

Natural History of Feeding-Tube Use in Nursing Home Residents With Advanced Dementia

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Objectives: Despite the evidence that feeding-tube use in persons with advanced dementia is not associated with improved outcomes, there remains striking variation in their use. Yet, little is known about the national incidence of feeding-tube insertions, the circumstances of their insertion, and post-insertion health care use.

Design: Secondary analysis of Minimum Data Set merged onto Medicare Claims Files.

Setting and participants: Nursing home residents (NHR) without a feeding tube.

Measurements: NHR were followed for up to 1 year to see whether a feeding tube was inserted and then followed for 1 year after insertion to examine health care use and survival.

Results: The incidence of feeding-tube insertion was 53.6/1000 residents. Most (68.1%) feeding-tube

insertions were performed in an acute care hospital with the most common reasons for admission being pneumonia, dehydration, and dysphagia. One year post-insertion mortality was 64.1% with median survival of 56 days. Within 1 year, 19.3% of those who had a feeding tube inserted required a tube replacement or repositioning within a median 145 days after the initial insertion. Over 1 year, tube feeding was associated with an average of 9.1 hospitalized days per person, 1.0 hospitalizations, 0.3 emergency room visits that did not result in a hospital admission.

Conclusion: Most feeding tubes are inserted in an acute care hospital. Feeding-tube insertions are also associated with poor survival and significant rate of health care use after insertion. (*J Am Med Dir Assoc* 2009; 10: 264–270)

Keywords: Feeding tubes; survival; health care utilization; nursing homes; elderly

Enteral feeding is a treatment used to provide nutrition to patients who have difficulty swallowing secondary to injury or acute illness. Percutaneous endoscopic gastrostomy (PEG) is a procedure created initially to minimize the morbidity associated with laparoscopic insertion of these tubes in pediatric patients.¹ Placement of PEG tubes has been thought to be inexpensive and low risk¹; as a result, the use of this procedure has evolved to include patients of varying ages and disease

states—from infants with failure to thrive or neuromuscular disorders to adults with dysphagia secondary to stroke, gastrointestinal disorders, and dementia. PEG is now considered the most appropriate and common method to provide long-term enteral feeding.

The use of PEG tubes in patients with advanced dementia is controversial. The perceived benefits of tube feeding by physicians and surrogate decision makers include improved survival, better nutritional status, and reduced risk of complications such as aspiration pneumonia.^{2–5} However, there is a significant body of literature to the contrary. Most studies fail to demonstrate that tube feeding in persons with advanced cognitive impairment accomplishes these outcomes.^{6–15} Despite the mounting evidence against any benefit to insertion of feeding tubes, the intervention continues to be extensively practiced.¹⁶

The prevalence of PEG tubes among nursing home residents with advanced cognitive impairment varies substantially. Studies have shown rates from 18.0% to 34.0% nationally,^{16–19} with substantial state variation ranging from 7.5% to 40.0%.¹⁸ There remain important gaps in our

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Funding for this research was based on grant from the National Institute of Aging (R01 AG024265).

The authors have no conflicts of interest.

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DOI:10.1016/j.jamda.2008.10.010

understanding of the use of this procedure in persons with advanced dementia. Most studies to date have examined only the prevalence of feeding-tube insertions. Understanding the incidence of feeding-tube insertion and characterizing the final locus of decision making regarding feeding-tube insertion will provide important information to shape strategies designed to decrease the use of feeding tubes. Additionally, there is little information detailing the occurrence of complications related to PEG tubes once inserted (eg, dislodgement, repositioning). Thus, the objective of this research was to examine the natural history of feeding-tube insertion and use in a national sample of nursing home residents with advanced cognitive impairment.

METHODS

Data Source

The study population was defined from the 2000 Minimum Data Set (MDS), which contains data on nursing home residents living in all Medicare- or Medicaid-certified US facilities. The population was drawn from the first full MDS assessment closest to April 1, 2000. MDS clinical data on individuals meeting eligibility criteria was matched to Parts A and B Medicare claims data from 2000 to 2002 allowing for 2 years of prospective follow-up.

