# Physicians' Expectations of Benefit from Tube Feeding

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# Abstract

**Objective:** Tube feeding is increasingly common, despite evidence for limited medical benefits. We interviewed treating physicians to describe their expectation of benefit for patients receiving a new feeding tube, and to determine whether expected benefits vary by patient characteristics.

*Methods:* We recruited treating physicians and surrogate decision-makers for 288 hospitalized patients in a prospective study of new feeding tube decisions. In structured interviews, physicians provided information on patients' diagnosis and whether they expected any of eight potential medical benefits for a specific patient; surrogates provided information about the patients' function, race, age, prior residence, and ability to eat by mouth. *Results:* We completed interviews with 173 physicians about tube feeding for 280 patients (response rate, 97%). Patients commonly had acute stroke (30%), neurodegenerative disease (16%), or head and neck cancer (22%); 70% were somewhat or severely malnourished. In half or more cases, physicians expected benefits of improved nutrition (93%), hydration (60%), prolonged life (58%), ease providing medication (55%), and less aspiration risk (49%). Physicians endorsed more expected benefits for patients with stroke or those completely unable to eat by mouth (p < 0.05).

*Conclusion:* Treating physicians expected multiple medical benefits for a diverse population of patients receiving feeding tubes. Physicians may be unaware of evidence, or expect more optimistic outcomes for their specific patient population. Further education and decision support may improve evidence-based decision-making about feeding tubes.

# Introduction

**U**SE OF FEEDING TUBES is increasingly common. The rate of placement of percutaneous feeding tubes doubled among Medicare beneficiaries from 1987 to 1993.<sup>1</sup> A recent Veterans' Administration study found the rate of use for hospitalized dementia patients decreased in the late 1990s.<sup>2</sup> However, a study in North Carolina found that the overall rate of use continued to increase through 2000, with greatest absolute increases for patients aged 75 and older.<sup>3</sup> The most common primary diagnoses among patients receiving feeding tubes are dementia (29%–35%), stroke (19%–41%), or head and neck cancer (13%–16%).<sup>4,5</sup>

Tube feeding has limited medical benefits in terms of survival, functional status, or risk of aspiration pneumonia, although survival varies by underlying diagnosis. Patients who receive a percutaneous feeding tube have a 30-day mortality risk of 18%–24% and a 1-year mortality risk of 50%–63%.<sup>6–9</sup> In a well-designed prospective study, Callahan

et al.<sup>5</sup> followed 150 patients with new feeding tubes and varied diagnoses, and found 30-day mortality of 22% and 1-year mortality of 50%. Among survivors, 70% showed no improvement in function or nutritional status. Survival rates are better for younger patients, and for patients with trauma, amyotrophic lateral sclerosis, or head and neck cancer.<sup>10,11</sup> For patients with advanced dementia, observational studies have shown no survival benefit when comparing those who do or do not receive a feeding tube.12-15 For patients with acute stroke, one large randomized trial found that early placement of feeding tubes did not improve survival or stroke recovery at 6 months compared to those who had a trial of oral feeding first.<sup>16</sup> Tube feeding is often initiated to prevent aspiration, but aspiration of oropharyngeal contents continues to occur and the risk of pneumonia remains high after placement.17,18

People who give informed consent for feeding tubes may not be aware of data on survival rates or other outcomes. In a prospective study of 288 patients with varied diagnoses

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who received new feeding tubes, we found that a majority of family or other surrogate decision-makers had high expectations of benefit from this procedure.<sup>11,19</sup> Over 85% of these decision-makers expected the feeding tube to lead to better health, longer life, and improved nutrition and quality of life. Seventy-seven percent expected decreased risk of choking and 66% expected reduced risk of pneumonia.

Physicians may share this optimism about tube feeding outcomes.<sup>20,21</sup> Three large survey studies have examined physicians' knowledge about tube feeding in advanced dementia. In two nationwide surveys, a majority of responding physicians reported aspiration to be an indication for tube feeding, and expected it to improve nutrition, decubitus healing, aspiration risk and survival.<sup>22,23</sup> In a survey of North Carolina physicians, Modi et al.<sup>24</sup> found that physician race and specialty are associated with willingness to recommend tube feeding for a hypothetical patient with advanced dementia. These studies provide information on physicians' general knowledge and attitudes, but do not explore how they apply this knowledge to the care of specific patients, and do not examine expectations for patients with varied diagnoses.

