

High Short-term Mortality in Hospitalized Patients With Advanced Dementia

Lack of Benefit of Tube Feeding

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Background: The influence of tube feeding on survival in hospitalized patients with advanced dementia is controversial.

Objective: To assess long-term survival in an inception cohort, incident tube feeding placement during the index hospitalization, and the influence of tube feeding on survival in this group of patients.

Subjects and Methods: Ninety-nine hospitalized patients with advanced dementia and an available surrogate decision maker were followed up through and after the index hospitalization for mortality and placement of a feeding tube. Other variables measured included advance directive status, presence of a long-term primary care physician, level of involvement of the surrogate decision maker, admitting diagnosis, prior hospitalizations, comorbidities, and diagnosis related group diagnostic category.

Results: A new feeding tube was placed in 50% (51/99) of the study patients during the index hospitalization, 31% (31/99) left the hospital without a feeding tube, and 17%

(17/99) were admitted with a feeding tube already in place. By stepwise logistic regression analysis, predictors of new feeding tube placement included African American ethnicity (odds ratio, 9.43; 95% confidence interval, 2.1-43.2) and residence in a nursing home (odds ratio, 4.9; 95% confidence interval, 1.02-2.5). Median survival of the 99 patients was 175 days. Eighty-five (85%) survived the index hospitalization, and 28 (28%) were still alive at last follow-up, a range of 1.3 to 4.2 years after enrollment in the study. Tube feeding was not associated with survival ($P=.90$). An admitting diagnosis of infection was associated with higher mortality (odds ratio, 1.9; 95% confidence interval, 1.01-3.6).

Conclusions: In this cohort of hospitalized patients with advanced dementia, risk of receiving a new feeding tube is high, associated with African American ethnicity, and prior residence in a nursing home, and has no measurable influence on survival. With or without a feeding tube, these patients have a 50% six-month median mortality.

Arch Intern Med. 2001;161:594-599

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ALZHEIMER DISEASE and related dementing illnesses are incurable, progressive disorders leading gradually to complete loss of cognitive function and subsequent death. By the year 2040, the prevalence of Alzheimer disease in the United States is estimated to rise to more than 9 million affected individuals.^{1,2} Costs of care increase with severity of the dementing illness with an annual US estimate of more than \$100 billion in 1993 alone, a figure that is expected to double by 2040.²

While the setting and type of care provided to persons with advanced dementia and acute superimposed illness is highly variable,³⁻¹³ hospitalization is a frequent sequela of acute illness in advanced dementia.³ This practice occurs despite the fact that hospitalization is a known hazard for frail elderly persons^{14,15} and its use in advanced

dementia has not been demonstrated to improve clinical outcomes.¹⁶⁻¹⁸ Similarly, the characteristics and predictors of decisions to use a feeding tube when oral intake declines are not well described.^{19,20} Although a recent systematic review of tube feeding in the care of patients with advanced dementia found little evidentiary basis for (or against) the practice,^{20,21} placement of a feeding tube is a common intervention in this population.²²⁻²⁴

In the context of an acute illness superimposed on a late-stage dementia, those charged with decisions about whether to hospitalize and whether to place a feeding tube must not only consider the purposes and goals of medical intervention and care for such a patient, but also must weigh the benefits and risks of hospitalization and tube feeding per se under this clinical circumstance. Knowledge of the likely outcomes of hospitalization, and the

SUBJECTS AND METHODS

STUDY SUBJECTS

Patients with advanced cognitive impairment admitted to Mount Sinai Hospital (a 1000-bed tertiary care teaching hospital) in New York City during a 3-year period (August 1994-June 1997) were identified by daily rounds conducted by one of us (J.M.). Eligibility criteria included hospitalization for an acute illness; advanced dementia defined as Functional Assessment Staging Tool (FAST)²⁶ stage 6d or greater with a stable neurological deficit for at least 1 month. Thus, patients with acute or subacute declines in mental status associated with delirium were excluded from the study. Reisberg stages 6d and below include patients incontinent of bladder (6d), and bowel (6e), with speech limited to fewer than 6 words (7a) or a single word (7b), inability to walk (7c), and sit (7d) without assistance, and inability to hold the head up without assistance (7f).²⁶ Stage was determined by the best observable mental status prior to hospitalization, based on medical history obtained from family or other caregivers and health professionals familiar with the patient's baseline condition.

