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Original Study

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

Tessa van der Maaden MSc [a,b], Jenny T. van der Steen PhD [a,b,*], Henrica C.W. de Vet PhD [a,c], Cees M.P.M. Hertogh MD, PhD [a,b], Raymond T.C.M. Koopmans MD, PhD [d,e,f]

[a] EMGO Institute for Health and Care Research, VU University Medical Center, Amsterdam, The Netherlands
[b] Department of General Practice and Elderly Care Medicine, VU University Medical Center, Amsterdam, The Netherlands
[c] Department of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, The Netherlands
[d] Department of Primary and Community Care, Radboud University Medical Center, Nijmegen, The Netherlands
[e] Joachim en Anna, Center for Specialized Geriatric Care, Nijmegen, The Netherlands
[f] Radboud Alzheimer Center, Nijmegen, The Netherlands

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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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* Address correspondence to Jenny T. van der Steen, PhD, Department of General Practice and Elderly Care Medicine, VU University Medical Center, EMGO Institute for Health and Care Research, Van der Boechorststraat 7, 1081 BT Amsterdam, The Netherlands.
E-mail address: j.vandersteen@vumc.nl (J.T. van der Steen).

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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

Table 1
Background and Functions of Observers

	% (n) of all 1791 Observations
Nursing staff (other ward)	52.9 (947)
(Medical) students	14.2 (255)
Administrative staff	11.1 (198)
Researchers	8.2 (147)
Paramedical staff	7.3 (130)
Management	3.9 (70)
Other	2.5 (44)
Total	100 (1791)

movement. The observers were not informed about the condition or treatments of the patient they observed.

The whole observation period comprised 15 days because both possible death and cure of the pneumonia were expected within this period.[4] Observations took approximately 10 minutes and were started as soon as possible, preferably already at the day of diagnosis (further referred to as day 0). Observers were instructed to visit the patient, if feasible, twice a day at day 0 and day 1, once a day from day 2 until day 10, and 1 last time at day 13, 14, or 15, so that the maximum number of observations was 13 per episode of pneumonia.

Analyses

To calculate the incidence of pneumonia, we summed incident cases of pneumonia during the months NHs or wards actively participated in the study. We included data of "missed patients" who met the inclusion criteria but were not included in the study as provided by the physicians. Descriptive statistics were used to describe patient characteristics, symptoms of pneumonia, and treatments initiated to relieve symptoms. To compare patients who were or were not treated with antibiotics and to compare patients who were observed with all included patients, independent *t*-tests and χ^2 tests were used, and to assess changes in treatments between baseline and follow-up, we used McNemar test or paired *t*-tests. Pearson correlation coefficients were used for associations between discomfort, pain, dyspnea, and sleepiness. We report changes in EOLD-CAD scores which range from 14–42, in terms of a proportion of the range (setting 14 to 0 and 42 to 1). We used Kaplan-Meier curves to plot survival. All statistical analyses were performed using SPSS v 20.0 (IBM Corporation, New York, NY).

Results

Pneumonia Incidence and Observational Data

During the pretest phase of the PneuMonitor study, 242 cases of incident pneumonia were included. This was equivalent to an incidence of pneumonia of 0.093 cases per psychogeriatric bed per year; or a patient developing pneumonia on average in 10.8 years.

We obtained observational data for 208 cases of pneumonia in 193 patients; 12 patients were included twice, and 1 patient had 3 episodes of pneumonia. The median first observation day was 1 day after the diagnosis of pneumonia (day 1), and the average number of observations per episode was 8.2. Common reasons for missing observations were late inclusion by the attending physician (not on the day of diagnosis); no trained observer being readily available (high work load; no observer available during the weekends); the observer, nursing staff, or family members were not comfortable with observations during the last phase of life; or the ward the patient resided was closed because of viral gastroenteritis.