To understand the clinical impact of physicians' expectation of benefit from tube feeding, we interviewed treating physicians for patients enrolled in a prospective study of new tube feeding decisions. Aims of this research were (1) to describe physicians' expectation of benefit for patients with a new decision for tube feeding and (2) to determine whether physicians' expectations of benefit from this procedure are associated with patients' clinical characteristics.

#### Methods

The study prospectively identified a series of patients receiving new percutaneous gastrostomy feeding tubes and enrolled the treating physician who participated in this decision. Study sites were two teaching hospitals in North Carolina; a 608-bed tertiary care hospital and a 500-bed community care hospital. The UNC Committee for the Protection of Human Subjects approved all research procedures.

TABLE 1. CHARACTERISTICS OF PATIENTS (N = 280)

Age in years (mean ± SD)	65 ± 17
Male	54%
Race	
White	65%
Black	33%
other	2%
Nursing home resident	36%
ADL score (mean; range, 5–15)	11
Nutritional status	
Somewhat malnourished	49%
Severely malnourished	21%
Primary diagnosis	
Stroke	30%
Neurodegerative disease	16%
Head and neck cancer	22%
Other	31%

ADL, activities of daily living.

#### Subjects

We identified potentially eligible hospitalized patients by screening daily schedules for gastroenterology and interventional radiology procedures between December 2000 and May 2002. Patients were eligible if they were aged 18 or older and receiving their first feeding tube. Patients were excluded if they had advanced malignancy other than head and neck cancer, if they had major trauma, if they died prior to enrollment interview, or if they lacked a surrogate decisionmaker. Capable patients gave informed consent and were interviewed. However, because few patients were able to be interviewed, all current or potential surrogate decision-makers were recruited. Results of these interviews have been reported separately.<sup>11</sup> All interviews were conducted in English, excluding non-English speakers. For each enrolled patient, we also recruited the attending physician who reported responsibility for the decision to place a feeding tube. This physician was usually the hospital attending of record. If this physician indicated he or she did not make the decision, they were asked for the name of the consultant or primary care physician who had primary responsibility for this decision.

## Data collection

Physicians and surrogate decision-makers who were primarily responsible for a decision about tube feeding were invited to participate in in-person interviews within a few weeks after feeding tube placement. Because very few patients were capable of interview, all measures for this analysis are derived from the baseline family and physician interviews. Surrogate decision-makers provided information on patients' functional status just prior to hospitalization, using a modified Katz activities of daily living (ADL) scale that excluded "eating," since this population was uniformly unable to eat independently.<sup>25</sup> Functional status scores had a potential range of 5-15, with higher scores indicating greater dependency. They also provided information on patient race, age, whether the patient previously resided in a nursing home, and whether the patient was able to take some food by mouth at the time the feeding tube was placed. Physicians provided a list of primary and secondary diagnoses and rated the patients' nutritional status on a 3-point Likert scale.

To measure physicians' expectation of benefits from tube feeding, the interviewer asked, "What medical benefits are anticipated from tube feeding?" then read a list of eight potential medical benefits to which the physician responded yes, the benefit was anticipated for that patient or no, the benefit was not anticipated. The list was developed through literature review, interviews with providers, and pretest of the instrument for comprehension by respondents. Potential benefits were: prolonging life; preventing aspiration; decreasing an upper gastrointestinal obstruction to feeding; improving hydration; improving nutrition; diminishing pain; increasing ability to provide medication; and facilitating nursing home placement. The interviewer also asked the respondent to identify which of these benefits was the most important reason for the feeding tube. Interviewers then asked the treating physician to provide an estimate of the patient's life expectancy with or without the feeding tube. They asked the physician to rate the patient's quality of life

Expected benefit	% Total (n = 280)	% <i>Stroke</i> (n = <i>84</i> )	% <i>Neuro</i> (n = 45)	% Cancer $(n = 62)$	% other (n = 87)
Improving nutrition <sup>a</sup>	93	86	93	94	98
Improving hydration	60	59	69	69	49
Prolonging life <sup>a</sup>	58	61	49	42	72
Providing medication	55	59	58	61	45
Preventing aspiration <sup>b</sup>	49	76	44	31	39
Facilitating NH placement <sup>b</sup>	22	38	16	2	24
Diminishing pain <sup>a</sup>	14	18	2	26	8
Decreasing obstruction <sup>b</sup>	12	7	2	34	6

TABLE 2. PHYSICIANS' EXPECTATION OF MEDICAL BENEFITS FROM FEEDING TUBES

 $^{a}p < 0.05.$ 

b' p < 0.01 for difference by diagnostic group.