Permission to approach surrogate decision makers for participation in the study was initially obtained from the patient's attending physician. Informed consent was obtained from the designated surrogate decision maker (ie, duly appointed guardian, health care agent, or next of kin). The study was approved by the Mount Sinai School of Medicine Institutional Review Board.

Initial assessment consisted of a complete medical history and physical examination by a physician member (D.E.M. or J.C.A.) of the study team. Subjects were then randomized to an intervention or a control (usual care) group for a prospective randomized trial of inpatient palliative care consultation, described elsewhere.^{12,25} The intervention consisted of consultative recommendations designed to maximize comfort and minimize painful and nonpalliative procedures; as well as extensive consultation and discussion with family, other surrogate decision makers, and the primary medical team about the goals of care. The intervention²⁵ had no effect on any measurable outcome except for a slight increase in the numbers of subjects discharged from the hospital with a palliative care plan documented in their medical record. Of 182 subjects initially identified as eligible for study participation and whose primary attending physician gave permission to approach the surrogate decision maker, consent was obtained in 99 cases, largely because of incapacity, unavailability, or unwillingness of surrogates to endorse their

relative's participation, as previously reported (**Table 1**).¹² The study subjects consisted of the 99 patients eligible for inclusion for whom both the primary attending physician and a surrogate decision maker were available and willing to give consent for their participation.

A research assistant (S.B.L.) blinded to the randomization status of the subjects gathered medical record information on demographics; preadmission medical history of prior hospitalizations or pneumonia; presence of an advance directive; residence of surrogate (local vs out of town); availability of a long-term primary care physician; comorbidities; and diagnosis related group diagnostic category. Main outcome measures included mortality both during and after the index hospitalization, site of discharge, length of hospital stay, do-not-resuscitate orders, and attempts at cardiopulmonary resuscitation and feeding tube placement before or during the index hospitalization. These outcome measures were determined from the date of admission during the index hospitalization until discharge or in-hospital death. The number of hospitalizations in the year preceding and after the index hospitalization were determined from surrogate interviews and review of hospital databases. Research assistant telephone contact was maintained on a 3-monthly basis through June 1999 with next of kin of study subjects until they were lost to follow up or the subject's death was reported.

STATISTICAL METHODS

Statistical analyses focused on determining factors that predicted placement of percutaneous feeding tubes and on variables that predicted survival. In the first analyses, we used χ^2 tests to examine the relationship between independent variables and the placement of a feeding tube on the index hospital admission. Variables that were of borderline significance ($P < .15$) were entered into a forward stepwise logistic regression model (entry criteria of $P < .10$ and removal criteria of $P > .15$). To determine factors that influenced survival, we performed a series of single-variable Cox proportional hazards regression models examining the relationship of the variable of interest to time of death. Variables of borderline significance ($P < .15$), and variables that have been previously shown to be related to survival in advanced dementia (ie, dementia stage, sex, age, prior hospitalizations, prior pneumonia, degree of involvement of surrogate decision maker, long-term primary care physician, presence of a pressure ulcer, presence of a feeding tube, and residence at home vs nursing home),²⁷⁻³² randomization status, and presence of a feeding tube were entered into the final survival model.

often associated decision to place a feeding tube, in terms of its influence on long-term survival, is critical to informed decision making on behalf of patients with advanced dementia. To this end, in the context of a study evaluating the influence of palliative care consultation for hospitalized persons with advanced dementia,^{12,25} we assessed long-term survival in an inception cohort, incident feeding tube placement during the index hospitalization, and the influence of tube feeding on survival in this group of patients.

RESULTS

One hundred ninety-two subjects were eligible to participate during the 3-year (August 1994-June 1997) study period. Informed consent could not be obtained from 93 (48%) primarily because there was no available surrogate decision maker or because the surrogate decision maker was unable or unwilling to participate in the informed consent discussion process (Table 1).¹² Ninety-nine eligible subjects (52%) had surrogate deci-

Table 1. Enrollment of 192 Eligible Subjects Who Were Hospitalized With Advanced Dementia*

Reason for Nonparticipation	No.
Total No. of Eligible Subjects	192
Primary attending physician refused permission to approach surrogate decision maker	10
Total No. of Remaining Eligible Subjects	182
No available surrogate decision maker	40
Surrogate decision maker unable to understand and participate in informed consent process	19
Surrogate decision maker refused informed consent	5
Subject imminently dying or medically unstable	8
Language barrier	3
Family conflict precluding enrollment	3
Subject transferred, discharged from the hospital, or died	5
Total No. of Subjects Randomized With Surrogate Decision Maker Informed Consent	99

*Of the 192 eligible subjects hospitalized between August 1994 and June 1997 with advanced dementia and the presence of stable neurological impairment for 1 month or longer, 99 subjects were enrolled in the study.

sion makers who gave informed consent and the subjects were enrolled in the study.

