Pneumonia: The Demented Patient's Best Friend? Discomfort After Starting or Withholding Antibiotic Treatment

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OBJECTIVES: To assess suffering in demented nursing home patients with pneumonia treated with antibiotics or without antibiotics. This study should provide the first empirical data on whether pneumonia is a "friend" or an "enemy" of demented patients and promote a debate on appropriate palliative care.

DESIGN: Prospective cohort study.

SETTING: Psychogeriatric wards of 61 nursing homes in the Netherlands.

PARTICIPANTS: Six hundred sixty-two demented patients with pneumonia treated with (77%) or without (23%) antibiotics.

MEASUREMENTS: Using an observational scale (Discomfort Scale—Dementia of Alzheimer Type), discomfort was assessed at the time of the pneumonia treatment decision and periodically thereafter for 3 months or until death. (Thirty-nine percent of patients treated with antibiotics and 93% of patients treated without antibiotics died within 3 months.) Physicians also offered a retrospective judgment of discomfort 2 weeks before the treatment decision. In addition, pneumonia symptoms were assessed at baseline and on follow-up. Linear regression was performed with discomfort shortly before death as an outcome.

RESULTS: A peak in discomfort was observed at baseline. Compared with surviving patients treated with antibiotics, the level of discomfort was generally higher in patients in whom antibiotic treatment was withheld and in nonsurvivors. However, these same patients had more discomfort before the pneumonia. Breathing problems were most prominent. Shortly before death from pneumonia, discomfort increased. Discomfort was higher shortly before death when pneumonia was the final cause of death than with death from other causes.

CONCLUSION: Irrespective of antibiotic treatment, pneumonia causes substantial suffering in demented patients. Adequate symptomatic treatment deserves priority attention. J Am Geriatr Soc 50:1681–1688, 2002.

Key words: dementia; discomfort; pneumonia; quality of life; well-being

In 1892, in his first edition of *Principles and Practice of Medicine,* Osler presented the view that pneumonia in older people was "the special enemy of old age."[1] A few years later he wrote: "Pneumonia may well be called the friend of the aged. Taken off by it in an acute, short, not often painful illness, the old man escapes those "cold gradations of decay" so distressing of himself and to his friends."[2] Absence of fever and obscure pneumonia symptoms have been described in older people since Osler's days,[1,3] suggestive of only minor suffering.

Over the last decade, Osler's views have been cited often in introductions to clinical articles;[4–16] some authors only cite his negative perspective[8–10] and others only the positive perspective.[11–16] The conflicting urges (i.e., to prolong life and not to prolong suffering or dying),[17,18] were present in Osler's days as they are now. Nevertheless, even if the goal of treatment is to avoid prolonged suffering, the best approach to treating pneumonia is not always clear. Until now, there have been no empirical studies of the degree of discomfort experienced by older nursing home patients treated with or without antibiotics for pneumonia.

This issue is particularly pressing in patients with dementia, in whom death certificate studies suggest that (broncho)pneumonia is the ultimate cause of death in 33% to 71% of cases.[19–22] Specifically for advanced dementia, questions have increasingly been raised about treatment decisions over the last decade.[23–26] For example, in a study of hospitalized patients, Morrison et al.[23] observed that pneumonia was not considered a terminal diagnosis in patients suffering from end-stage dementia, despite the high probability of death. They questioned whether these patients should have received as many burdensome procedures as cognitively intact persons. The potential benefit of treatment is decreased in dementia patients, considering their di-

minished life expectancy, altering the "risk-benefit ratio."[24] This ratio may be further altered because aggressive treatment of pneumonia in demented patients might cause suffering;[23,27-30] for example, intravenous antibiotics or hydration frequently require restraints to prevent removal of the intravenous line.[11,23] For some demented patients, initiating good palliative care might lead to less suffering.[31] Furthermore, withholding curative treatment (antibiotics) might not even compromise the chances of surviving pneumonia in severely demented patients.[32]