Study Population

Study participants included all nursing home residents aged 66 years or older who had advanced dementia (defined by a cognitive performance score [CPS] score of at least 4) and no feeding tube at the time of their baseline MDS assessment in 2000. The CPS is a validated scale constructed from 5 MDS variables that categorizes cognitive function into 7 categories, ranging from intact (0) to moderately severe impairment (4), severe impairment (5), and very severe impairment with eating problems (6).²⁰ In addition, subjects were required to match to the 100% Part A and random 20% Part B Medicare claims files from 2000 to 2002. Individuals were excluded if they had any Medicare Managed Care Organization enrollment during the study period, if they had any evidence of a feeding tube in Medicare claims in the 6 months prior to baseline date, or if they were comatose according to the baseline MDS. Our study population was further partitioned into a subset who had a feeding tube inserted within a year of their first MDS assessment (N = 5209). This group was then followed for 1 year after feeding-tube insertion, as the literature suggests that patients with dementia have 1-year mortality rates ranging from 39% to 90% following PEG insertion.⁶

Study Variables

Both sets of claims data were used to determine feeding-tube use among residents. Feeding-tube insertions were defined from ICD-9 procedure codes of 43.1, 43.11, 43.19, and 44.32, as well as the CPT-4 codes of 43246, 43653, 43750, 43830, 43832, 44372, 44373, and 74350. These codes have been verified with Centers for Medicaid and Medicare Services (CMS) as the standard codes that should be used

by providers to bill for PEG insertions and have been used in the literature.^{21–23}

In addition to mortality, we tracked feeding-tube replacements (defined by CPT code 43830 and ICD-9 code 97.02), repositioning (CPT code 43761), and removal (CPT codes 43247 and 43363 and ICD-9 code 97.51) within the 1-year window. We also tracked general health care use such as hospitalizations, inpatient days, emergency room (ER) visits that did not result in a hospital admission, and specifically identified ER visits related to feeding-tube complications.

Statistical Analyses

Using data from the baseline MDS, we described demographic, clinical characteristics, advanced directives, and recent health care use for nursing home residents with advanced dementia who did and did not have feeding tubes over the 1-year follow-up period. Clinical characteristics include the Morris activities of daily living (ADL) score—ranging 0 to 28, based on 7 areas of observed physical function rated on a scale of 0 (total independence) to 4 (total dependence)—and the changes in health, end-stage disease and symptoms and signs (CHESS) comorbidity index, ranging from 0 (not unstable) to 5 (highly unstable). Then, we analyzed the circumstances surrounding the feeding-tube insertion through a descriptive analysis of whether the PEG tube was inserted during an acute care hospitalization or not, and, if so, the primary and admitting diagnoses and diagnosis-related groups associated with the insertion, and the specialty of the physician inserting the feeding tube. These data come from Parts A and B claims associated with the insertion (through the ICD-9 and CPT codes described above). Finally, we examined 1-year post-insertion health care use and mortality derived from Medicare claims and denominator file. Among those who received a feeding tube, we described the rate, frequency, and duration to feeding-tube replacement, repositioning, and removal, as well as death. Additionally, over the same 1-year period, we described the overall average health care use rates of inpatient days, hospitalizations, emergency room (ER) visits not resulting in admission, and feeding-tube-related ER visits not resulting in admission. We also present the Kaplan-Meier 1-year survival curve after receiving a feeding tube, and describe 1-year post-insertion survival after the first feeding-tube repositioning.

RESULTS

Nationally, the overall incidence of feeding-tube insertion was 53.6 per 1000 elderly nursing home residents with advanced dementia. **Figure 1** shows state variation in the incidence of feeding tubes in the continental United States. Rates per 1000 vary widely from lows of 2.1 (Utah), 3.5 (Maine), 4.1 (North Dakota), and 4.2 (Iowa) to highs of 108.3 (Mississippi) and 100.5 (Alabama). **Table 1** compares the characteristics of subjects who received feeding tubes within 1 year from baseline and those who did not. Compared with those without feeding tubes, feeding-tube recipients were younger (83.0 versus 84.8 years, $P < .01$)

