

Lower Respiratory Infections in Nursing Home Residents With Dementia: A Tale of Two Countries

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Purpose: A focus on palliative care for residents with dementia is much more common in Dutch nursing homes than in the United States. We compared treatment and mortality in U.S. and Dutch nursing home residents with lower respiratory infections (LRI), which are often the immediate cause of death in dementia.

Design and Methods: We studied two prospective cohorts—a study of pneumonia ($n = 706$) conducted in 61 psychogeriatric nursing homes throughout the Netherlands and 701 subjects with likely dementia from a study of LRIs in 36 nursing homes in Missouri.

Results: Nursing home residents with dementia were more often treated without antibiotics in the Netherlands (23%) than in Missouri (15%). Indicators of severe illness operate in opposite directions: more severe illness is associated with antibiotic treatment in the United States, but with palliative treatment without antibiotics in the Netherlands. **Implications:** Our

findings are consistent with others in indicating problems with transition to palliative care for U.S. nursing home residents with dementia.

Key Words: *Nursing homes, Aged, Dementia, Palliative care, Lower respiratory infection*

According to a recent meta-analysis, at least 1.9 million Americans over age 65 have Alzheimer's disease—the most common form of dementia—with 1.4 million moderately to severely affected (U.S. General Accounting Office, 1998). Most of these individuals end their lives in nursing homes (Hux et al., 1998), and 60% or more of U.S. nursing home residents are cognitively impaired (Fries et al., 1997; Ribbe et al., 1997). End-of-life care for nursing home residents with dementia is thus a major issue.

In the last several years, there has been widespread recognition of the importance of palliative care, that is care directed at symptom management rather than curing disease or extending life. However, there is no systematic approach in the United States to identify residents with dementia who should be treated palliatively, particularly with respect to conditions that are often the immediate cause of death, such as infections, malnutrition, and dehydration. For example, among elderly patients with pneumonia admitted to a New York hospital, those with severe dementia had a 53% six-month mortality, compared with 13% for cognitively intact patients (Morrison & Siu, 2000). However, invasive procedures were quite similar in both groups. In another study, 23% of long-stay nursing home residents with moderate-to-severe dementia were hospitalized within a 6-month period (Fried & Mor, 1997). Furthermore, some nursing homes frequently hospitalize terminally ill residents just before death (Smith, Kellerman, & Brown, 1995).

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In late dementia, neurological impairments frequently include immobility and swallowing disorders, both of which predispose patients to develop pneumonia (Marrie & Slayter, 1996). Lower respiratory infections (LRIs), predominantly pneumonia, may be the immediate cause of death for one third of all nursing home residents (Gross, Neufeld, Libow, Gerber, & Rodstein, 1988) and for 50%–70% of patients with dementia (Beard et al., 1996; Burns, Jacoby, Luthert, & Levy, 1990; Molsa, Marttila, & Rinne, 1986; Thomas, Starr, & Whalley, 1997). We took advantage of contemporaneous prospective studies in Missouri and the Netherlands to compare treatment and mortality of nursing home residents with dementia who develop an LRI. We approached this analysis from the perspective of attempting to understand how very different approaches to palliative care for patients with advanced dementia would affect treatment decisions.

Palliative Care for Advanced Dementia in the United States and the Netherlands

Although there are some notable U.S. models of palliative care for nursing home residents with advanced dementia, such care appears unusual. Ladislav Volicer and colleagues (1994) have created a special care unit with a focus on resident comfort rather than maximizing survival. In a nonrandomized comparison, they showed significantly less resident discomfort and resource use than in a similar unit with a traditional approach to care. However, in 1997, 70% of U.S. nursing homes had no hospice patients (Zerzan, Stearns, & Hanson, 2000), and, as noted previously, nursing home residents with moderate-to-severe dementia are frequently hospitalized (Fried & Mor, 1997).

Travis, Loving, McClanahan, and Bernard (2001), in a mixed-method study, found that for nursing home residents the transition to palliative care was often problematic and punctuated by episodes of aggressive care. In further work, they identified a hierarchy of barriers to palliation and end-of-life care: failure to address treatment futility (operationalized to include poor prognosis for survival or rehabilitation), lack of communication among decision makers, no agreement on a course of care, and failure to implement a timely plan of care (Travis et al., 2002). Hanson, Danis, and Garrett (1997) have studied perspectives of bereaved family members and of nursing home physicians and staff. Families reported particular dissatisfaction with physician communication. Nurse's aides, nurses, and physicians identified lack of training, a regulatory emphasis on rehabilitation, and limited resources as barriers to good end-of-life care (Hanson, Henderson, & Manon, 2002).