Although Osler was able to express and to change his opinion about the "friendliness" of pneumonia, many demented patients are not. Therefore, assessing suffering from pneumonia in demented patients is challenging. Difficulties in communication due to aphasia[33] and patients' limited ability to evaluate their situation[34] may lead to a failure to appreciate how much pain and distress patients experience. Nonetheless, instruments to assess discomfort, well-being, and quality of life, even in severely demented patients, have been developed during the last decade, using observation as the basis of assessments.[35-38] The first developed assessment tool, which had just become available at the time of study design, the Discomfort Scale—Dementia of the Alzheimer Type (DS-DAT) shows acceptable psychometric properties.[31,36,39,40] With this instrument, we undertook an explorative study to assess the magnitude of discomfort that demented patients with pneumonia experience.

In this paper, we address the following three questions. Is *suffering* (discomfort) due to pneumonia recognizable in demented nursing home patients, and is this different in differently treated patients? What specific *symptoms and signs* of pneumonia are obvious in these patients, and how do these relate to discomfort? Is *death from pneumonia* specifically associated with less discomfort? These questions pertain to the central issue of this paper: Is withholding antibiotic treatment in demented patients appropriate palliative care?

METHODS

Study Population

We performed a prospective observational study during the course of pneumonia in moderate to severely demented patients on psychogeriatric wards of 61 Dutch nursing homes affiliated with our department. Some questions asked about patient status before the pneumonia. Twenty-four percent of all long-term psychogeriatric care beds in the country were represented in this study.[41] Between October 1996 and July 1998, 706 consecutive patients who suffered from pneumonia according to a diagnosis of the treating physician were identified. Of these, 23 did not suffer from dementia, and 21 had missing data on mental status. Therefore, the number studied was 662. *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition* criteria[42] were used for purposes of defining Alzheimer's disease and vascular dementia. Other types of dementia and the presence of pneumonia were determined by the facility-based nursing home physician.[43,44] All subjects were residents in the nursing home for at least 4 weeks before diagnosis of pneumonia. A patient could be included only once even if a second episode of pneumonia occurred during the study period. Most patients were treated with anti-

biotics (AB+; 77%), whereas antibiotics were withheld from others (AB–; 23%). In 90% of antibiotic prescriptions, the aim was stated to be patient cure rather than simply symptom relief. The decision to treat or not was determined by the nursing home physician based on expected treatment effectiveness and the patient's wishes as best as could be determined. Dutch physicians are culturally and legally empowered to withhold medically ineffective treatment.[45] Therefore, it is not surprising that expected effectiveness appeared a major issue in decision-making in our study.[46,47] Most (96%) of the patients in whom antibiotic treatment was withheld were expected to die soon; almost two-thirds were expected to die even if antibiotics were started.[47]

No examinations other than those routinely performed by nursing home physicians or staff were performed. Family members were informed of the study by use of a pamphlet and had the opportunity to object to the study. No objections were forthcoming. In some nursing homes, committees of family members approved the study. The Medical Ethics Committee of the VU University Medical Center approved the study protocol.

Data Collection

Each patient was followed for 3 months, during which cure, as judged by the treating physician, and death were monitored. The physicians completed questionnaires about each patient at the time of the current treatment decision, describing the baseline condition and the patient's condition 2 weeks previously. Follow-up assessments were performed at 3 days, 10 days, 1 month, and 3 months after this baseline evaluation. In addition, questionnaires were completed at the time of cure, as judged by the attending physician, or death. In the latter case, the immediate cause of death was assessed in a manner similar to that used on the standard Dutch death certificate.