Table 2
Patient Characteristics

Characteristics	Observed Cases (n = 208)
Demographics	
Female, % (n)	58.2 (121)
Age, mean (SD)	85.1 (6.7)
Length of stay, months, median (range)	19 (0–138)
Advance directive, % (n)	2.6 (5)
Dementia type, % (n)	
Alzheimer	39.3 (75)
Vascular	23.6 (45)
Mixed	19.4 (37)
Other	7.9 (15)
Unknown	9.9 (19)
Dementia severity, mean BANS-S score, mean (SD)	16.2 (4.7)
Full ADL dependency in 7 items, % (n)	16.7 (31)
Dressing	48.7 (91)
Walking	38.5 (70)
Eating	24.7 (47)
Comorbid disease	
COPD, % (n)	22.3 (43)
Diabetes, % (n)	22.3 (43)
Average number (SD) in addition to dementia	3.4 (2.3)
Delirium, % (n)	14.6 (30)
Full urinary incontinence, % (n)	45.8 (88)
Hydration status*: dehydrated, % (n)	34.5 (71)
Nutritional status†: cachectic, % (n)	28.2 (58)
Clinical judgment of illness severity (range 1–9), mean (SD)	5.4 (1.4)
Prognostic score (range 0–31), mean (SD)	14.2 (5.5)

COPD, chronic obstructive pulmonary disease.
*Hydration status as judged by the attending physician; "mildly dehydrated," "dehydrated," and "severely dehydrated" were combined into "dehydrated."
†Nutritional status as judged by the attending physician; "cachectic" and "severely cachectic" were combined into "cachectic" and "normal," "adipose" and "very adipose" were combined into "not cachectic."

Population and Treatments

The mean age in the observed cases was 85.1 (SD 6.7); 58.2% was female (Table 2). Mortality within 14 days following the diagnosis of pneumonia was 21.6%. In the majority of cases, patients had auscultation abnormalities upon physical examination (95.1%), general malaise (81.3%), and an elevated body temperature (75.9%) (Table 3). Most (89.4%) of the observed cases were treated with antibiotics. In 71.2% of cases, patients received 1 or more treatments to relieve symptoms of pneumonia at baseline, and antipyretics (44.2%), oxygen (23.1%), and opioids (14.9%) were applied most frequently (Table 4). At follow-up after approximately 2 weeks, more patients had received

Table 3
Pneumonia Symptoms at Baseline as Judged by the Attending Physician

	Observed Cases (n = 208)
Symptoms pneumonia (new or acutely worse), % (n)	
Auscultation abnormalities	95.1 (193)
General malaise	81.3 (165)
Elevated body temperature	75.9 (154)
Coughing	68.0 (140)
Dyspnea	57.6 (117)
Tachypnea	55.4 (112)
Decreased alertness	37.9 (78)
Tachycardia	35.9 (70)
Sputum production	29.3 (56)
Orthopnea	10.2 (20)
Lowered body temperature	3.5 (7)
Pleuritic chest pain	3.3 (6)
Cheyne-Stokes respiration	2.5 (5)
Number of symptoms (out of 13 listed), mean (SD)	5.4 (1.8)

Table 4
Treatments

Treatment, % (n)	Baseline	Follow-up*	*P* Value†
Antibiotics	89.4 (185)	90.9 (169)	1.000
Rehydration, intravenous	0 (0)	1.6 (3)	.500
Rehydration, hypodermoclysis	3.9 (8)	2.1 (4)	1.000
Rehydration, encourage fluid intake	41.3 (85)*	35.4 (67)*	.019
Treatments to relieve symptoms of pneumonia			
Antipyretics	44.2 (92)	38.3 (74)	.082
Oxygen	23.1 (48)	22.3 (43)	.648
Opioids	14.9 (31)*	21.2 (41)*	.001
Hypnotics	3.8 (8)	6.2 (12)	.344
Bronchodilators	13.5 (28)	16.1 (31)	.508
Corticosteroids	3.4 (7)*	7.8 (15)*	.008
Anticholinergics	1.9 (4)	2.1 (4)	1.000
Antipsychotics	1.9 (4)	1.6 (3)	1.000
Other	4.3 (9)	3.1 (6)	.508
Any treatment to relieve symptoms	71.2 (148)*	68.9 (133)*	.021
Number of treatments to relieve symptoms, mean (SD)	1.1 (1.0)	1.1 (1.1)	.872

*Approximately 14 days from diagnosis.
†McNemar test or paired samples *t*-test (number of treatments to relieve symptoms).

opioids (baseline 14.9%, follow-up 21.2%, $P = .001$) and corticosteroids (baseline 3.4%, follow-up 7.8%, $P = .008$). Other treatments were not significantly different at follow-up.