Except for many studies on advance directives, other research on end-of-life care in nursing homes

in the United States is quite limited. Keay and colleagues (Keay, Fredman, Taler, Datta, & Levenson, 1994; Keay, Taler, Fredman, & Levenson, 1997) have proposed guidelines for assessing palliative care quality and have reviewed care in four Baltimore facilities. Engle (1998) has argued for providing quality care during a "living-dying interval," which may last months or years, rather than the all-too-frequent focus on the last 2 to 3 weeks of life.

In the Netherlands, palliative care is common in nursing homes at the end of life. In 53% of all deaths in Dutch nursing homes, some form of treatment was limited; in 23% of all deaths, artificial administration of food and/or fluids was specifically limited (van der Heide et al., 1997). These differences in care occur in the context of important differences between the United States and the Netherlands. These differences exist on at least two levels: a different social and legal understanding of end-of-life decisions and a different organization of care in nursing homes. Many are aware that, in the Netherlands, physician-assisted death (physician-assisted suicide and euthanasia) has been decriminalized if carried out in accordance with specific regulations. Previously, it was tolerated for years under limited circumstances (van der Maas et al., 1996; van der Wal et al., 1996). However, these studies also showed that physician-assisted death is very uncommon in nursing homes, in part because patient competence to make decisions is required. Despite this limitation, the widespread acceptance of physician-assisted death in the Netherlands undoubtedly is accompanied by a common attitude that life-sustaining treatment may be foregone.

Furthermore, discussions by the authors with Dutch nursing home physicians suggest that they use a much broader interpretation of medical futility than in the United States. Consistent with this impression, Dutch nursing home physicians responding to a survey on decision making concluded that 30% of 228 residents diagnosed with pneumonia did not have a medical indication for curative treatment (van der Steen, 2002). In contrast, in the United States, medical futility, although extensively discussed, has not found wide applicability in decision making (Helft, Siegler, & Lantos, 2000). Codes of ethics declare that physicians do not have a duty to render futile care, but there is little consensus on what constitutes futility.

Turning to nursing home organization, a recent international comparison found the Netherlands had 325 nursing homes with 53,800 beds (26 beds per 1,000 elderly persons; Ribbe et al., 1997), about half the U.S. prevalence of 53 beds per 1,000 elderly persons. Units are divided into somatic and psychogeriatric, the latter mostly residents with dementia. Costs per bed are 1½ times the U.S. cost (Ribbe et al., 1997), and Dutch residents are much less commonly hospitalized than in the United States (Frijters et al., 1997). A smaller number of nursing

home beds and a higher cost per bed reflect that Dutch nursing homes tend to admit individuals with skilled nursing needs (somatic units) or severe behavioral or functional problems from dementia (psychogeriatric units). In the Netherlands, lesser institutional care needs are provided for in “homes for the aged,” which encompass some individuals who would be in U.S. nursing homes, as well as many who might reside in residential care facilities in the United States. Furthermore, in the Netherlands, on-site physicians (one full-time equivalent physician per 100 residents) are specialists in nursing home medicine with a distinctive postgraduate training program (Hoek, Penninx, Ligthart, & Ribbe, 2000). Having physicians constantly in nursing homes means that they will often have ample opportunity to get to know residents and their families and to develop these relationships over time. This continuing contact may facilitate decision making at the time of illness and lead, in at least some cases, to advance orders for palliative treatment of infections. In contrast, few U.S. nursing homes have physicians on-site for other than occasional visits.

These large differences between the United States and the Netherlands in approach to end-of-life care and organization of nursing home care suggest that there should be significant differences in decision making about and treatment of LRIs in nursing home residents with dementia. The Dutch Pneumonia Study—conducted on psychogeriatric nursing home units and further discussed in the current paper—found that 23% of residents with pneumonia had antibiotics withheld for palliative reasons (van der Steen, Ooms, Adér, Ribbe, & van der Wal, 2002). These residents had extraordinarily high mortality (90% at 30 days). Comparing residents with dementia and an LRI in each country, the treatments they receive, and associated mortality outcomes has the potential to clarify how different approaches to care affect dementia patients at the end of life.