Physicians indicated discomfort at baseline and at all follow-up times using the 9-item observational DS-DAT. This scale was developed in a severely demented, predominantly male Alzheimer population.[36] It runs from 0 (no observed discomfort) to a theoretic maximum of 27 (high level of observed discomfort). The items are noisy breathing, negative vocalization, sad facial expression, frightened facial expression, frown, tense body language, fidgeting, and (absence) of content facial expression and of relaxed body language. Scores were based on frequency, intensity, and duration of the observed behavior. Missing data were replaced with the patient mean if no more than three items were missing; missing data were thus replaced for less than 5% of cases. To calculate summed scores, the scores of the two "positive items" were reversed. The physicians were instructed to use the scale during a training session in which an instructional videotape was shown. Several studies have demonstrated the validity of the DS-DAT, including findings of lower discomfort in patients on dementia special care units with a focus on comfort care.[31,40,48] Interobserver and intraobserver reliability of the DS-DAT are also acceptable.[36,39] There was only minor variation when the same physician rated the same videotaped patient 5 months later. The intraclass correlation coefficient for intrarater reliability was as high as 0.97.[39] Internal consistency was good, with values of Cronbach's alpha ranging from 0.76[40] to 0.86–0.98.[31,36] Because the DS-DAT was de-

signed for direct observation, a separate study on validity and reliability of retrospectively collected data was performed. No difference in score was found between actually observed and retrospectively collected data by three nursing home physicians on the same 52 patients 2 weeks afterwards. In addition, reliability was acceptable (the intraclass correlation coefficient was 0.55; J. T. van der Steen et al., unpublished data).

Using questionnaires, other data collected by the physicians were age, gender, and three activities of daily living (ADLs), which were assessed using 4-point scales for dependency in dressing, walking, and eating.[49] At baseline and after 3 and 10 days, data on symptoms of pneumonia were collected.

Statistical Analyses

To compare the discomfort of individual patients at different times, we used paired sample t tests (distributions sufficiently resembled normal distributions). In AB– patients, statistical significance was not tested 1 month and 3 months after baseline, because the number of survivors was too small. Independent sample t tests were used to compare levels of discomfort between two patient groups. Chi-square tests were used to test differences between proportions of symptomatic treatment started. In AB+ patients only, Pearson correlation coefficients (r) were used for associations between discomfort and number of symptomatic treatments started or burdensome symptoms.

Regression Analyses

Linear regression was used in AB+ patients to predict levels of discomfort shortly before death in patients having died from pneumonia or from some other cause. Patients who were cured and did not suffer from recurrent pneumonia were assumed to have died from some other cause. Each patient's last recorded discomfort was related to the patient's cause of death. Ninety-five percent confidence intervals (CIs) for beta, which represents the adjusted difference in discomfort between groups, were computed. Analyses were repeated with "death from pneumonia" as defined by pneumonia being the immediate cause of death according to the death certificate.

Confounders

Discomfort was more intensively surveyed shortly after the treatment decision. The reason for this was that, at onset of pneumonia, major changes were expected, as opposed to after about 2 weeks, when many patients were expected to have been cured or to have died. Therefore, the consequence of looking backward from the time of death is that discomfort was not measured at standardized time intervals from death. This could confound a relationship between cause of death and discomfort if, as could be expected, cause of death were related to duration of survival with high discomfort just before death. To prevent potential confounding by intensity of measurements, all results were adjusted for the period between the last measurement and death by inclusion of this period in the multivariate model. Similarly, results were also adjusted for dressing, walking, and eating dependencies as proxies for ADLs, because preliminary analyses indicated that specific dependencies were

found predictive for short-term or mid-term mortality. Possible other confounders were age and sex.

DS-DAT Items

We also looked at which individual DS-DAT items contributed most to discomfort. For example, the item "noisy breathing" was expected to contribute more in pneumonia deaths than in deaths from other causes. Therefore, all regressions were repeated with the outcomes "score on the item noisy breathing" and "score on all other items." In addition, the course of scores on separate items was described.

RESULTS

Patients

The average age ± standard deviation of the demented patients under study was 83.7 ± 7.6 years; 62% were female. Fifty-nine percent of the patients suffered from Alzheimer's disease, 20% from vascular dementia, 10% from mixed dementia, and 11% from some other type of dementia. Many patients had been completely ADL dependent before the pneumonia (85% in dressing, 68% in walking, and 66% in eating).