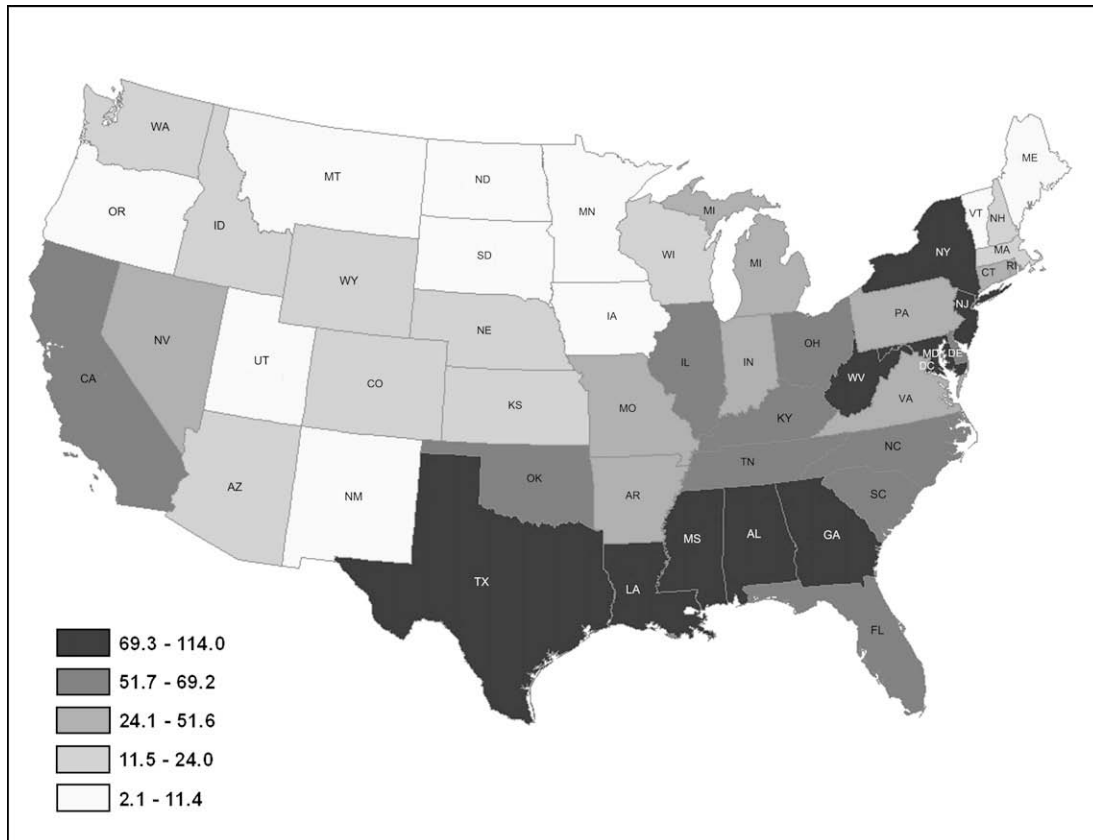


Fig. 1. Rate of Feeding-Tube Incidence Per 1000 Nursing Home Residents with Advanced Dementia by State, 2000–2001.

and more likely to be male (32.6% versus 25.3%, $P < .01$). Racial and ethnic minorities were much more likely to be feeding-tube recipients compared with white subjects, specifically African-Americans (25.0% versus 8.0%, $P < .01$), Asian/Pacific Islanders (1.6% versus 0.8%, $P < .01$), and Hispanics (6.1% versus 2.4%, $P < .01$).

The 2 groups did not tend to differ by impairments or disease characteristics. They were similar in level of cognitive impairment (through CPS scores), comorbidity levels, and in the likelihood of having had a decline in cognitive status. Those with feeding tubes did tend to be slightly more impaired physically with higher ADL scores (22.9 versus 21.4, $P < .01$), and a greater likelihood of having a deterioration in ADL self-performance in the preceding 9 months (37.7 versus 35.5, $P < .01$). Feeding-tube recipients were more likely to have a stage 3 or stage 4 pressure ulcer and significantly less likely to have no ulcers (all $P < .01$). Nursing home residents who did not get feeding tubes were significantly more likely to have an expected life of 6 months or less compared with patients with feeding tubes (4.1 versus 0.5, $P < .01$).