Data and Methods

Subjects

We report data from two prospective cohort studies: the Missouri LRI Study (Mehr et al., 2001a, 2001b) and the Dutch Pneumonia Study (van der Steen, 2002; van der Steen et al., 2002). In this paper, we consider all 706 of the Dutch subjects and the first episode of illness in 701 of the 1,044 U.S. subjects. These U.S. subjects were very likely to have dementia because of either an explicit diagnosis of dementia or a score of two or more on the Minimum Data Set (MDS) Cognitive Performance Scale (see “Data Collection and Measures”).

The Dutch Pneumonia Study prospectively identified subjects from psychogeriatric units in 61 nursing homes located throughout the country. Between October 1996 and July 1998, nursing home physicians

diagnosed 706 consecutive residents with pneumonia who also met the following criteria: (1) psychogeriatric disease (97% explicitly had a dementia diagnosis) and (2) presence in the nursing home for at least 4 weeks. Diagnosis was on the basis of physicians’ clinical judgment and usually did not include consideration of radiographic or laboratory data. A resident could be included only once even if a second episode of pneumonia occurred during the study period. The study protocol was approved by the Medical Ethics Committee of the VU University Medical Center.

In the Missouri LRI Study, 1,406 episodes of LRI, predominantly pneumonia, in 1,044 residents, were prospectively identified in subjects residing in 36 nursing homes in central Missouri and the St. Louis area between August 1995 and September 1998. Subjects were required to be in the nursing home at least 2 weeks before the illness and to be at least 60 years old. Because the Missouri LRI Study was primarily focused on outcomes, we excluded the small number of residents who had an explicit “no antibiotics” order from their attending physicians: 40 of 2,790 exclusions (1.4%).

Trained project nurses evaluated Missouri residents who had symptoms compatible with an LRI, including either respiratory or general symptoms. The study definition of LRI, which includes pneumonia and other LRI, was a modification of a surveillance definition for long-term care facilities (McGeer et al., 1991). The definition incorporated six signs and symptoms specific for respiratory problems (e.g., new cough, new sputum production) or general illness indicators (e.g., fever, acute decline in cognitive function) and chest radiographic findings if available. Most evaluations included a chest radiograph, complete blood count, and a chemistry panel. Details of identification, evaluation, and the precise LRI definition are described elsewhere (Mehr et al., 2001a, 2001b). Institutional Review Boards at the University of Missouri-Columbia Health Sciences Center and Washington University School of Medicine approved the protocol. Additionally, several hospital Institutional Review Boards conducted their own evaluations before granting permission to review medical records, and two nursing homes had ethical review panels that approved the project.

Data Collection and Measures

In both studies, extensive data were collected at initial enrollment, and residents were followed for 3 months. In the Dutch study, enrollment was at the time of the treatment decision by the nursing home physicians and, in the U.S. study, at the time of the resident’s evaluation by a project nurse. Hereafter, in both cases, we will refer to this point as “the time of diagnosis.” In the Dutch study, nursing home physicians recorded all data at specified intervals. At the time of diagnosis, this included specific

diagnoses, treatments, and whether residents were being treated without antibiotics with palliation as the goal of therapy, with antibiotics but still with palliation as the goal, or with antibiotics with cure as the goal. The physicians also indicated their ratings for the Bedford Alzheimer Nursing Severity Scale (BANS-S) 2 weeks earlier (Volicer, L., Hurley, Lathi, & Kowall, 1994).

In the Missouri study, project nurses recorded clinical and patient assessment data, including collecting a new nursing home MDS Version 2.0 (Health Care Financing Administration, 1995). From the MDS, we obtained activities of daily living (ADLs) data and the Cognitive Performance Scale (CPS; Morris et al., 1994), which measures cognitive impairment. The Missouri investigators also abstracted information from medical records, including hospital records if the resident were hospitalized, to identify diagnoses, treatments, and medications. All antibiotic use between 30 days before and 30 days after the time of diagnosis was recorded. Radiology reports were rated as negative, possible, or probable for pneumonia using defined criteria. A brief survey of participating attending physicians was used to collect provider data, such as age and clinical training. Facility size was identified from public documents. The prevalence of advance directives during late 1997 was determined in a systematic sample of 25% of records in each facility.