The Course of Discomfort and Treatments Instituted

The majority (88%) of AB+ patients received oral antibiotics. Most patients (more AB– patients than AB+ patients) received some kind of symptomatic treatment aimed at relief of pneumonia symptoms (Table 1). Antipyretics/nonsteroidal antiinflammatory drugs were given most often; in AB– patients, opioids and benzodiazepines were given frequently as well.

The levels of discomfort varied during the course of pneumonia (Figure 1). The average level of discomfort was highest at the time of the decision whether to treat with antibiotics and returned to the level before the onset of the pneumonia within 10 days after the decision (if the patient survived). This level was generally maintained during the follow-up at 3 months.

Figure 2 shows discomfort in AB– patients and AB+ patients separately. Discomfort was higher in AB– patients throughout the course, but the shape of the curves was similar. The increase from 2 weeks before the treatment decision was similar in AB– patients and AB+ patients (3.6 and 4.4 points on the DS-DAT scale, respectively; $P = .153$). This refers to relative increases of 42% and 69%, respectively. Moreover, decreases in discomfort 3 days or 10 days from the treatment decision were not different in AB– and AB+ patients ($P = .645$ and $P = .880$, respectively).

Figure 3 also shows the course of discomfort according to treatment group, but separately for 3-month survivors and nonsurvivors. On the whole, including before the pneumonia, discomfort levels of surviving AB+ patients were lower than those of nonsurviving AB+ patients and those of AB– patients. Although AB– patients showed higher discomfort throughout the course of pneumonia, discomfort of surviving AB– patients (12) also returned to the levels before pneumonia. Compared with their prior levels, after 3 months, about as many patients had a higher discomfort score (44% for AB+ and 45% for AB– patients) as had a lower score (45% AB+, 55% AB– patients); of AB+ patients, 11% had a similar score.

Table 1. Symptomatic Treatments for Relief of Pneumonia Symptoms Started at Baseline in Patients in whom Antibiotic Treatment was Withheld (AB– Patients) or Started (AB+ Patients)

Initial Treatment Instituted	Total (n = 662)	AB– (n = 155)	AB+ (n = 507)
	%		
Antipyretics, nonsteroidal antiinflammatory drugs	35	45*	33*
Oxygen	13	14	13
Opioids	10	37*	2*
Hypnotics/sedatives/anxiolytics (benzodiazepines)	10	26*	5*
Other (e.g., nebulizers, corticosteroids, mucolytics, anti-emetics)	13	13	13
Any symptomatic treatment	57	85*	48*

*$P < .05$ for difference between AB– and AB+ patients.

Discomfort was not different for Alzheimer's disease than for vascular dementia, mixed dementia, or other types of dementia, for any measurement in time. At the time of the treatment decision, discomfort was higher in male patients than in female ($P = .006$).

The number of symptomatic treatments started at baseline was related to high discomfort at baseline ($r = 0.22$, $P < .001$) and 2 weeks before ($r = 0.14$, $P = .001$) but also 3 days ($r = 0.18$, $P < .001$) and 10 days afterward ($r = 0.22$, $P < .001$). The number of symptomatic treatments was not significantly related to decreases in discomfort within 3 days ($r = 0.04$) and within 10 days ($r = 0.02$) (analyses refer to AB+ patients only).

Specification of Discomfort

The observed contribution of the individual DS-DAT items to total discomfort before and at the onset of pneumonia was proportional. Before the pneumonia, the "positive" items, content facial expression (mean: 1.9 points) and relaxed body language (1.7 points), and the "negative" item tense body language (0.9 points) showed the

highest scores. The seven negative items all showed the same pattern, with a peak at the time of the treatment decision. However, the noisy breathing item showed the highest peak (1.8 points vs 0.6–1.3 for other negative items). The two positive items showed a decrease in score at the time of the treatment decision, to 1.3 and 1.4 points, respectively.

