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## Prospective Observations of Discomfort, Pain, and Dyspnea in Nursing Home Residents With Dementia and Pneumonia.

van der Maaden T<sup>1</sup>, van der Steen JT<sup>2</sup>, de Vet HC<sup>3</sup>, Hertogh CM<sup>1</sup>, Koopmans RT<sup>4</sup>.

### Author information

### Abstract

**OBJECTIVES:** To describe observations of suffering in patients with dementia from the diagnosis of pneumonia until cure or death.

**DESIGN:** Prospective observational study between January 2012 and May 2014.

**SETTING:** Dutch nursing homes (32).

**PARTICIPANTS:** Nursing home patients with dementia and pneumonia (n = 193).

**MEASUREMENTS:** Independent observers performed observations of patients with dementia scheduled 13 times within the 15 days following diagnosis of pneumonia; twice daily in the first 2 days- to observe discomfort (Discomfort Scale-Dementia of Alzheimer Type; range 0-27), comfort (End Of Life in Dementia-Comfort Assessment in Dying; range 14-42), pain (Pain Assessment in Advanced Dementia; range 0-10), and dyspnea (Respiratory Distress Observation Scale; range 0-16).

**RESULTS:** Observational data were obtained for 208 cases of pneumonia in 193 patients. In 71.2% of cases, patients received 1 or more treatments to relieve symptoms such as antipyretics, opioids, or oxygen; 89.4% received antibiotics. Discomfort was highest 1 day after diagnosis [mean Discomfort Scale-Dementia of Alzheimer Type score 8.1 (standard deviation, SD 5.8)], then declined, and stabilized around day 10 [mean 4.5 (SD 4.1)], or increased in the days preceding death. Observed pain and dyspnea followed a comparable pattern. Discomfort patterns did not differ much between cases treated with and without antibiotics.

**CONCLUSIONS:** Pneumonia in patients with dementia involved elevated levels of suffering during 10 days following diagnosis and in the days preceding death. Overall observed discomfort was low compared with prior Dutch studies, and the number of treatments to relieve symptoms was higher. Future studies should examine whether symptoms of pneumonia can be relieved even more, and what treatments are the most effective.

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**KEYWORDS:** Nursing homes; dementia; discomfort; observation; pneumonia; suffering

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