NH, nursing home.

on a continuum from 0 ("death") to 100 ("perfect health") before and after feeding tube placement.

#### Analysis

To describe physicians' expectations of potential benefits we report the percent of patients for whom physicians expected each potential benefit, and their median estimates for life expectancy and quality of life. To test whether patient characteristics are associated with physicians' expectations of benefit, we compared the frequency of each expected benefit by patient diagnosis, age, race, gender, functional status, residence in a nursing home, and partial ability to eat before the feeding tube in bivariate analyses using Pearson's  $\chi^2$  tests

 TABLE 3.
 NUMBER OF MEDICAL BENEFITS ASSOCIATED

 WITH PATIENT CHARACTERISTICS

Patient characteristic	Number of benefits (mean)
Primary diagnosis	
Stroke	4.1 <sup>a</sup>
Neurodegenerative disease	3.4
Head and neck cancer	3.8
Other	3.5
ADLs	
Independent $\geq 2$	3.7
Not independent	3.7
Nursing home resident	
Yes	3.7
No	3.7
Patient able to eat	
Yes	3.4 <sup>a</sup>
No	3.9
Gender	
Female	3.7
Male	3.7
Race	
White	3.7
African American	3.9
Age (correlation)	R = 0.056

 $^{\mathrm{a}}p \leq 0.05, \ t$  test or one-way analysis of variance, corrected for clustering by physician.

ADLs, activities of daily living.

for categorical comparisons. Next, we summed the answers to the questions about potential benefits into an index of number of positive answers (possible values from 0–8). We examined the association of the number of expected benefits to these patient characteristics, using t tests and one-way analysis of variance for categorical independent variables and Pearson's correlation for age. Finally, we developed a multivariable regression model with the summed expected benefits score as the dependent variables and patient characteristics as the independent variables. The standard errors of all analyses were corrected for any intraclass correlation due to clustering by physician, since some physicians were interviewed about more than one patient.

# Results

Of 416 eligible patients receiving new feeding tubes during the study period, we enrolled 288 patients with surrogate decision-makers. We completed physician interviews for 280 of these patients, for a response rate of 97%. Interviews included 173 unique treating physicians; 117 physicians treated 1 patient, 37 treated 2 patients, and 19 treated 3 or more patients enrolled in the study. Participating physicians were usually general internists or family medicine physicians (70.1%), with smaller number of surgeons (16.9%), neurologists (6.8%), and medical oncologists (6.1%).

Patients were on average 65 years of age, dependent for most activities of daily living, and one third resided in a nursing home prior to the placement of the feeding tube (Table 1). Thirty percent had acute stroke, 16% neurodegenerative disease, 22% head and neck cancer, and 31% other underlying diagnoses on the hospital admission when the feeding tube was placed.

#### Decision-making process

Physicians reported treating the patient for a median of 3-4 weeks prior to the tube feeding decision, consistent with their role as hospital attending physician. In response to the question, "Who ultimately made the decision to place the feeding tube?" 62% answered the physician, 18% the family, 11% the patient, and 10% reported shared decision-making. Physicians reported that other health professionals influenced the decision, including speech therapists (31%) and

patients' primary care physicians (39%). One third of patients had a modified barium swallow, one fourth a bedside swallowing evaluation, and 8% a fiber optic swallowing study prior to the decision on feeding tube placement.

#### Physicians' expectation of medical benefit

In response to questions about potential medical benefits expected from the patient's new feeding tube, physicians endorsed an average of 3.7 of these benefits per patient. The most common expected benefits were improving nutrition and improving hydration (Table 2). For approximately half of the patients, physicians endorsed prolonged life, increased ability to provide medications, and prevention of aspiration as benefits of the feeding tube. The benefit varied by diagnosis. For example, physicians were more likely to expect prevention of aspiration and help with nursing home placement for stroke patients, but decrease in gastrointestinal obstruction was more often an expectation for cancer patients. In response to the open-ended question, physicians also reported 31 other expected benefits, including "rehabilitation and improving strength," "allow healing of fistula in neck," and "anticipation of severe mucositis precluding adequate oral nutrition." When asked to name which medical benefit was the single most important reason for the feeding tube, the two most common responses were improving nutrition (52%) and preventing aspiration (17%).