To create a common ADL scale, we equated the four-level ADL items of the BANS-S and the five-level MDS self-performance scale by combining the middle categories to create three-level scales distinguishing independence (0), need for assistance (1), or full dependency (2). Using eating, walking, and dressing—ADL items available in both instruments—we created a summary ADL scale with a range of 0–6 by summing the recoded scores for the individual items. We also used this ADL scale in developing a common definition for severe dementia in both U.S. and Dutch subjects. For Missouri subjects, we required a CPS of 5 or 6, combined with an ADL score of 4 or more. We attempted to equate CPS scores and BANS-S scores using a small sample of Dutch subjects in another study who had an MDS and a BANS-S completed at the same time (D. L. Gerritsen, unpublished data). We defined severe dementia in the Dutch subjects as having a BANS-S of greater than 15 and meeting the same ADL standard of a score of 4 or more on the summary scale. Thus, all residents in both countries classified as having severe dementia were expected to have profound cognitive deficits and significant ADL impairment, including full dependency in at least one ADL.

Although data collection approaches and instruments clearly differed in the two studies, there were many common variables collected that permit joint analysis. These variables included age, gender, illness symptoms and signs (e.g., cough, decreased alertness, fever, respiratory rate, pulse), data on physical

functioning (e.g., three ADLs, continence, swallowing problems), chronic diseases, and most treatments. Furthermore, even where directly comparable data do not exist, frequently data can be compared on a conceptual level. For example, although chest x-rays were rarely performed in the Netherlands, we report results for U.S. residents to shed light on treatment decisions in U.S. residents in comparison with the clear evidence that residents with dementia who are more severely ill are less likely to receive antibiotics in the Netherlands (van der Steen et al., 2002).

Analyses

We first report data on several treatments received in each country, including lack of antibiotic treatment, type of antibiotic used, if any, and hospitalization. From the Dutch data, we report antibiotics prescribed after diagnosis for treatment of the pneumonia, if any. Nontreatment with antibiotics was clearly indicated to be for palliative purposes. In the Missouri data, we lacked specific data on the intent of antibiotic treatment or nontreatment. Therefore, we defined antibiotic treatment for the LRI as any antibiotic prescribed from 2 days before diagnosis until 30 days after diagnosis. We reasoned that this would most clearly capture intent to treat infections with antibiotics.

We then performed bivariable analyses to describe differences in groups receiving antibiotics and not receiving antibiotics, as well as mortality within each country. We expected factors associated with lack of antibiotic use to differ substantially between the two countries. We also performed cross-national comparisons for these variables. *T*-tests were used to test differences in means for age and respiratory rate. Chi-square statistics were computed to test for differences in proportions (all other variables). Multivariable analyses in U.S. subjects used logistic regression with no antibiotic treatment as the dependent variable. We included as potential variables for inclusion resident characteristics, indicators of illness severity, provider characteristics, and facility characteristics. We confirmed our results treating nursing home as a random effect in a mixed model to address the clustering of residents within nursing homes. Because these results were almost identical, the simple logistic model is reported. Multivariable analyses for 635 of the Dutch subjects have previously been reported (van der Steen et al., 2002) and are related to new U.S. analyses in the “Results” and “Discussion” sections.

Results

Comparing U.S. and Dutch nursing home residents, there are several striking differences in care and treatments received for LRI (Table 1). Although restraints and urinary catheters are about equally

Table 1. Interventions Received by U.S. and Dutch Nursing Home Residents With Dementia and a Lower Respiratory Infection

Treatment	No. of Residents (%)		p Value
	U.S. (n = 701)	Dutch (n = 706)	
Restraints at the time of evaluation ^a	97 (13.8)	68 (11.9)	0.30
Tube/parenteral feeding at time of evaluation	86 (12.3)	9 (1.3)	<0.0001
Urinary catheter at time of evaluation	55 (7.9)	46 (6.6)	0.35
Initiation of oxygen within 1 week of evaluation	79 (11.3)	96 (13.6)	0.19
Initial antibiotic therapy (2 days before evaluation to 30 days after)			<0.0001
No antibiotics given	103 (14.7)	164 (23.4)	
An oral penicillin, doxycycline, tetracycline, or beta-lactam/beta-lactamase inhibitor	102 (14.6)	430 (60.9)	
Fluoroquinolones (oral or parenteral)	76 (10.8)	11 (1.6)	
Other oral antibiotic regimens	225 (32.1)	32 (4.5)	
Parenteral regimens ^b	195 (27.8)	69 (9.8)	
Hospitalization within 30 days of evaluation	182 (26.0)	4 (0.6)	<0.0001
Hospitalization in ICU within 30 days of evaluation	20 (2.9)	0	

Notes: All reported statistics are chi-square tests for differences in proportions. The five mutually exclusive antibiotic regimens, including no antibiotics, were considered together in a single test with 4 degrees of freedom. ICU = intensive care unit.

