spanish. Two hundred seventy seven persons were unable to be located. Among the 770 bereaved family members we were able to locate, 545 (70.8%) participated in the survey.

Method- Measures

- Outcome
 - 8 Core Items of Family Evaluation of Hospice Care Survey (Cronbach's alpha = 0.74)
 - Rating of the quality of care with a score of 0-40 (higher score = higher quality rating)
 - Based on the work of Volicer and colleagues¹⁶, respondents were also asked to rate on a scale of 1-10 their perceptions of decedents' peacefulness during death and the overall quality of the decedents' dying experience.

Methods - Analytic Approach

- Descriptive frequencies
- Associations of bereaved family members perceptions of the quality of care with receipt hospice services defined as 1) No hospice; 2) Hospice “at the right time”; and 3) Hospice “too late”
- Because of the skewed distribution, each of the dependent measures was categorized in 3 or 4 ordered categories. A multivariate cumulative model was used to examine the association of hospice use with each outcome, adjusting for socio-demographic characteristics and whether patients were referred to hospice too late. The Huber-White correction was applied for sampling of death certificates by hospital referral region.

| Characteristic | Without Hospice (N=278) | Hospice At Right Time (N=227) | Hospice Too late (N=33) |
|-------------------|-------------------------|-------------------------------|-------------------------|
| Age (mean,SD) | 86 (7) | 86 (7) | 88 (6) |
| Black (%) | 12.6 | 7.9 | 3.0 |
| Male (%) | 35.0 | 33.9 | 15.2 |
| Hospital Death | 24.1 | 13.7 | 9.1 |
| Respondent Child | 60.4 | 63.0 | 69.7 |
| Respondent Spouse | 10.4 | 11.9 | 12.1 |
| | | | |

Bereaved Family Member Perceptions of Unmet Needs and Rating of the quality of Care:

| Measure | No Hospice Services (n=271) | Hospice Services (n=221) | Hospice Services, but Too Late (n=33) |
|---------------------------|-----------------------------|--|---------------------------------------|
| Rated Care as Excellent | 39.3 | 48.7 AOR 1.5 (95% CI 1.1-2.0) | 20.0 |
| Composite Problem Score | 46.0 | 33.4 AOR .52 (95% CI .35-.76) | 67.3 |
| Unmet Need Dyspnea | 19.1 | 5.9 | 31.3 |
| Unmet Need What to expect | 22.5 | 12.5 | 48.5 |

*Ratings and Quality of dying in Among Persons
With and Without Hospice*

| <i>Outcome</i> | <i>Non-hospice (n=252)</i> | <i>Hospice (n=200)</i> | <i>Hospice, too late (n=32)</i> | Adjusted Results |
|--|--------------------------------|----------------------------|-------------------------------------|--------------------------|
| Ratings of Quality of Care (mean, 95% CI) | 31.8 | 33.8 | 25.2 | 1.6 (95% CI 1.4-2.0) |
| Peacefulness of dying (mean, 95% CI) 0= peaceful | 1.8 | 1.2 | 2.4 | 0.57 (95% CI .42-.78) |
| Quality of dying (mean, 95% CI) 10= very good | 8.4 | 8.8 | 7.5 | 1.6 (95% CI 1.2-2.2) |

*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.

Limitations

- Perceptions of bereaved family members
- Among those located, the completion rate was only 71%
- Studied only 5 states in USA that varied on use of feeding tubes

Conclusion

- Bereaved family members of dementia patients who received hospice care “at the right time” reported less unmet needs, fewer concerns with quality of care, higher rating of the quality of care, and higher ratings of the quality of dying.



Thank you –