The majority of patients suffered from symptoms of pneumonia at baseline (Table 2). General malaise was present in the vast majority of patients. General malaise, tachypnea, and decreased alertness were more common in AB– patients, whereas cough was more common in AB+ patients. General malaise and cough lasted longest; almost one-third of the AB+ patients still suffered from these symptoms 10 days after the treatment decision (Table 3). Associations with discomfort were strongest for restlessness, shortness of breath, and general malaise. Fever was negatively associated with discomfort at baseline but positively after 3 days (mean differences in DS-DAT scores between patients suffering and not suffering from fever: –1.8 and 1.5 points, respectively).

Discomfort Shortly Before Death from Pneumonia

Discomfort increased shortly before death (0.06 point higher discomfort per day closer to death, 95% CI = 0.01, 0.12; unadjusted). Thirty-nine percent of AB+ patients
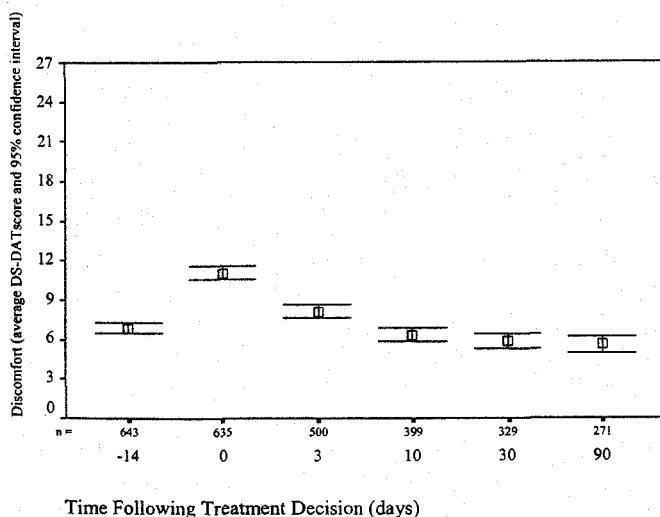
Figure 1. Course of discomfort in demented patients. Chronbach's alpha varied between 0.81 and 0.84 for different times. DS-DAT = Discomfort Scale—Dementia of Alzheimer Type (normal range 0–27).
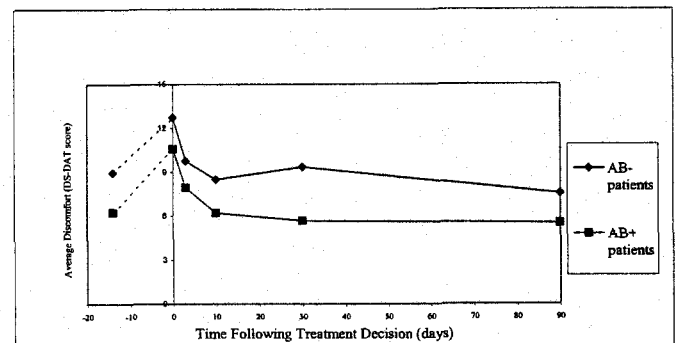
Figure 2. Course of discomfort in patients in whom antibiotics where withheld (AB– patients) and patients treated with antibiotics (AB+ patients), survivors and nonsurvivors. Dotted lines mean retrospective assessment. DS-DAT = Discomfort Scale—Dementia of Alzheimer Type (normal range 0–27).
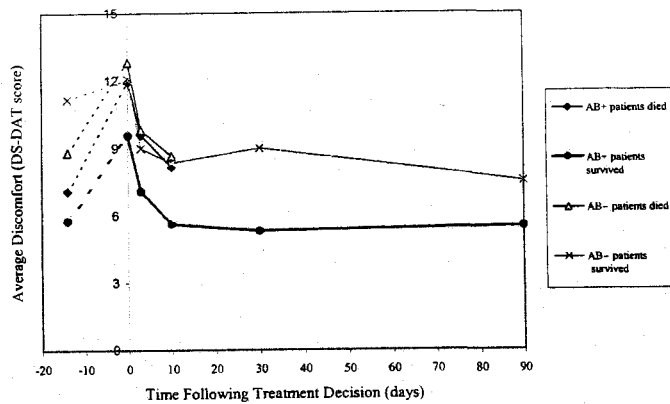
Figure 3. Course of discomfort in patients who died within 3 months and patients who survived pneumonia. Dotted lines mean retrospective assessment. DS-DAT = Discomfort Scale— Dementia of Alzheimer Type (normal range 0–27).