^aExcludes bed rails, geri-chairs, velcro straps, or gait belts used in transfers.

^bMostly a second- or third-generation cephalosporin with or without another antibiotic.

common in both countries, artificial feeding (enteral or parenteral) is much more common in the United States, and treatment without antibiotics is more common in the Netherlands. Among Dutch residents overall, 60.9% (79% of those who received an antibiotic) received an oral penicillin (mostly amoxicillin), amoxicillin/clavulanate (a beta-lactam/beta-lactamase inhibitor combination), tetracycline, or doxycycline. None of these medications would be considered aggressive therapy in the United States, where, in contrast, 14.6% of residents (17% of those who received an antibiotic) received one of these regimens. Hospitalization is quite rare in Dutch residents (0.6%), but 26% of U.S. residents were hospitalized within 30 days, including 20 intensive care unit admissions in the United States without any in the Netherlands. Of those hospitalized in the U.S., 98% received antibiotics. Only 20 U.S. subjects (2.9%) had a Do Not Hospitalize directive. Similarly, a 25% systematic sample of resident records in all facilities participating in the Missouri LRI Study found just 3.7% with a Do Not Hospitalize order.

Table 2 shows characteristics of those in the United States and the Netherlands treated with and without antibiotics. Comparing those receiving or not receiving antibiotics cross-nationally, most differences were statistically significant, and, in particular, severe dementia and temperature more than 38.3 °C (101 °F) were both much more common in the Netherlands. Among those not treated with antibiotics, a much higher proportion of Dutch residents were completely dependent in dressing and eating, had severe dementia, and had several indicators of more severe acute illness (rapid pulse,

respiratory distress, high temperature). These differences, both for those treated and not treated with antibiotics, likely reflected two factors: residents in the Netherlands on psychogeriatric units frequently have advanced dementia, and the Dutch Pneumonia Study used physician judgment rather than standardized criteria to identify pneumonia. In the Missouri LRI Study, only 44% of those with x-ray evidence of pneumonia had a temperature of 38 °C or higher (Mehr et al., 2001a).

Nonetheless, Table 2 shows interesting differences in direction of effect within countries. In both countries, ADL dependency and severe dementia (related constructs conceptually in that as dementia progresses, there is increasing ADL dependency) are associated with a lower probability of antibiotic treatment. However, with indicators of clearer or more severe acute illness, the associations are reversed in the two countries. In the Netherlands, residents receiving antibiotics had a lower mean respiratory rate, and a smaller proportion had a fast pulse rate than those not receiving antibiotics. There was no difference in the proportion having temperature above 38.3 °C. In contrast, U.S. residents receiving antibiotics were *more* likely to have a fast pulse, a temperature more than 38.3 °C, probable pneumonia on chest x-ray, and an elevated white blood count (the latter two data were generally not available in the Netherlands but are associated with more severe illness). Mean respiratory rate was not associated with antibiotic use in the United States.

Figure 1 shows mortality by antibiotic treatment. Among the 23% of Dutch subjects not treated with antibiotics, 90.2% died within 30 days; mortality

Table 2. Characteristics of U.S. and Dutch Nursing Home Residents Treated With and Without Antibiotics^a

