

The Clinical Course of Advanced Dementia

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Received during: CCI Journal Club

Abstract: Dementia is a leading cause of death in the United States but is underrecognized as a terminal illness. The clinical course of nursing home residents with advanced dementia has not been well described.

Methods: We followed 323 nursing home residents with advanced dementia and their health care proxies for 18 months in 22 nursing homes. Data were collected to characterize the residents' survival, clinical complications, symptoms, and treatments and to determine the proxies' understanding of the residents' prognosis and the clinical complications expected in patients with advanced dementia.

Results: Over a period of 18 months, 54.8% of the residents died. The probability of pneumonia was 41.1%; a febrile episode, 52.6%; and an eating problem, 85.8%. After adjustment for age, sex, and disease duration, the 6-month mortality rate for residents who had pneumonia was 46.7%; a febrile episode, 44.5%; and an eating problem, 38.6%. Distressing symptoms, including dyspnea (46.0%) and pain (39.1%), were common.

In the last 3 months of life, 40.7% of residents underwent at least one burdensome intervention (hospitalization, emergency room visit, parenteral therapy, or tube feeding). Residents whose proxies had an understanding of the poor prognosis and clinical complications expected in advanced dementia were much less likely to have burdensome interventions in the last 3 months of life than were residents whose proxies did not have this understanding (adjusted odds ratio, 0.12; 95% confidence interval, 0.04 to 0.37).

Conclusions: Pneumonia, febrile episodes, and eating problems are frequent complications in patients with advanced dementia, and these complications are associated with high 6-month mortality rates. Distressing symptoms and burdensome interventions are also common among such patients. Patients with health care proxies who have an understanding of the prognosis and clinical course are likely to receive less aggressive care near the end of life.

Strengths/uniqueness: This is a very good study that looks at the clinical epidemiology and trajectory of end stage dementia. The definitions for cognitive and functional assessment are very clear. It addresses the issue of caregivers' input and their influence on the direction of the management and its intensity. Under-referral to the hospice care of 29.9% of those who died in study period is concerning especially with high percentage of patients being symptomatic.

Weaknesses: The definition of eating problems could have been enhanced with standardized nutritional tools. The practical difficulty in determining when the eating problems occurred is an issue. The onset of eating problems is either taken on the day of baseline interview or between 2 assessment dates once it was noted.

The study also seems to have predominantly recruited white women and it may not apply to the general population.

The severity of symptoms is not well documented as in the study only it only looked at the presence and frequency of the symptoms especially pain and dyspnea

The use of oral anti-biotics was not mentioned and the clustering of IV anti-biotics, fluids and s/c fluids did not provide sufficient information regarding the predominant treatment.

The baseline co-morbid problems were not well characterized as only cancer, heart failure and chronic obstructive lung disease were mentioned.

The authors could have considered the occurrence of pneumonias, eating problems and febrile episodes as sentinel events.

Relevance to Palliative Care:

This paper is still a very good paper as it is very relevant to prognosticating in advanced dementia population.