For 34 of the 242 included cases, no observations were obtained, and treatments and mortality among these cases differed from the cases that were observed. Of these 34 cases, 58.8% died within 14 days, and death was a main reason for missing observations. In all included cases, 14-day mortality was 26.9% compared with 21.6% for the observed cases only. Moreover, the observed cases more often received antibiotic treatment (89.4% vs 84.5%), and treatment with opioids was less common (14.9% vs 20.6%). Other treatments and characteristics were not significantly different for all cases compared with observed cases only.

Course of the Outcomes Over Time

The mean DS-DAT score of cases that were observed on the day of diagnosis was 7.2 (SD 5.6), and this score increased initially to reach a peak value of 8.1 (SD 5.8) at day 1 (Figure 1, A). From then on, discomfort decreased steadily until it stabilized around day 10, with a DS-DAT score of 4.5 (SD 4.1). On day 10, the average DS-DAT score was 56% of the highest score at day 1.

The EOLD-CAD score was the lowest on day 1 [34.9 (SD 5.2)] (Figure 1, B). After that, the mean scores increased steadily which indicates that comfort increased, until day 10 [38.6 (SD 3.8)] when the score was 18% higher than the lowest level on day 1, and then stabilized similar to the DS-DAT.

Observations with the PAINAD and the RDOS followed a pattern comparable to the DS-DAT and EOLD-CAD (Figure 1, C and D). For both pain and dyspnea, the highest level was reached on the second observation on day 0 [2.0 (SD 1.7) and 3.9 (SD 2.2) respectively], from then on, observed pain and dyspnea decreased, and stabilized around day 10 [0.89 (SD 1.5) and 1.7 (SD 1.7), respectively] to 45% and 44% of the highest score.

Figure 1, D shows that only during the second observation on day 0, the mean PAINAD score was above the cut-off value for probable pain of 2. During this observation, 52.9% of patients scored higher than 2. At day 6, this was 28.0%, and at day 10, 20.4% experienced pain above the cut-off value. Mean RDOS scores were mostly above the cut-off level of 3, which indicates respiratory distress during the first 2 observation days (Figure 1, D). During the second observation of day 0, most (64.7%) patients scored higher than 3 on the RDOS. This decreased to 32.8% on day 6 and 14.6% on day 10.

The lowest level of observed sleepiness was reached shortly after the diagnosis of pneumonia, at the second observation of day 0, when 61.8% of observed cases was in a light or deep sleep [mean level: 3.9 (SD 1.9)]. The number of cases that was asleep decreased to 33.5% at day 2, and was more or less stable from then on (26.8% at day 14) (Figure 1, E).

During 24.8% of all observations, nonpharmacologic measures that may improve comfort were observed, comprising positioning (eg, postural drainage, support by pillows), oxygen administration, nebulization, cooling, and playing music. Observed nonpharmacologic measures were most frequently observed during the first 2 days from diagnosis (45.0% and 45.7%).

Correlations of the Outcomes

On day 1, when the highest levels of discomfort were measured, the DS-DAT scores correlated with the EOLD-CAD ($r = -0.829$, $P < .001$), PAINAD ($r = 0.825$, $P < .001$) and RDOS ($r = 0.694$, $P < .001$); but we found statistically significant correlations between the 4 observation instruments on all observation days.

On the day of diagnosis, the level of observed sleepiness correlated with DS-DAT scores ($r = -0.370$, $P = .003$) and EOLD-CAD scores ($r = +0.289$, $P = .020$). On the day of dying, sleepiness correlated with the DS-DAT ($r = -0.673$, $P = .023$), the PAINAD ($r = -0.832$, $P = .003$), and the EOLD-CAD ($r = 0.616$, $P = .044$), which indicates that discomfort and pain were higher in patients who were awake. The level of observed sleepiness did not correlate with any of the observations on other days.