Nursing home residents who had a feeding tube inserted were less than those who did not get tube fed to have advance directives limiting aggressive care: Do Not Resuscitate (DNR) order (33.5 versus 63.1, $P < .01$); Do Not Hospitalize (DNH) order (0.9 versus 5.1, $P < .01$); No Artificial Hydration and Nutrition order (3.9 versus 12.9, $P < .01$). In addition,

tube-fed nursing home residents have a lower likelihood of having a designated health care proxy through a durable power of health attorney (18.3 versus 34.4, $P < .01$).

In addition, [Table 1](#) characterizes prior use and reveals that feeding-tube recipients are significantly more likely to have had at least 1 hospitalization in the preceding 3 months (40.4 versus 29.2, $P < .01$) and at least 1 ER visit (12.6 versus 9.7, $P < .01$) than those without a feeding tube. They were also less likely to be in hospice care (0.2 versus 2.3, $P < .01$).

Circumstances of Feeding-Tube Insertions

Two thirds of all feeding tubes (68.1%) were inserted during an acute care hospitalization. [Table 2](#) shows the most common primary diagnoses associated with feeding-tube insertion during a hospitalization: aspiration pneumonia, dehydration, dysphagia, urinary tract infection, malnutrition, and pneumonia. Additionally, gastroenterologists were the most common specialty performing insertions (54.7%), followed by surgeons (28.5%); radiologists accounted for less than 2% of insertions.

One-Year Post-Insertion Outcomes

Among severely demented nursing home residents who had a feeding tube inserted, the overall 1-year mortality rate is 64.1% with median survival of 56 days after insertion. [Figure 2](#) shows the Kaplan-Meier 1-year survival curve among

Table 1. Descriptive Characteristics of Nursing Home Residents with Advanced Dementia Who Did and Did Not Receive Feeding Tubes (N = 97,111)

Variable	Among Nursing Home Residents with Advanced Dementia (in %)	
	With Feeding Tube Inserted	Without Feeding Tube Inserted
Overall N	5209	91,902
Sociodemographic characteristics		
Mean age, y	83.1*	84.8*
Female	67.4*	74.7*
Race/ethnicity		
White, non-Hispanic	67.1*	88.5*
Black, non-Hispanic	25.0*	7.9*
Hispanic	6.1*	2.4*
Asian/Pacific Islander	1.6*	0.8*
American Indian/Alaskan native	0.3	0.4
Disease characteristics		
CPS score		
4 Moderately severe impairment	36.4*	33.6*
5 Severe impairment	28.9*	36.3*
6 Very severe impairment with eating problems	34.8*	30.1*
Mean activity of daily living (ADL) additive score (0–28)	22.9*	21.4*
Change in ADL self-performance in the last 9 months		
No change	58.9†	60.7†
Improved	3.4†	3.9†
Deteriorated	37.7*	35.4*
Mean CHES comorbidity index (0–5)	1.5	1.5
Presence of stage of decubitus ulcer		
No ulcers	74.0*	81.6*
Stage 1	5.0†	4.2†
Stage 2	12.8*	9.4*
Stage 3	3.5*	2.2*
Stage 4	4.7*	2.7*
Have condition/disease that make unstable	48.1	47.4
Have end-stage disease	0.5*	4.1*
Advanced directives		
Have guardian	6.8†	7.7†
Have Do Not Resuscitate (DNR) order	33.5*	63.1*
Have Do Not Hospitalize (DNH) order	0.9*	5.1*
Have order to withhold artificial hydration and nutrition	3.9*	12.9*
Have living will	10.6*	22.6*
Have durable power of attorney–health	18.3*	34.4*
Care characteristics		
At least 1 hospitalization in past 3 months	40.4*	29.2*
At least 1 emergency room visit (without overnight) in past 3 months	12.6*	9.7*
In hospice	0.2*	2.3*
Have any use of physical restraints	1.3	1.0
Have any use of antipsychotics	27.2	26.6

*Difference between “with feeding tube” and “without feeding tube” significant at the 99% level.

†Difference significant at the 95% level.

elderly nursing home residents who had a feeding tube inserted and died within the year (N = 3337).

Among those who have a feeding tube inserted, almost 20% had the feeding tube either replaced or repositioned (see Table 3). This number is substantial given that many will die prior to requiring an adjustment, as median 1-year survival was 56 days (as compared with median duration of 143 days until an adjustment occurs). All feeding-tube adjustments involved tube replacement. Among the 1986 nursing home residents who had a feeding tube replaced, 28.9% required at least 2 replacements (Table 3).