and 93% of AB– patients died within 3 months. Of the 195 deaths in AB+ patients (12 outcomes were missing), 154 (79%) died from pneumonia (129 from the initial pneumonia episode and 25 from recurrent pneumonia). Forty-one (21%) died from some other cause after being cured from pneumonia. In this case, the death certificate typically listed conditions such as congestive heart failure or cachexia as the "immediate cause of death." Those dying from pneumonia had an average discomfort score shortly (median: 3 days) before death of 10.6 ± 6.1. Those who died from other causes had an average discomfort score shortly (median: 13 days) before death of 7.7 ± 6.1. Baseline characteristics (age, sex, illness severity, dependencies, type of dementia, baseline discomfort and average number of symptomatic treatments started) were not different between patients dying from pneumonia and patients dying from some other cause.

Death from pneumonia was also related to discomfort in the last days before death when adjusted for time to death. In death from pneumonia, discomfort was an average 2.6 points higher on the 28-point DS-DAT scale than in death from other causes (95% CI = 0.4–4.8, adjusted for period of last measurement to death, as in all other analyses). Additional adjustment for age, sex, and ADL dependencies did not change the results. (Discomfort was on average 2.6 points higher, CI = 0.4–4.9.) Independent of these characteristics, male sex was a predictor of high discomfort shortly before death (1.9, 95% CI = 0.1–3.8). The individual item "noisy breathing" accounted for one-quarter of the difference in discomfort between pneumonia deaths and other deaths (0.66 points) and the other eight items for three-quarters (1.9 points). Using cause of death as reported on the death certificate as the outcome led to similar results.

DISCUSSION

In spite of advances in palliative care since Osler's period, our results indicate that death from pneumonia may not be a relatively "friendly" death in demented nursing home patients. Suffering is more severe shortly before death from pneumonia than before death from other causes, as assessed in patients treated with antibiotics. The adjusted average score was about 30% higher in demented patients who died from pneumonia, and this was not due to baseline differences in frailty or discomfort. Moreover, during the pneumonia, discomfort was *higher* in patients in whom antibiotic treatment was withheld than in treated patients, despite more symptomatic treatments. Finally, the intensity of suffering may be severe; the level of observed discomfort at the time of the antibiotic treatment decision is about 50% higher than 2 weeks before treatment, in patients treated and not treated with antibiotics.

Throughout the course, AB+ patients who survived their pneumonia had lower levels of discomfort than AB+ patients who died and AB– patients, but AB+ patients had lower levels of discomfort than AB– patients before onset of pneumonia. Although lasting for about 1 week, discom-

Table 2. Prevalence of Burdensome Symptoms of Pneumonia at Baseline by Treatment Group

Symptom	Total (n = 662)	Patient Group	
		AB– Patients (n = 155)	AB+ Patients (n = 507)
		%	
General malaise	92	96*	90*
Fever†	78	80	77
Cough	70	63*	72*
Shortness of breath	59	65	57
Breathing frequency 25 or more breaths per minute	57	69*	54*
Decreased alertness	49	77*	41*
Sudden behavior changes compared with before the pneumonia			
Confusion	24	20	25
Restlessness	20	21	20

* $P < .05$ for difference between patients not given (AB–) and given (AB+) antibiotics.
†Temperature >38.8°C or >37.8°C twice within >24 hours.