Observations Close to Death

Of all observed patients, 18.8% died within a week after diagnosis of pneumonia; 21.6% died within 2 weeks, and 44.3% died within 6 months (Figure 2). Among the patients who died within 2 weeks, 95.0% received morphine in the 24 hours before death, and 22.5% of cases were pharmacologically sedated. An increasing number of cases were in a light or deep sleep in the days preceding death (Figure 3). Furthermore, the closer an observation was to death, the higher the observed discomfort, especially for patients who were awake (Figure 4). Observed discomfort increased from 7 days before death. The number of visible nonpharmacologic measures did not increase in the days preceding death.

Antibiotics and Outcomes

The majority of cases (89.4%) received antibiotic treatment. Most frequently prescribed antibiotics were amoxicillin/clavulanate (64.3%) and amoxicillin (20.0%), and antibiotics were predominantly administered orally (91.7%). Cases treated with antibiotics differed from cases for which antibiotics were withheld [AB−, 10.6% (24)]. Among the observed cases, the patients not treated with antibiotics had more severe dementia [BANS-S AB− 18.4 (SD 3.5), AB+ 16.8 (SD 4.8); $P = .018$] and were more severely ill (scored 1–9) as judged by the attending physician at time of the diagnosis [AB− 6.6 (SD 1.3); AB+ 5.3 (SD 1.4); $P < .001$]. Moreover, patients who did not receive antibiotic treatment were more often dehydrated as judged by the physician (AB− 54.5%; AB+ 32.1%; $P = .036$). Treatment at baseline and follow-up that were more frequent for AB− patients included treatment with opioids (baseline: AB− 50.0%, AB+ 10.8%, $P < .001$; follow-up: AB− 58.8%, AB+ 17.6%, $P < .001$) and with hypnotics (baseline AB− 18.2%, AB+ 2.2%, $P = .005$; follow-up AB− 29.4%, AB+ 4.0%, $P = .002$); AB+ patients more often received oxygen (AB− 4.5%; AB+ 25.4%, $P = .028$) and bronchodilators (AB− 0; AB+ 15.5%, $P = .034$) at baseline but not at follow-up. No significant differences between the AB+ and