SUBJECT CHARACTERISTICS

Characteristics of study subjects are given in **Table 2**. The average subject was 84.8 years old (age range, 63-100 years), 80 (81%) were women, 39 (39%) were black, 36 (36%) were white, and 22 (22%) were Hispanic. Twenty-nine subjects (29%) were admitted from home and 69 (70%) were admitted to the hospital from a nursing home. An advance directive (ie, a living will, proxy appointment, or clear oral or written evidence of the patient's wishes) was available for the index admission in 15 (15%) of the subjects. The most common admitting diagnosis was pneumonia (44 [44%] of 99 subjects), followed by other infectious illnesses (14 subjects [14%]) and gastrointestinal disorders (12 subjects [12%]).

FEEDING TUBES

A feeding tube was present on admission in 17 subjects (17%). Of the 99 study subjects, 80 (80%) did not have a feeding tube on admission and were not admitted to the hospital specifically for this purpose. Two subjects (2%) were brought into the hospital specifically for the purpose of placing a feeding tube. Of the 82 subjects without a feeding tube on admission, 51 (62%) had a percutaneous endoscopic gastrostomy tube placed during the index hospitalization. Thirty-one (31%) of the 99 subjects left the index hospitalization without a feeding tube. The regression model examining predictors of feeding tube placement is given in **Table 3**. In the logistic regression analysis African American ethnicity (odds ratio [OR], 9.43; 95% confidence interval [95% CI], 2.1-43.2) and residence in a nursing home (OR, 4.9; 95% CI, 1.02-2.5) were significantly associated with receiving a new feeding tube during the index hospitalization.

Table 2. Characteristics of 99 Subjects Hospitalized With Advanced Dementia

Characteristic	No. (%) of Subjects
Median age (range), y	84.0 (63-100)
Female	81 (81.8)
Ethnicity	
Black	39 (39)
White	36 (36)
Hispanic	22 (22)
Asian	2 (2)
Residence before admission to the hospital	
Home	28 (29)
Nursing home	71 (70)
Advance directive present during index admission*	15 (15.2)
Do-not-resuscitate status	57 (57.6)
Randomized to intervention	48 (48.5)
Reisberg dementia stage†	
6f-7b	47 (47.5)
7c-7d	25 (25.3)
7e-7f	27 (27.3)
Pressure ulcer during index hospitalization	55 (55.6)
Feeding tube status	
Present on admission to the hospital	17 (17.2)
Placed during index hospitalization	51 (51.5)
No tube	31 (31.3)
Admitting diagnosis	
Pneumonia or urinary tract infection	61 (61.6)
Dehydration or metabolic abnormality	12 (12.1)
Other‡	26 (26.3)
Median length of stay in hospital (range), d	12 (2-93)
Poor oral intake before admission to the hospital	22 (22.2)
Long-term primary care physician	29 (29.3)

*Advance directive indicates the presence on the medical record of a health care proxy, a living will, or recorded evidence of patients' previously expressed wishes.

†Adapted from Reisberg dementia stages.²⁶

‡Other includes hip fracture, gastrointestinal bleeding, congestive heart failure, drug toxic reaction, stroke, peripheral vascular disease, and pulmonary embolism.

Table 3. Multiple Logistic Regression Model for Placement of a New Feeding Tube During the Index Admission*

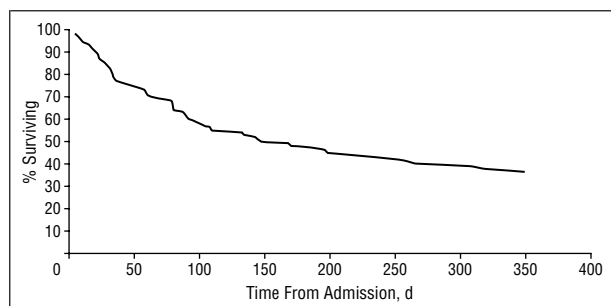
Risk Factor	Hazard Ratio	95% Confidence Interval
Nursing home resident	4.9	1.02-2.5
Pressure ulcer	1.88	0.6-6.2
No primary care physician	2.46	0.4-13.4
Advance directive	0.32	0.04-2.8
Race†		
Black	9.43	2.1-43.2
Hispanic	1.79	0.4-8.1
Hospitalized for pneumonia in the last year	8.44	0.9-81.1

*Eighty subjects excludes 2 Asian subjects and 17 subjects admitted to the hospital with a feeding tube already in place.