Table 3. Burdensome Symptoms of Pneumonia in the 410 Patients Treated with Antibiotics (AB+ Patients) Surviving at Least 10 Days and Associations with Discomfort at the Same Time

Symptom	At Baseline	After 3 Days	After 10 Days
	% (Correlation Coefficient)		
General malaise	89 (0.13)*	58 (0.31)*	30 (0.23)*
Fever[†]	76 (−0.13)*	19 (0.12)*	7 (0.09)
Cough	74 (0.08)	61 (0.16)*	30 (0.21)*
Shortness of breath	53 (0.27)*	24 (0.22)*	10 (0.29)*
Breathing frequency 25 or more breaths per minute	50 (0.20)*	25 (0.10)	15 (0.22)*
Decreased alertness	37 (0.05)	16 (0.16)*	11 (0.14)*
Sudden behavioral changes compared with before the pneumonia			
Confusion	25 (0.13)*	12 (0.14)*	8 (0.27)*
Restlessness	20 (0.28)*	11 (0.27)*	8 (0.27)*

*Significantly correlated with discomfort at that time.
†Temperature >38.8°C or >37.8°C twice within >24 hours.

fort of surviving patients, both AB+ and AB− patients, did not remain elevated over the long term. Discomfort returned to the lower levels of the time before the pneumonia.

In general, we observed a higher peak in discomfort than Hurley et al.[31] in a study of fever patients (among them patients suffering from urinary tract infections). In that study, observed discomfort increased less than 50%, and peak levels were lower. These discomfort scores ranged from about 6 to 7 in a dementia special care unit to about 10 in a traditional long-term care unit. These scores were mostly for patients who were treated with antibiotics. Palliatively treated patients (mostly without antibiotics) rated in between.[31] However, the high discomfort levels and lack of association between decrease in discomfort and symptomatic treatment found in our study pose questions about the effectiveness of treatment initiated for symptom relief.

Discomfort as measured by the DS-DAT is composed of a broad range of behaviors and was associated with a number of pneumonia symptoms. Although, as would be expected, breathing problems were an important consideration in discomfort due to pneumonia, they was not the only consideration, because three-quarters of the discomfort measured by the DS-DAT was due to other items.

Study Limitations and Strengths

Symptom measures in demented patients, such as the DS-DAT, are inherently problematic. There is no agreed upon criterion standard for discovering the quality of life in such patients, because the patients themselves often cannot communicate directly about their subjectively experienced discomfort.[50,51] Nonetheless, we believe the DS-DAT is a valuable instrument to indicate the suffering levels in these patients. In our findings, the interpretation that breathing problems is a marker of suffering could be challenged but seems appropriate given the item's wording. The description of the item "noisy breathing," includes, for example, "breathing looks strenuous, labored, or wearing" and "gasping."[36] In addition, parallel increases in discomfort for all items were observed, which is consistent with the fact that the DS-DAT has shown adequate internal consistency,[31,36,40] as confirmed in the current study.

A second issue is that the DS-DAT seemed to show a floor effect, because only low scores on the 28-point scale (0–27) were regularly observed. This probably reflects the fact that it is unlikely that extreme behaviors for all nine items would occur during a 5-minute observational period.

A third issue is possible observer bias due to assessments made by treating physicians. This might be important, for example, in retrospectively collected data on more subjective issues, such as discomfort. Although retrospective assessment in itself was assessed as sufficiently reliable (J. T. van der Steen et al., unpublished data), physicians may have recalled discomfort differently in patients in whom antibiotics were withheld. It is conceivable that physicians specifically overestimated discomfort before the pneumonia in patients treated without antibiotics but who were otherwise relatively well (Figure 3), but retrospective assessments were sometimes performed with the help of the nursing staff, who were mostly not familiar with the goals of the study.