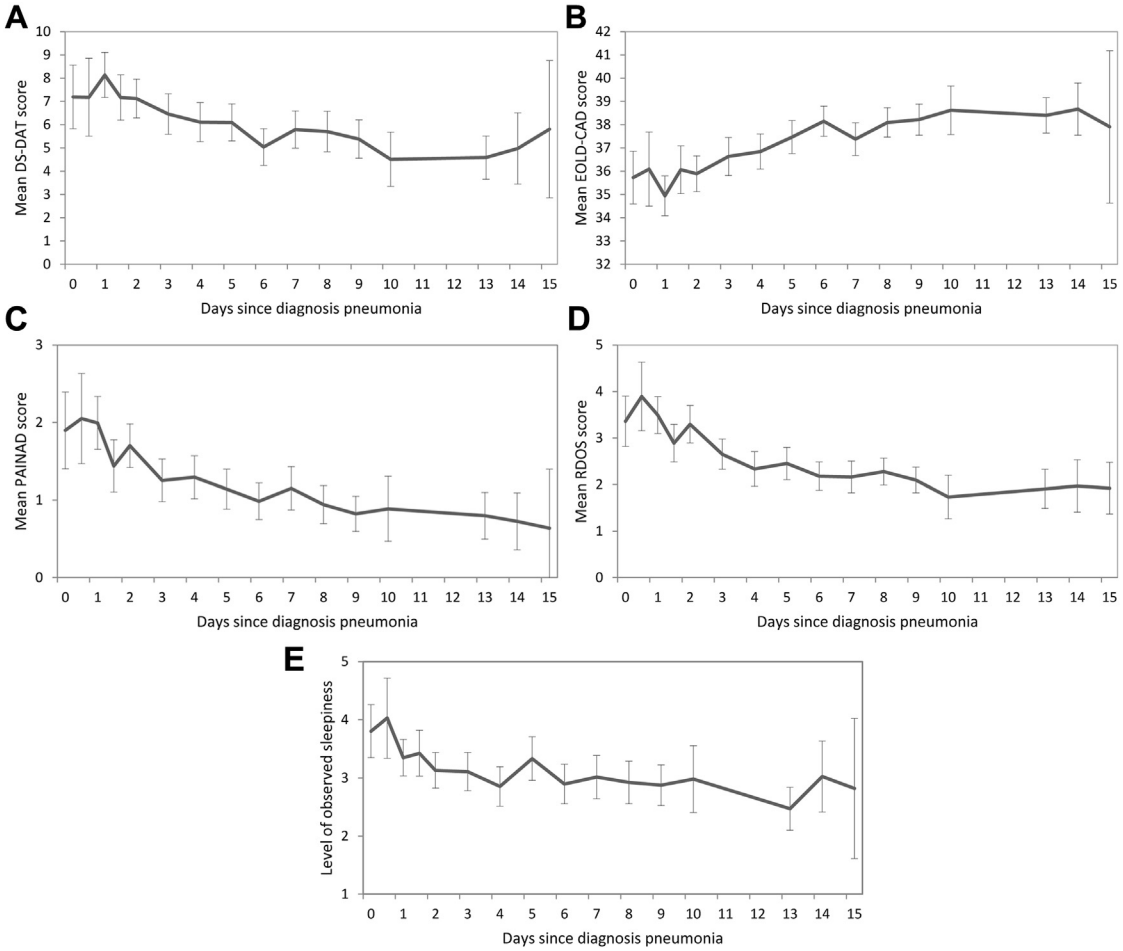

Fig. 1. (A) Mean DS-DAT score (range 0–27) per day [95% confidence interval (CI)]. (B) Mean EOLD-CAD score (range 14–42) per day (95% CI). (C) Mean PAINAD score (range 0–10) per day (95% CI). (D) Mean RDOS score (range 0–16) per day (95% CI). (E) Mean level of sleepiness (mean of scores 1: awake and alert; 2: awake; 3: awake but sleepy; 4: falling asleep; 5: in a light sleep; 6: in a deep sleep) (95% CI). Range of the number of observations per day, variable for the different outcomes: day 0 (first observation): 63–66; day 0 (second observation): 34–35; day 1 (first observation): 137–140; day 1 (second observation): 94–100; day 2: 156–160; day 3: 132–138; day 4: 135–138; day 5: 132–140; day 6: 131–133; day 7: 131–136; day 8: 125–130; day 9: 124–127; day 10: 48–49; day 13: 62–66; day 14: 40–42; and day 15: 11.

AB− patients were found for other treatments or for patient characteristics and symptoms at baseline.

We assessed differences in the course of suffering and sleepiness over time between AB− and AB+ patients. The overall course of discomfort, pain, and dyspnea was similar for both groups, but for AB− patients, suffering fluctuated more over time. Data were sparse for AB− cases because of a lower number of AB− patients overall, among whom more died within few days after diagnosis and for whom fewer observations were available. For these reasons, we do not distinguish these groups in describing the course of suffering over time.

Discussion

Following up to earlier findings that pneumonia in patients with dementia involved severe discomfort,[4] this study provides a detailed picture of how suffering develops in the 15 days from the diagnosis of pneumonia until cure or death. Discomfort, pain, and dyspnea in dementia patients with pneumonia were strongly correlated. Suffering peaked 1 day after the diagnosis of the pneumonia, then declined, and was stable after 10 days for patients who survived the pneumonia. For patients who died, both suffering and observed sleepiness increased in the days preceding death. However, on the day of diagnosis and the day of dying, discomfort was higher in patients who were awake.

Levels of Suffering

The highest level of observed discomfort on the DS-DAT was 8.1 on day 1 which decreased to a score of 4.5 after 10 days. This was low compared with earlier work, the Dutch Pneumonia Study, conducted in The Netherlands between 1996 and 1998, in which DS-DAT levels averaged 11 at the moment of the treatment decision, and 7 at 10 days afterwards.[4] Methodological differences might in part account for the difference between the 2 studies. First, instead of observations by an independent observer, observations in the earlier cohort were performed by the attending physician who was familiar with the patient, and whose view is potentially biased, which have may influenced the observations. However, the observers in both studies were trained using the same instructional video tape. Second, in the Dutch Pneumonia Study, observations took place at the moment of the treatment decision, before any treatment effect could have occurred. In contrast, in the PneuMonitor study the day after the diagnosis of pneumonia (day 1) was the median first observation day, and in some cases, we may have failed to observe the onset of the effect of symptom-relieving treatments. However, as levels of suffering were still rising during the first observation day, the presence of a large gap between observed discomfort on the first observation day and actual discomfort at the moment of diagnosis is unlikely.