†Reference category is white.

SURVIVAL

Median survival of the 99 enrolled subjects was 175 days (198 days in the intervention group and 147 days in the control or usual care group [$P = .41$]) (**Figure**). The haz-



Survival for 99 subjects with end-stage dementia.

ard model is given in **Table 4**. Admitting diagnosis of infection (ie, pneumonia or urosepsis) was associated with mortality (OR, 1.9; 95% CI, 1.01-3.6). Eighty-five subjects (85%) survived the index hospitalization. Twenty-eight (28%) were still alive at the time of last follow-up contact (June 1, 1999), a range of 465 to 1502 days (ie, 1.3-4.2 years) after study enrollment. Median survival following admission in subjects receiving a feeding tube during the index hospitalization was 195 days (range, 21-1405 days) as compared with 189 days among subjects who did not receive a feeding tube (range, 4-1502 days). Tube feeding was not associated with survival ($P = .9$) (Table 4).

COMMENT

In this cohort of acutely ill and hospitalized patients with advanced dementia, median survival was 6 months despite hospitalization and use of life-sustaining measures including the administration of parenteral fluids, antibiotic agents, and artificial nutrition. Prior studies in hospital,³³ long-term care,³⁴ and hospice³⁵ settings have all found similarly high mortality rates in persons with advanced dementia, of a magnitude comparable to the prognosis observed in chronic end-stage liver disease or multiorgan system failure with sepsis^{36,37} and some metastatic cancers.³⁸ Despite the high risk of death associated with advanced dementia, it is generally not perceived by family and health care providers to be a terminal illness, owing, at least in part, to the variability in individual life expectancy demonstrated in this and other studies.^{39,40}

The prevalence of hospitalization for acute illness in severe dementia is unknown since the discharge diagnosis and claims associated with the illness usually reflect the primary reason for admission, such as pneumonia. Studies of hospitalization rates of nursing home residents with pneumonia vary by a factor of 5.³ Propensity to hospitalize has been shown to be related both to clinical factors^{3,5-7,9,10} and to the number of hospital beds per capita.⁴ As we have previously reported,¹² over one third of the eligible subjects for this study could not be randomized because they lacked an available or functional surrogate decision maker: the absence of a functional surrogate decision maker may also be a risk factor for hospitalization as there is no family member to advocate for continued care at home or in the nursing home during a supervening illness.^{5,6,8,10-12,41} Since decisions to hospitalize for acute illness should be based on expectation of benefit in terms of articulated goals of care

Table 4. Cox Proportional Hazards Regression Model for Mortality After Index Hospitalization in 99 Subjects With Advanced Dementia

Risk Factor	Hazard Ratio	95% Confidence Interval
Nursing home	1.02	0.5-2.0
Intervention status	1.18	0.7-1.9
Reisberg dementia stage*		
7c and 7d	0.97	0.5-1.8
7e and 7f	0.92	0.5-1.7
Presence of a pressure ulcer	1.07	0.6-1.8
Feeding tube status†		
Present on admission to the hospital	1.2	0.5-2.8
Placed during index hospitalization	0.97	0.5-1.9
Race‡		
Black	1.10	0.6-2.1
Hispanic	0.55	0.3-1.2
Admitting diagnosis§		
Dehydration or metabolic abnormality	1.6	0.6-4.3
Pneumonia or urinary tract infection	1.9	1.0-3.6

*Reference category is Reisberg dementia stages 6d to 7b.²⁶

†Reference category is no tube feeding.

‡Reference category is white.

§Reference category is other diagnosis.

for a given individual—whether the goals are primarily focused on maximal possible prolongation of life or on the relief of symptom distress, or both—the fact that mortality rates are high and seem to be similar independent of venue suggests that hospitalization may not be the best way to achieve either goal.⁴² Randomized trials of home or nursing home care vs hospital care in acute illness superimposed on advanced dementia are needed to address this question.