Median survival among those 381 nursing home residents who died after a feeding-tube replacement was 54 days.

Thus, among those who had their feeding tube replaced during the year after insertion, about 40% subsequently died within that year, generally after 2 months post-replacement. Among all residents who had a replacement (N = 986), overall median survival post-insertion was 313 days.

In the year following a feeding-tube insertion, nursing home residents experienced an average of 9.1 inpatient hospital days (with 1 day at the 50th percentile and 11 days at the 75th percentile), 1.01 hospitalizations (with 1 hospitalization at both the 50th and 75th percentiles), 0.27 ER visits that did not result in a hospitalization, and 0.05 ER visits specifically for feeding-tube complications (with 0 visits at both 75th percentiles).

Table 2. Top Discharge Diagnoses Associated with Insertion of Feeding Tube in the Hospital (N = 3654)

Description	ICD-9 code(s)	%
Aspiration pneumonia	507.0	16.7
Dehydration	276.5	9.9
Dysphasia	787.2; 438.82	7.4
Urinary tract infection	599.0	6.2
Malnutrition	263.9	5.7
Pneumonia	486	5.4
CVA	434.91; 436	5.2
Septicemia	038.9	3.9

CVA, cerebrovascular accident.

DISCUSSION

This study describes, for the first time, the incidence of tube feeding in a nationwide sample of nursing home residents with advanced dementia and details the circumstances around feeding-tube insertion. In 1 year, the incidence of feeding-tube insertion was very high (56/1000 nursing home residents), but varied widely across the states. Over two thirds of tube-feeding insertions occurred during inpatient hospitalization, and outcomes in the year following the procedure were poor: 64.1% died in the year following the procedure, and 1 in 5 tube-fed residents experienced a tube-related complication necessitating a hospital transfer. Thus, practice of tube feeding nursing home residents with advanced dementia is associated with considerable individual burden and health care use. These results provide further observations to better inform decisions to place feeding tubes in nursing home residents with end-stage dementia and underscore the hospital as a critical care setting to target interventions aimed at improving this decision-making process.

National Incidence and Variation of Feeding-Tube Insertion

Previous studies have demonstrated striking variation in the prevalence of feeding tubes with national estimates of 18% to 34%^{16,18,19,22}; only 1 study examined incidence of feeding tubes and found a 2-year incidence rate of 9.7% in the state of Washington.¹² Merging the national MDS data repository with Medicare claims, we were able to examine the incidence of feeding-tube use among persons with advanced cognitive impairment defined as CPS of 4, 5, and 6. Our study provides the first national estimate of a 1-year incidence of feeding tubes of 53.6 per 1000 nursing home residents, with striking state variation. Our rate is lower than that previously reported for Washington through more accurate measurement of PEG insertions by our use of national Medicare claims data, rather than MDS, which does not distinguish between different types of tubes. Unlike other studies using Medicare claims data, we also incorporated information from Part B claims, which solely identified 30% of all insertions.

Final Locus of Decision Making for Feeding-Tube Insertion

An important contribution of this study is the finding that the final locus of decision making for feeding tubes among nursing home residents with advanced dementia is an acute

care hospitalization. Most PEG tubes are inserted in the hospital and for conditions whose diagnoses would necessitate hospitalization. If the decision to insert a feeding tube is primarily occurring at the hospital rather than in the nursing home, this raises questions about the extent to which advanced directives may be followed, and whether alternatives such as hand feeding can be sustained during an acute care hospitalization. Knowing the final locus of decision making for tube insertions is crucial in order to adequately target and shape interventions to decrease the presumed overuse of feeding tubes.

Survival and Health Care Use After Feeding-Tube Insertion

The previous literature reported that between 39% and 90% died after feeding-tube insertion.^{6,11,23,24} Our results of 64% mortality rate lie well within this range. Once a PEG tube is inserted, survival is poor. Half of those who die within a year of insertion die within 2 months. Overall, median survival is 165 days. Using national data, our article is one of the first articles to characterize the health care use after feeding-tube insertion. Only one previous study described use after insertion such as complications associated with a feeding tube and whether such complications led to hospitalizations.¹⁰ However, the description of health care use was limited because the purpose of the research was to estimate the costs associated with feeding-tube use, and it only applied to a limited geographic area. Our national study found that about 20% of those receiving a feeding tube require either a repositioning or replacement of the tube and the median survival after a repositioning (the most common adjustment) is only 54 days. Because the use of feeding tubes among the population of elderly with advanced cognitive impairment has not been associated with improved survival advantage or clinical benefit, these results suggest that this additional health care use has unclear benefits.