A fourth issue in our study is the type of comparison we could make in discomfort shortly before death. Patients who died from causes other than pneumonia had recently suffered from pneumonia as well. The ideal study design would look specifically at suffering before death and would include a broader sample, but the current design was chosen to be most clinically relevant to the treatment decision at the onset of pneumonia.

The diagnosis of pneumonia was made by physician judgment and was probably fairly accurate, because patients suffered from a large number of symptoms and the diagnosis was seldom revised. Furthermore, at least 89% met consensus criteria for lower respiratory tract infections.[52] Moreover, in a sample of 14 consecutive patients treated with antibiotics in one of the participating nursing homes, the diagnosis could be radiographically confirmed in 12 patients. Physicians were careful not to include patients whose diagnosis was ambiguous;[53] this might have led to a slight overestimation of baseline discomfort in pneumonia patients because mainly the most obvious cases of pneumonia were included.

Discomfort was not measured daily but at varying intervals. We adjusted for the period between the last mea-

surement and death to minimize bias. (This bias is obvious in Figure 3, where discomfort seems to decrease before death.) However, also in view of limited power due to the relatively small number of patients dying from other causes, a better design would include more frequent measurements.

Finally, the type of symptomatic treatment started was assessed at baseline only. A higher number of symptomatic treatments might be expected shortly before death from pneumonia, because, at baseline, a higher number was found in patients showing most discomfort. Because of the observational nature of the study and lack of follow-up data on symptomatic treatments, conclusions with regard to the adequacy of symptomatic treatments should be drawn carefully.

Considerations Regarding Care and Research

Despite these limitations of our observational study, the results are of relevance for the care of demented patients suffering from pneumonia. Osler may have been correct in calling death from pneumonia "friendly" in his time, but, in our time, death from pneumonia means a relatively difficult death for the many demented nursing home patients who ultimately die from pneumonia. Suffering is obvious and severe, compared with other deaths. Pneumonia may even mean a "painful" escape, because suffering is also severe compared with how the patient had been before, even in patients allowed to die without antibiotics. Therefore, we think symptom relief in treatment of pneumonia deserves more attention in demented nursing home patients.

When not only the severity of suffering but also the duration is considered, patients in whom death is highly likely might have been better off without antibiotics. After the onset of pneumonia, these patients did not suffer from higher levels of discomfort than patients dying in spite of antibiotic treatment. This might be due to use of more appropriate symptomatic treatments, but ineffective antibiotic therapy likely results in as much discomfort as when no antibiotic treatment is given. Fatal processes in these patients may be similar (van der Steen JT et al., unpublished data). Alternatively, when survival is likely, antibiotic treatment—at least oral treatment—may contribute to a shorter duration of discomfort, rather than to lower levels of discomfort, because discomfort levels before the pneumonia were already low in these patients.

Our study is the first to investigate the degree of suffering in death from pneumonia and to suggest that it is not an easy process. Confirmation of the results in another study would be desirable. We consider adequate symptomatic treatment of great importance. Although breathing difficulties were common, which is not surprising, many patients did not receive treatment to relieve this symptom. Moreover, treatment of symptoms did not seem to lead to an immediate decrease in discomfort. Therefore, symptomatic treatment may not have been adequate in quality or in quantity. Our findings are consistent with conclusions of a recent review on palliative care in nursing home residents, that "dying residents experience high rates of untreated pain and other symptoms."[54] A strategy focussed on improving quality of life might include more use of opioids and avoidance of restraints;[31] such a strategy might result in lower DS-DAT scores.[31,48] In addition, the relief of symptoms deserves more attention in patients who are expected to be cured but nevertheless do suffer from the pneumonia. An approach integrating efforts to prolong life and palliative care might be considered.[29] Future research may be aimed at methods of treating discomfort adequately and at early recognition of patients at high risk of discomfort, because, from the perspective of intensity of suffering, we are far from calling pneumonia "the demented patient's friend."

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