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Original Study

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

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A B S T R A C T

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.

Over the years, awareness about the importance of comfort in patients with dementia has increased, and the fact that palliative care applies to, at least, advanced dementia is now generally accepted. In more advanced stages of dementia a treatment goal primarily aimed at maximization of comfort may be appropriate.[1–3]

Many nursing home (NH) patients with dementia develop infections such as pneumonia. Pneumonia has been associated with severe discomfort for all patients with dementia, but patients for whom antibiotics were withheld experienced even more discomfort than those treated with antibiotics.[4] Discomfort for patients dying from pneumonia was higher than for patients dying from other causes,[5] and patients with dementia dying from respiratory infections experienced the largest symptom burden.[6] Although there is poor

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evidence about how to best enhance comfort specifically for patients with dementia and pneumonia,[7] the approach to relieve the symptoms of pneumonia may have changed. For example, in The Netherlands in 2006–2007, a general trend toward more symptom relief was found in patients with dementia and pneumonia compared with 1996–1998.[8]

Dyspnea and pain contribute to suffering in patients with dementia and pneumonia. Furthermore, a patient who is awake may experience more discomfort or pain than a patient who is asleep. Previously, discomfort in patients with dementia and pneumonia was examined using observations performed by the attending physician at fixed time intervals during the course of pneumonia.[4] However, the attending physician was not independent and was not blinded for condition and treatment of the patient.

Although discomfort has shown to be high in patients with pneumonia and dementia, no studies have investigated its course on a day-to-day basis. The aims of this study were to describe the course of symptoms and treatments initiated in patients with dementia and pneumonia, to offer a detailed picture of suffering (defined as discomfort, lack of comfort, pain, and dyspnea) and observed sleepiness from diagnosis until cure or death, and to assess differences between patients treated with or without antibiotics.

Methods

Study Population and Setting

Data were collected in the context of the prospective "PneuMonitor study" (data collection from January 2012 until May 2015), with the overall aim to reduce discomfort in NH residents with pneumonia and dementia. This article describes data from the pre-test phase (January 2012 until May 2014) that comprised patients in all participating NHs before an intervention to enhance comfort was introduced.

Thirty-two NHs across The Netherlands covering 11 of the 12 provinces participated in the study with 1 or more psychogeriatric wards. Dutch NHs employ specialized elderly care physicians (formerly called NH physicians) who are responsible for treatment decisions and medical care.[9,10] Patients with dementia were eligible if they had a physician's diagnosis of pneumonia (as most probable diagnosis). The same patient could be included multiple times in the case of recurrent pneumonia.

Family members were informed about the study by means of a letter at the start of the data collection or at NH admission. Family members were given the opportunity to object against transfer of coded data about their family member to the researchers. The Medical Ethics Review Committee of the VU University Medical Center (Amsterdam, The Netherlands) approved the study protocol. The PneuMonitor study is registered in The Netherlands National Trial Register (ID number NTR5071).

Assessment of the Outcomes

Discomfort was assessed using the Discomfort Scale-Dementia of Alzheimer Type (DS-DAT); a validated observation scale to measure discomfort in patients with dementia. The scale consists of 7 negative items and 2 positive items with 4 response options scored 0–3. Items are scored according to the frequency, intensity, and duration of observed behavior while observing the patient for 5 minutes. The scores for the 2 positive items are reverse coded before all scores are summed into a total score ranging from 0 (no observed discomfort) to 27 (high level of observed discomfort).[5,11,12]

The Comfort Assessment in Dying (CAD) is 1 of 3 End-of-Life in Dementia (EOLD)-Scales and was used prospectively for all patients in this study. EOLD-CAD contains 14 items of which 3 are positive. The presence of each item can be scored from 1 (a lot) to 3 (not at all), so that a higher score indicates more comfort. The 3 positive items are reversed so that the total score for comfort ranges from 14–42 points.[13–16]

Pain was assessed with the Pain Assessment in Advanced Dementia (PAINAD). The PAINAD lists 5 items scored 0 to 2 points. Total scores range from 0 to 10. A cut-off value for probable pain is established at a score of 2 points.[17–19]

The Respiratory Distress Observation Scale (RDOS) is an instrument to observe dyspnea in patients unable to self-report. The RDOS consists of 8 items scored 0 to 2 and summed scores range from 0 (no dyspnea) to 16 (the most severe dyspnea).[20] A cut-off value for respiratory distress was established at 3 points, with 0–2 points signifying little or no distress.[21]

Because discomfort may be lower in patients who are asleep or unconscious, (eg, because of palliative sedation), the level of sleepiness was observed using a 6-level scale that was dichotomized by combining the scores "awake and alert," "awake," and "awake but sleepy" into "awake" and "falling asleep," "in a light sleep," and "in a deep sleep" into "asleep." To describe observed sleepiness over time and assess correlations with the outcomes of the observational instruments, we used the observed sleepiness as a continuous scale.

Observers also registered the use of visible nonpharmacologic measures such as extra pillows to improve posture, or oxygen administration during each observation.

Other Measures and Treatments

The attending physicians completed questionnaires at baseline and after approximately 2 weeks (follow-up) for all patients. Data were collected about patients' demographics and health condition including urinary incontinence, comorbid diseases, nutritional and hydration status, and delirium as judged by the attending physician. Dementia severity was assessed using the 7-item Bedford Alzheimer Nursing Severity-Scale (BANS-S) that discriminates more severe stages of dementia,[22] and clinical judgment of illness severity was estimated by the physician on a scale ranging from 1 (not ill) to 9 (moribund).[23] Furthermore, information was provided about dependency in 3 activities of daily living (ADL; dressing, walking, and eating) each assessed on a 5-point scale, and about whether patients were fully ADL-dependent on 7 ADL items (dressing, transfer, eating, toilet use, personal hygiene, bed mobility, and locomotion on unit).[24] Finally, an 8-item prognostic score was used to estimate the risk of dying within 2 weeks when treated with antibiotics.[25]

Besides patients' characteristics, physicians provided information about the presence of symptoms of pneumonia at baseline such as coughing, sputum production, and dyspnea as judged by the attending physician, and about treatments initiated to relieve symptoms at baseline and changes in symptom-relieving treatments at follow-up after approximately 2 weeks. A last questionnaire was completed by the attending physician only for patients who died during the study, to provide details about antibiotic treatment in the last week before death, treatment with opioids in the last 24 hours, and about whether continuous palliative sedation (the deliberately lowering of a patient's level of consciousness in the last stages of life)[26] was provided or not.

Observers and Observations

The observers were not familiar with the patients. They had various backgrounds; some were NH staff working on wards not participating in the study, and others had no relationship with the NH (Table 1). The researchers trained all observers with an instructional video to perform observations using the observational instruments. Observers were instructed to plan observations if possible at the same time each day, not during meals and not shortly after burdensome procedures such as washing, toileting, or transfers. Patients were observed in their current position, whether this was at rest or during