Physicians declined to answer questions regarding life expectancy for 64 patients. For the 216 remaining patients, life expectancy without the feeding tube was a median of 1–2 months and it increased to an anticipated life expectancy of a median of 1–3 years with the feeding tube in place. They rated the patients' quality of life a median of 40 on a 100 point scale prior to the feeding tube and expected it to improve to 50 after its placement.

# Association of patient characteristics with expected medical benefit

In bivariate analyses, patients' primary diagnosis and ability to eat were associated with the number of medical benefits physicians expected from tube feeding. The number of expected benefits was somewhat higher for patients with stroke, and for patients who were completely unable to eat prior to use of a feeding tube (Table 3).

We also examined the association of patient characteristics with specific types of benefits. Physicians expected reduced risk of aspiration for 76% of patients with a primary diagnosis of stroke compared to rates of 31% to 44% for other diagnoses (p = 0.01). Physicians expected to reduce GI obstruction for 34% of patients with head and neck cancer compared to rates of 2–7% for other diagnoses (p = 0.01).

In the multivariable model, only diagnosis was independently associated with the number of expected benefits, and this association did not remain significant after correcting for the intraclass correlation due to multiple patients for some treating physicians.

#### Discussion

Our study found that physicians who participated in clinical decisions to place feeding tubes did so with expectation of medical benefits. Physicians expected improved nutrition for nearly all patients, although somewhat less often for patients with stroke. For half of their patients they expected prolongation of life, easier administration of medication, and reduced risk of aspiration. The frequency with which they expected improved outcomes for their patients contrasts with the available evidence. Even when accounting for differences by diagnosis, there is no strong evidence tube feeding improves survival in stroke or dementia, or that this procedure reduces risk of aspiration in any condition. Physicians' expectations may have been communicated during clinical decision-making, as we also found high expectations for benefit in parallel interviews with the family decision-makers for these patients.<sup>11</sup>

The optimistic views of the physicians in this study may be more complicated than simply a lack of knowledge about the outcomes of feeding tubes. Physicians may have known the published data, yet expect better than average outcomes for their specific patients. Physicians in this study expected a greater number of benefits for patients with stroke or head and neck cancer, than for those with neurodegenerative disease, and this trend is consistent with published evidence. Decision-making is not simply influenced by information, but also by the certainty and urgency of a given choice.<sup>26</sup> Patient or family preferences, the compassionate desire to offer hope and help, and the perceived lack of other treatment options may also influence how physicians discuss this clinical decision.

Our study was limited to two hospitals in a state with a relatively high rate of feeding tube use. Generalizability is enhanced by the high response rate from physicians and the choice of one tertiary and one community hospital site, but physicians in other regions of the country may give somewhat different responses. While information on varied survival rates by diagnosis, and absence of benefit related to aspiration was clearly published at the time of this study, additional evidence has since been published and may now be more influential. An additional limitation is recall or favorable response bias when physicians are asked about a decision already made. This bias may have led them to rate expected benefits higher. In the absence of a comparison group of patients who had similar illness but no feeding tube, we cannot speculate how physicians applied their knowledge differently for those cases.

We conclude that physicians involved in clinical decisionmaking for patients who receive feeding tubes report expectations of substantial clinical benefits from this procedure. If physicians communicate these relatively positive expectations to patients and families, they may support the increased use of this procedure. Physicians and surrogate decision-makers may need education and greater practical support for assisted feeding options in order to change this pattern of medical practice.

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#### Author Disclosure Statement