Characteristic	U.S.		Dutch	
	With Antibiotics (<i>n</i> = 598)	Without Antibiotics (<i>n</i> = 103)	With Antibiotics (<i>n</i> = 542)	Without Antibiotics (<i>n</i> = 164) ^b
ADL dependencies 1–2 weeks before the illness				
Completely dependent in eating ^{§§}	30.8*	40.8	28.2 ^{†††}	60.7
Completely dependent in walking ^{†††}	60.0**	74.5	42.7 ^{†††}	63.2
Completely dependent in dressing ^{†††,§§}	49.8**	67.0	65.6 ^{†††}	83.4
Facility has 180 or more licensed beds ^{†††,§§§}	24.6	16.5	72.5	68.7
Female ^{†,§§§}	68.9**	84.5	62.8	61.0
Presence of a DNR order	63.9	67.6	n/a	n/a
Probable pneumonia on chest x-ray ^c	57.9***	31.3		
Pulse ≥ 100 ^{§§§}	27.7**	13.6	32.8 ^{†††}	52.7
Severe dementia ^{†††,§§§}	37.6**	53.4	52.7 ^{†††}	80.4
Temperature more than 38.3 °C ^{†††,§§§}	23.8**	10.9	54.1	54.9
White blood cells ≥ 15,000 per mm ³	17.2***	2.2	n/a	n/a
Mean age (<i>SD</i>) ^{d,†,§,§}	85.5 (8.0)	84.8 (8.5)	84.0 (7.4) [†]	82.4 (7.7)
Mean respiratory rate (<i>SD</i>) ^{d,§§}	26.9 (7.3)	26.7 (7.2)	26.9 (9.4) ^{†††}	30.3 (10.4)

Note: ADL = activity of daily living; DNR = Do Not Resuscitate; n/a = not available.

^aNumbers represent percentage within column unless otherwise indicated. For significance comparisons within countries for those treated with vs. without antibiotics, we used the following symbols—for U.S. residents: **p* < .05, ***p* < .01, ****p* < .001; for Dutch residents: †*p* < .05, †††*p* < .001. For international significance comparisons, we used the following symbols—for residents who received antibiotics: †*p* < .05, †††*p* < .01, ††††*p* < .001; for residents who did not receive antibiotics: §*p* < .05, §§*p* < .01, §§§*p* < .001.

^bIn van der Steen and colleagues (2002), 165 residents were identified as not treated with antibiotics. One person was not initially treated, but was treated within 2 days; therefore, this individual was included as treated with antibiotics in the current paper.

^cOnly 36 Dutch subjects had chest x-rays, 22 for validation of physician diagnoses in one facility, so the results are not representative. Therefore, we have not reported Dutch results.

^dMean differences within countries and between countries were compared statistically with *t* tests. All other statistical comparisons in this table are χ^2 tests with 1 *df*.

was 29.8% (*p* < .0001) in those treated with antibiotics. In contrast, 85% of U.S. subjects with dementia received antibiotics, and 30-day mortality was virtually identical for both those treated with and without antibiotics (16.7% and 17.5%, respectively, *p* = .85).

Table 3 shows a logistic regression model for lack of antibiotic treatment in U.S. subjects. As in bivariable comparisons, high white blood count, higher probability of pneumonia on chest x-ray, and high temperature were all independently associated with a higher probability of antibiotic treatment, whereas severe dementia was associated with a lower probability of antibiotic treatment. Men and residents in the largest facilities had a lower probability of nontreatment, and older provider age was more commonly associated with nontreatment. In no case did introducing interaction terms between severe dementia and other variables lead to significant interaction and main effect terms. This suggests that, even in residents with severe dementia, those with clearer evidence of significant illness were more likely to be treated with antibiotics. For example, even among residents with severe dementia, antibiotics were received by 88% of those with a temperature more than 38 °C, 87% of those with probable pneumonia on chest x-ray, and 100% of those with a white blood count greater than 14,200 per mm³. Because ADL dependency is an expected outcome of the progression of dementia (and consequently therefore part of our

definition of severe dementia), we did not include ADL dependency in the logistic regression analysis. If ADL dependency is included instead of dementia severity, greater ADL dependency is also associated with a lower probability of antibiotic treatment.

The Dutch investigators previously performed a multilevel logistic regression analysis in 635 of their 706 subjects to look at factors associated with nontreatment with antibiotics (van der Steen et al., 2002). They excluded from this analysis those treated with antibiotics only after a delay and 50 additional subjects for whom antibiotic treatment was intended only for symptom relief rather than cure. Significant independent predictors of nonuse of antibiotics included: increased dementia severity, larger number of pneumonia symptoms and signs, insufficient drinking, dehydration, treatment in summer, aspiration as possible or probable cause of pneumonia, and not having previously suffered from pneumonia. As with the bivariable analysis, Dutch nursing home residents with more indicators of severe lower respiratory infection are less likely to receive antibiotic treatment, whereas the opposite is true in the United States.