Our study is largely confirmatory of the characteristics associated with greater prevalence of feeding tube: non-white,^{13,17-19} male,^{17,19} and lack of advanced directives.^{13,15,18,19}

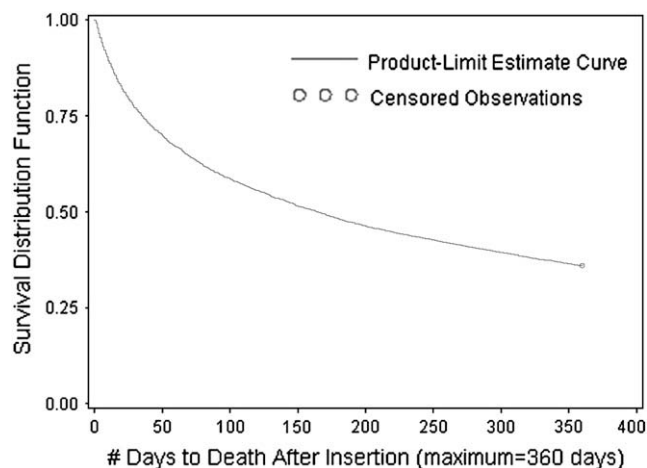


Fig. 2. Kaplan-Meier 1-Year Survival after Receiving a Feeding Tube.

Table 3. Timing and Rates of Feeding-Tube Adjustment (N = 5209)

Procedure/Event	Procedure/Event within 1 Year of Feeding-Tube Insertion					
	N	Rate per 100 Insertions	# Days after Insertion (in Percentiles)			% >1 Given Had at Least 1 Procedure
			10th	Median	90 th	
Replacement	986	18.9	17	146	302	28.9
Repositioning	38	0.1	0	44	320	13.2
Removal	134	2.6	9	146	308	8.2
Replacement or reposition	1004	19.3	16	144	301	29.4

Additionally, our results confirm that the lack of advanced directives appear to be associated with feeding-tube insertions. Both demographic factors have been found to be important on the individual as well as the nursing home facility level.¹⁹

There are important limitations to be acknowledged in the interpretation of these results. We had only limited information on preferences for feeding tubes, which were only available in MDS assessments that were from an annual assessment or an assessment done because of a change in condition, rather than reflecting a more contemporaneous decision at the time of insertion. Additionally, we focused attention only on those nursing home residents for whom we had Medicare claims, meaning those who were covered by fee-for-service (FFS) Medicare. Thus, our incidence estimates should be considered representative only among FFS Medicare beneficiaries.

CONCLUSION

To date, very little work had been done describing the epidemiology of feeding-tube use among the elderly with advanced dementia especially on a national level, and, particularly the circumstances under which tubes were inserted and what happens after insertion other than mortality. A growing body of evidence suggests that the use of feeding tubes for this population is not beneficial. Our findings confirm that the incidence of feeding-tube insertions varies similar to previously reported variation feeding-tube prevalence. Important new findings is that slightly more than two thirds of PEG feeding tubes are inserted during an acute care hospitalization suggesting that the hospital is the final locus of decision making. Interventions to reduce the variation in the rate of feeding-tube insertion may be best targeted at the acute care hospital. Similar to previous studies, we report a short survival time after feeding-tube insertion. Despite this short survival time, 1 in 5 feeding tubes are replaced or repositioned resulting in frequent ER visits. The median survival after replacement was 54 days. These results of high health care use but shortened survival suggest the need for improved decision making regarding feeding-tube insertion for nursing home residents with advance cognitive impairment.

ACKNOWLEDGMENTS

The authors thank Mrs. Cindy Williams for help in preparation of the manuscript and Mr. Chris Brostrup-Jensen for the preparation of data analytic files.

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