In our advanced dementia cohort, there was no survival advantage among subjects who received a feeding tube during the index hospitalization as compared with those discharged from the hospital without a feeding tube. By multiple regression analysis, African American ethnicity and residence in a nursing home were associated with a higher risk of receiving a new feeding tube. A large study of Medicare claims data also found a higher frequency of feeding tube placement in African American, as opposed to white, patients.²³ Reasons for the racial difference in propensity to receive a feeding tube are unknown, but the finding persists after adjustment for the higher likelihood of residence in a nursing home in our African American subjects. Further, the racial disparity in feeding tube placement could not be explained by the surrogate decision maker's geographic proximity to the hospital, by the absence of a long-term primary care physician, or by the prevalence of advance directives in the different ethnic groups. As suggested by a recent report,⁴³ the economic hardship associated with care of a relative with chronic advanced illness⁴⁴⁻⁴⁶ may have contributed both to a higher risk of nursing home placement and in decisions to use tube feeding among our African American subjects. We were unable to adjust for educational and socioeconomic variables among subjects and their surrogate decision makers that might have accounted for this ethnic difference both in nursing home

residence and in decisions to use tube feeding. Other investigations of the influence of ethnicity on medical decision making have suggested that mistrust, associated fears of undertreatment, and differing cultural evaluations of the benefits and risks of artificial nutrition and hydration, may contribute to decisions to use life-sustaining technologies, including tube feeding.⁴⁷⁻⁵⁰

The decision to use a feeding tube when oral intake cannot be easily sustained may be related to the variable and uncertain prognosis of advanced dementias and the desire of family and physicians to prevent the anticipated burdens of malnutrition and dehydration. Despite data suggesting that among cognitively intact patients refusal of food and water in the context of terminal illness is not painful⁵¹ and the common observation of aversive feeding behaviors in advanced dementia⁵² (ie, refusing to eat or swallow, spitting out food, or holding food in the mouth), inadequate intake of food and water is often thought to lead to distressing hunger, thirst, and hastened death. Similarly, tube feeding is believed to prevent aspiration pneumonia and other infections, improve function, promote physical comfort, and prolong life. As was recently reviewed,¹⁹⁻²¹ evidence does not exist to support (or refute) these assumptions. Data from the study reported here suggest that tube feeding has no measurable influence on survival, at least in this cohort of severely demented patients hospitalized with acute comorbid illness. Multiple other observational studies have confirmed both high short-term mortality rates and lack of survival advantage to tube feeding in the context of advanced dementia.^{19-21,53,54}

Limitations of this study include bias in the sample related to its conduct in a tertiary care teaching hospital in New York City. The high evidentiary standard for decisions to forego artificial nutrition and hydration under New York state law⁵⁵ could lead to a higher prevalence of tube feeding among patients lacking decisional capacity and advance directives. Other socioeconomic factors typical of patients cared for in an urban teaching hospital may be associated with the lesser ability of families to care for patients at home as well as limited availability of long-term primary care physicians. However, frail nursing home patients with advanced dementia are commonly transferred to acute care hospitals for treatment of intercurrent illness^{27,56} and the high risk of feeding tube placement and mortality observed is consistent with data from a wide range of clinical and geographic settings. Second, these data apply only to persons with advanced dementia who have a surrogate decision maker able to participate in medical decision making. The high proportion of otherwise eligible subjects who could not be included in this study because they had no functional surrogate decision maker represent a growing population of patients for whom there is no current societal consensus on a mechanism for medical decisions.⁴¹ There is, however, no evidentiary basis to suggest that the group of patients with dementia without surrogate decision makers is at any different risk of gastrostomy or death than those who do have involved family members. Finally, small sample size may have limited our ability to identify additional predictors of feeding tube placement and mortality in this cohort.

CONCLUSIONS

In a cohort of hospitalized patients with acute illness and advanced dementia, the risk of receiving a new feeding tube is high. With or without tube feeding, these patients have a 50% six-month median mortality, similar to that observed in a wide range of reports from other clinical settings. These data have implications for the development of evidence-based standards of medical care for the growing population of persons with advanced dementia.

Accepted for publication August 22, 2000.

This work was supported by grants from The Greenwall Foundation, and The Kornfeld Foundation, New York, NY. Dr Meier is the recipient of the National Institute on Aging Academic Career Leadership Award (K07AG00903). Dr Morrison is the recipient of a Mentored Clinical Scientist Development Award (K08AG00833) from the National Institute on Aging, Bethesda, Md.

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