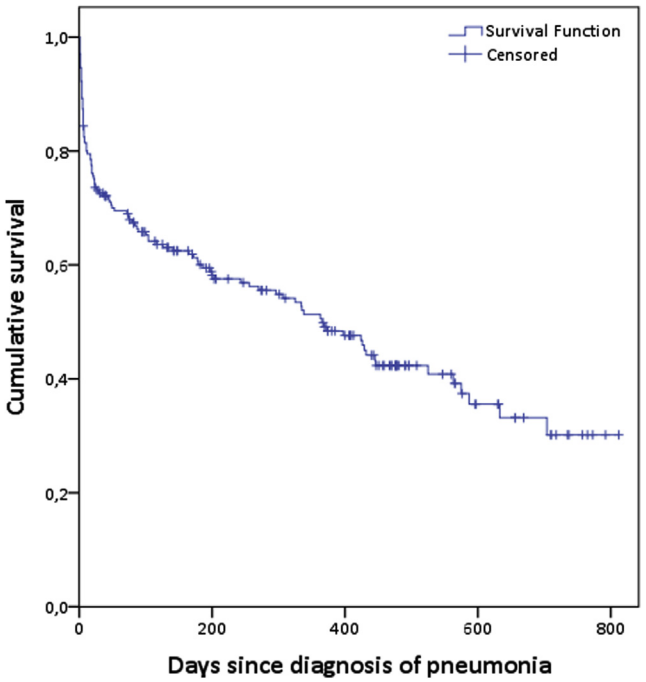

Fig. 2. Cumulative survival in days since the diagnosis of pneumonia.

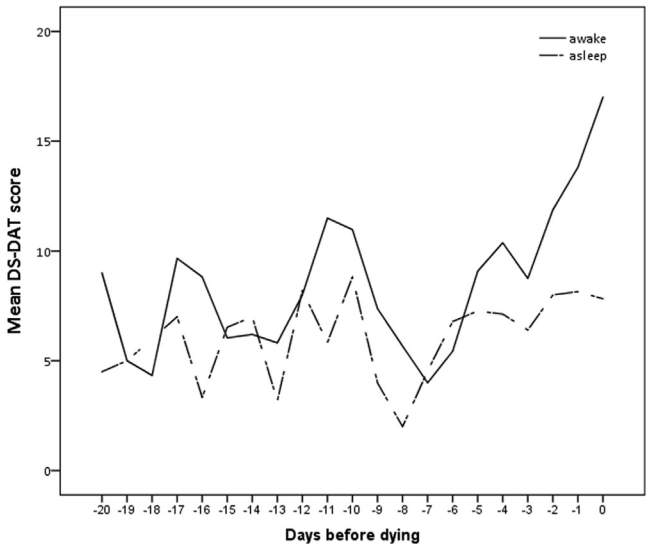

Fig. 4. Mean DS-DAT score (range 0–27) in the 20 days preceding death for patients who died within 20 days from the diagnosis of pneumonia (n = 52) for patients who were aware or asleep. Number of observations per day (awake/asleep): day 20: (5/2); day 19: (3/2); day 18: (3/1); day 17: (6/5); day 16: (7/7); day 15: (6/5); day 14: (5/4); day 13: (4/3); day 12: (2/5); day 11: (4/5); day 10: (9/5); day 9: (6/4); day 8: (3/2); day 7: (2/6); day 6: (7/7); day 5: (12/8); day 4: (8/12); day 3: (9/10); day 2: (9/22); day 1: (5/27); day 0: (3/8).