Discussion

End-of-life care for patients with dementia is problematic for several reasons. The course of dementia is slow and progressive, but precisely

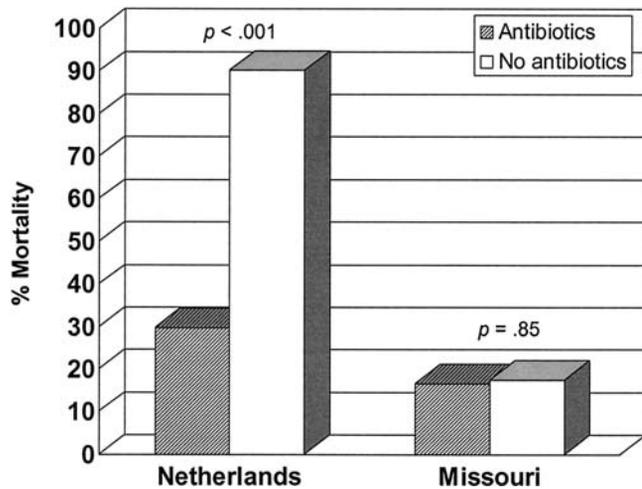


Figure 1. Thirty-day mortality for nursing home residents with lower respiratory infections, by treatment antibiotics.

defining a terminal phase is difficult (Luchins, Hanrahan, & Murphy, 1997; Volicer, B. J., Hurley, Fabiszewski, Montgomery, & Volicer, L., 1993). However, hospitalized patients with severe dementia treated for pneumonia or hip fracture have about 50% six-month mortality (Morrison & Siu, 2000). In advanced dementia, patients often have little or no ability to communicate, which exacerbates care problems, such as the inadequate treatment of pain in nursing homes (Bernabei et al., 1998; Zerzan et al., 2000). Furthermore, decisions must often be made by proxies who may or may not know what patient preferences would be and may feel conflicted about making decisions that limit care (Forbes, Bern-Klug, & Gessert, 2000). Although Do Not Resuscitate orders are now common in the United States (Teno et al., 1997), few residents have physician orders limiting use of antibiotics or hospitalization, except in scattered locations. In the state of Oregon, substantial statewide efforts have led to more systematic implementation of advance care planning, and data regarding the proportion of residents in six facilities with orders limiting hospitalization suggest a much higher rate (at least 29%) than elsewhere in the United States (Tolle, Tilden, Nelson, & Dunn, 1998).

Over a century ago, Sir William Osler 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 to himself and to his friends" (Osler, 1899, p. 109). In Osler's day, care for pneumonia was only supportive, but today it can include antibiotics and even admission to an intensive care unit. Such options mandate careful consideration of when aggressive care is no longer indicated.

We found striking differences in management among residents with dementia who had an LRI in U.S. and Dutch nursing homes. Hospitalization and parenteral antibiotics were very common in the United States, although rare in the Netherlands.

Table 3. Predictors of No Antibiotic Treatment in U.S. Residents, Logistic Regression Analysis^a

Variable	Coefficient	Odds Ratio (95% CI)
Intercept	-2.2129	
White blood cells \geq 15,000 per mm ³	-2.0027	.14 (.03-.57)
Temperature $>$ 38.3 °C	-.9860	.37 (.18-.78)
Chest x-ray results ^b	-.6885	.50 (.39-.65)
Male	-.6847	.50 (.28-.91)
180 or more licensed beds in facility	-.6436	.52 (.28-.98)
Provider age ^c	.0274	1.32 (1.09-1.59)
Severe dementia	.6575	1.93 (1.23-3.03)

Note: CI = confidence interval.

^aC-statistic = .77, Hosmer-Lemeshow goodness-of-fit statistic, $p = .71$ with a nonsignificant result indicating acceptable fit.

^bCoding for x-ray results was as follows: 0 = negative, 1 = possible, and 2 = probable or definite.

^cOdds ratio shown is for a 10-year change in provider age.

Whereas nontreatment with antibiotics was moderately more common in the Netherlands than in the United States, there were major differences between the two countries in who was treated and not treated, as well as in mortality.