On the day of diagnosis, more than one-half of observed patients scored above the cut-off level for pain on the PAINAD scale.[19] In comparison, in patients with dementia and a lung, skin, or viral infection admitted to United Kingdom hospitals this was 22% in rest and 63% on movement (care task such as repositioning in bed or standing from chair).[27] Mean levels of the RDOS scores dropped below the cut-off level for distress only at the third observation day and, thus, on average, persisted longer than pain following the diagnosis of pneumonia.[21]

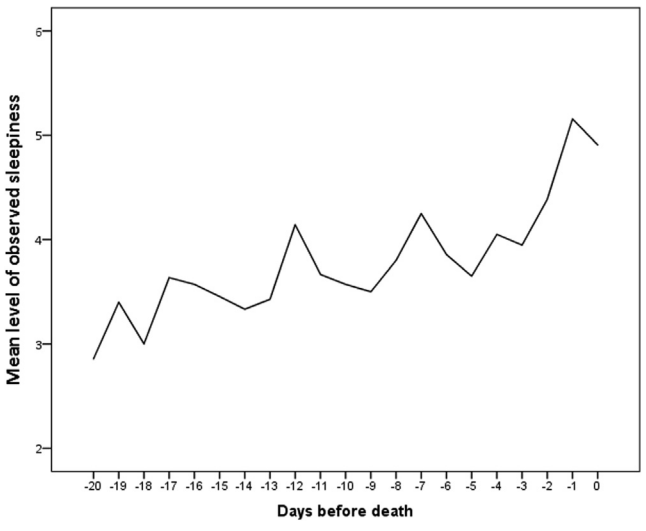

Fig. 3. Mean level of observed sleepiness (mean of scores 1: awake and alert; 2: awake; 3: awake but sleepy; 4: falling asleep; 5: in a light sleep; 6: in a deep sleep) in the 20 days preceding death for patients who died within 20 days after the diagnosis of pneumonia (n = 52). Number of observations per day: day 20: 7; day 19: 5; day 18: 3; day 17: 11; day 16: 13; day -15: 11; day -14: 8; day 13: 7; day 12: 8; day 11: 9; day 10: 15; day 9: 10; day 8: 5; day 7: 8; day 6: 13; day 5: 20; day 4: 20; day 3: 18; day 2: 30; day 1: 31; and day 0: 11.

Course of Suffering and Treatment

Levels of suffering decrease during the first days following diagnosis of pneumonia. When symptom-relieving treatments such as analgesics are provided, effects on observed comfort are expected soon after administration. Antibiotics are sometimes prescribed with the intention to relieve symptoms of pneumonia, but the actual effects of antibiotic treatment on enhancing comfort remain unclear.[28–31] When antibiotic treatment initiates recovery, improvement in the patient's situation should be visible within 48 hours. Therefore, the decrease in suffering following the peak level 1 day after the diagnosis of pneumonia may be attributed to the combined effect of antibiotic treatment, patient recovery, and effective symptom-relieving treatments. After 10 days, suffering stabilized, which is similar to observations on the course of discomfort in patients with dementia and pneumonia in earlier research, where patients were observed at 3 days and 10 days after diagnosis only.[4]

Remarkably, various treatments to relieve the symptoms of pneumonia, such as opioids and oxygen, were applied more often in this study compared with the earlier Dutch Pneumonia Study.[4] An increased focus on the importance of comfort and palliative care, resulting in more treatments initiated to relieve the symptoms of pneumonia may account for less suffering, from shortly after the treatment decision until cure or death. Although more symptom-relieving treatments were applied compared with the study in 1996–1998, even more symptom relief was initiated in a smaller sample (n = 72) in a study in 2006–2007, which was a country-wide study as well.[8] For example, oxygen was provided in 13% of cases in 1996–1998, in 29% in 2006–2007, and in 23.6% in this study (2012–2014); similar patterns were seen for opioids, antipyretics, and corticosteroids. However, in 2006–2007 patients were not observed to assess discomfort.

Mortality for both patients with and without antibiotic treatment was much lower compared with an earlier study. Fourteen-day mortality was 21.6%, compared with 38% in the Dutch Pneumonia Study, and more patients were treated with antibiotics (90% vs 77%) However, it has been shown that although antibiotics may prolong life in a

minority of patients with advanced dementia,[32] hydration status affected survival even more profoundly than antibiotic treatment in nursing home residents, many of whom had dementia.[33] Patients in the current study appeared less often dehydrated or malnourished, and were judged slightly less severely ill by the attending physician (clinical judgment of illness severity 5.4 compared with 5.9) than observed in the earlier work.[8] The incidence of pneumonia was similar to the Dutch Pneumonia Study: 0.093 vs 0.095 cases of pneumonia per bed per year. Apparently, developing pneumonia was equally common in both cohorts, despite an overall better health condition. Possibly, this better health condition of patients before they develop pneumonia led to a lower illness severity, which in turn may have resulted in lower levels of discomfort.