Among Dutch subjects with a clinical diagnosis of pneumonia not treated with antibiotics, there was evidence of more preillness disability, more significant acute illness, and much higher mortality than those who received antibiotics. In contrast, U.S. subjects not treated with antibiotics had very similar mortality to those treated with antibiotics and frequently appeared to have a more equivocal or less severe acute illness. Although probably some U.S. subjects were deliberately not treated for palliative reasons, it is difficult to ascertain how many such individuals there might have been, and, given the low overall mortality, the number was probably small. For example, among the 280 individuals in the United States with severe dementia, only 55 (20%) did not receive treatment with antibiotics. In multivariable results from the United States, even residents with severe dementia were more likely to receive antibiotics if they exhibited clearer evidence of significant acute illness; such residents appeared less likely to receive antibiotics in the Dutch multivariable analysis.

These important differences undoubtedly reflect organizational differences in care in the two nations, as well as different cultural contexts for end-of-life decisions. In the Netherlands, having physicians in the nursing home all the time provides many more opportunities for families and physicians to discuss and plan care. In North Carolina, family members of deceased nursing home residents frequently reported dissatisfaction with physician communication (Hanson et al., 1997). Undoubtedly, one reason is relatively infrequent visits to nursing homes by most physicians

in the United States. Many acute febrile illnesses are treated by physicians without in-person evaluation (Burton et al., 2001). Infrequent contact with families and lack of consensus standards for initiating discussions of treatment limits, such as for hospitalization or antibiotic therapy, make understandable the low prevalence of orders limiting such care. Furthermore, in the midst of a busy office or hospital practice, U.S. physicians have every incentive not to initiate discussions of treatment limitations at the time of an acute illness. Thus, indirectly, our findings emphasize the importance of future efforts to improve communication in the United States about end-of-life care in the nursing home. This conclusion is convergent with the finding of Travis and colleagues (2002) that the highest level barrier to initiating palliative care was a failure to identify the poor prognosis for rehabilitation or prolonged survival.

Our work is subject to several limitations. First, the Dutch study included residents throughout the Netherlands, but the Missouri LRI Study included only central Missouri and the St. Louis area. Whereas the Missouri subjects and nursing homes were similar to national samples (Mehr et al., 2001b), findings should be extrapolated with caution. In particular, nursing home residents in Oregon have low hospitalization rates at the end of life (Tolle et al., 1998), which is consistent with a different approach to palliative care.

A second limitation concerns subject comparability across the two studies. Residents of psychogeriatric units in the Netherlands overall have more severe dementia than the residents studied in the United States, and the Dutch study used the physician's clinical impression of pneumonia as an entry criterion rather than specific diagnostic criteria. This approach likely led to inclusion of residents with clearer illness who may have been more severely ill. However, it is not likely many Dutch residents did not have an LRI. Even making the conservative assumption that missing information for a symptom meant its absence, the vast majority of Dutch subjects met the Missouri LRI Study definition (82% and 84% of those treated and not treated with antibiotics, respectively; van der Steen, 2002). Moreover, subject differences are unlikely to account for the divergence we found in how illness severity relates to the choice of treatment with antibiotics or not. Magnitudes may be biased, but differences in direction of effect should not occur. Differing illness severity certainly influences mortality differences, and further work is in process to address this issue for residents treated with antibiotics. For residents not treated with antibiotics, the cross-national differences are so extreme that they are unlikely to be accounted for just by differing illness severity, and illness severity is not related to treatment choice in the same way (i.e., different direction of effect). This difference makes attempts to adjust for disease severity problematic.

A final limitation is that we did not collect direct data on physician decision making in Missouri. We recorded antibiotics prescribed in either the nursing home or the hospital, but we could not determine how many residents received limited treatment because the physician wanted to provide only palliative treatment. We also acknowledge the possibility that some use of antibiotics occurred even where palliative care was intended. Nonetheless, to the extent that many U.S. physicians regard antibiotic treatment as nearly compulsory for severe infections, this perspective suggests a significant problem in the transition to palliative care. The care patterns documented in this paper clearly demonstrate very limited use of strictly palliative care in the United States in residents with dementia who have an LRI.

In conclusion, nursing home residents with dementia in the Netherlands are treated much less aggressively than in Missouri, and withholding antibiotic treatment for severely ill residents is more common in the Netherlands. Although several factors are likely involved, these findings suggest problems in the transition to palliative care for U.S. nursing home residents. Further work on how such transitions occur and how they can be facilitated is needed.

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