Suffering Before Death

Suffering increased in the days preceding death. Scores of DS-DAT and PAINAD before death were high, and scores of EOLD-CAD were low (indicating lower comfort) compared with another Dutch study where patients with dementia were observed in the days before death (most patients died of cachexia/dehydration).[13] This contrast does not seem to be attributable to differences in treatments in the last days of life, and confirms earlier findings that death from pneumonia involves a high symptom burden and is less comfortable than death attributed to dehydration after food and fluid intake problems.[6]

When death neared, more patients were asleep. From patients dying within 14 days after the diagnosis of pneumonia, 22.5% was continuously sedated until death, which was comparable to what was found in a Dutch study among dementia patients in the end of life more generally, where 21% received palliative sedation.[6] Inducing a lowered consciousness state by palliative sedation is common in the days before death[34,35]; this may reduce suffering in patients who die from pneumonia. On the day of death, patients were more comfortable when observed asleep (observed sleepiness and discomfort were negatively correlated). Furthermore, discomfort increased in the days before death, especially for patients who were awake, suggesting that providing palliative sedation is a realistic option to enhance comfort in the days before death in patients with dementia and pneumonia. However, this may raise the question of when providing palliative sedation is appropriate. Patients may be more comfortable, but consciousness is reduced, and the process of dying may be accelerated.[36,37]

Strengths and Limitations

This study is the first to provide a detailed overview of suffering in patients with dementia and pneumonia. By performing regular (almost daily) observations by observers who were blinded for treatment and patient's health condition, using 4 different observational instruments and observations of sleepiness, an in-depth picture of suffering is provided. Because an increase in suffering was observed during the first observation day, and the decrease of suffering after that stabilized within the 15-day observation period, our observations probably comprise both the highest and the lowest levels of suffering. Still, some limitations should be acknowledged. The diagnosis of pneumonia was made by physician judgement, mostly without laboratory or x-ray confirmation, which may in cases lead to false positives, but most closely resembles clinical practice. Next, in 35 cases, observers were not able to start observations, and as these cases were often patients who died soon after the diagnosis of pneumonia, these patients differed from patients who were observed. We, therefore, may have selectively excluded patients who were dying and were not treated with antibiotics. For only 1 out of 10 (10.6%) patients included in the study, antibiotics were withheld, and because these patients more often died in the first days after the diagnosis of pneumonia, the number of observations we obtained for patients not treated with antibiotics was limited. In these patients, the patterns of observed suffering were irregular compared with the patterns of patients who received antibiotics because of a lower number of observations and was, therefore, more difficult to interpret. Because sleepiness was observed by observers blinded for condition and treatment of the patients, we could not discriminate between daytime sleep and decreased consciousness because of other causes such as the pneumonia, a delirium, or palliative sedation. Although the EOLD-CAD instrument was developed to assess comfort in dying retrospectively, the instrument has been used prospectively with success in patients expected to die, and we used it prospectively for all patients.[13] The observational instrument we applied to observe dyspnea, the RDOS, has been validated, but has not been used before in patients with dementia.

Conclusions

Levels of suffering in patients with dementia and pneumonia increased until 1 day after the diagnosis, then decreased, and were stable after 10 days (or increased in the days preceding death). Observed discomfort was lower compared with a prior Dutch study, more treatments to relieve the symptoms of pneumonia were initiated, and the general health condition of patients appeared better. These results may initiate a discussion about to what extent it is possible, and whether it should be pursued to take comfort to an even higher level in patients with dementia and pneumonia. Future studies should examine what treatments are the most effective in relieving pneumonia symptoms, in particular in the days preceding death.

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Supplementary Data

Supplementary Data related to this article can be found online at http://dx.doi.org/10.1016/j.jamda.2015.08.010.

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