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#### References

- 1. Verrilli D, Welch HG: The impact of diagnostic testing on therapeutic interventions. JAMA 1996;275:1189–1191.
- Braun UK, Rabeneck L, McCullough LB Urbauer DL, Wray NP, Lairson DR, Beyth RJ: Decreasing use of percutaneous endoscopic gastrostomy tube feeding for veterans with dementia—Racial differences remain. J Am Geriatr Soc 2005;53:242–248.
- Lewis CL, Cox CE, Garrett JM, Hanson L, Holmes GM, Howard A, Carey TS: Trends in the use of feeding tubes in North Carolina Hospitals: 1989 to 2000. J Gen Intern Med 2004;19:1034–1038.
- Rabeneck L, Wray NP, Petersen NJ: Long-term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes. J Gen Intern Med 1996;11:287–293.
- Callahan CM, Haag KM, Weinberger M, Tierney WM, Buchanan NN, Stump TE, Nisi R: Outcomes of percutaneous endoscopic gastrostomy among older adults in a community setting. J Am Geriatri Soc 2000;48:1048–1054.
- Grant MD, Rudberg MA, Brody JA: Gastrostomy placement and mortality among hospitalized Medicare beneficiaries. JAMA 1998;279:1973–1976.
- Fishman DN, Levy AR, Gifford DR, Damblyn R: Survival after percutaneous endoscopic gastrostomy among older residents of Quebec. J Am Geriatr Soc 1999;47:349–353.
- Wolfsen HC, Kozarek RA, Ball TJ, Patterson DJ, Botoman VA, Ryan JA: Long-term survival in patients undergoing percutaneous endoscopic gastrostomy and jejunostomy. Am J Gastroenterol 1990;85:1120–1122.
- Kaw M, Sekas G: Long-term follow-up of consequences of percutaneous endoscopic gastrostomy (PEG) tubes in nursing homes patients. Dig Dis Sci 1994;39:738–743.
- Mitchell SL, Tetroe JM: Survival after percutaneous endoscopic gastrostomy placement in older persons. J Gerontol A Biol Sci Med Sci 2000;55:M735–739.
- Carey TS, Hanson LC, Garrett JM, Lewis C, Pfifer N, Cox CE, Jackman A: Expectations and outcomes of gastric feeding tubes. Am J Med 2006;119:527.e11–16.
- Meier DE, Ahronheim JC, Morris J, Baskin-Lyons S, Morrison RS: High short-term mortality in hospitalized patients with advanced dementia: Lack of benefit of tube feeding. Arch Intern Med 2001;161:594–599.
- 13. Mitchell SL, Kiely DK, Lipsitz LA: The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. Arch Intern Med 1997;157:327–332.
- Murphy LM, Lipman TO: Percutaneous endoscopic gastrostomy does not prolong survival in patients with dementia. Arch Intern Med 2003;163:1351–1353.

- 15. Mitchell SL: A 93-year-old man with advanced dementia and eating problems. JAMA 2007;298:2527–2536.
- Dennis MS, Lewis SC, Warlow C; FOOD Trial Collaborators: Effect of timing and method of tube feeding for dysphagic stroke patients (FOOD): A multi-centre randomized controlled trial. Lancet 2005;365:764–772.
- 17. Cogen R, Weinraub J: Aspiration pneumonia in nursing home patients fed via gastrostomy tubes. Am J Gastroenterol 1989;84:1509–1512.
- 18. Finucane TE, Bynum JPW: Use of tube feeding to prevent aspiration pneumonia. Lancet 1996;348:1421–1424.
- Lewis CL, Hanson LC, Golin C, Garrett JM, Cox CE, Jackman A, Phifer N, Carey TS: Surrogates' perceptions about feeding tube placement decisions. Patient Educ Counsel 2006;61:246–252.
- Von Preyss-Friedman SM, Uhlmann RF, Cain KC: Physicians' attitudes toward tube feeding chronically ill nursing home patients. J Gen Intern Med 1992;7:46–51.
- Hodges MO, Tolle SW, Stocking C, Cassel CK: Tube feeding: internists' attitudes regarding ethical obligations. Arch Intern Med 1994;154:1013–1020.
- Vitale CA, Hiner T, Ury WA, Berkman CS, Ahronheim JC: Tube feeding in advanced dementia: An exploratory survey of physician knowledge. Care Manage J 2006;7:79–85.
- Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA: Barriers to limiting the practice of feeding tube placement in advanced dementia. J Palliat Med 2003;6:885–893.
- Modi SC, Whetstone LM, Cummings DM: Influence of patient and physician characteristics on percutaneous endoscopic gastrostomy tube decision-making. J Palliat Med 2007;10:359–366.
- Weinberger M, Samsa GP, Schmader K, Greenberg SM, Carr DB, Wildman DS: Comparing proxy and patients' perceptions of patients' functional status: Results from and outpatient geriatric clinic. J Am Geriatr Soc 1992;40:585–588.
- 26. Kennedy T, Rehehr G, Rosenfield J, Roberts SW, Lingard L: Exploring the gap between knowledge and behavior: A qualitative study of clinician action following an educational intervention. Acad Med 2004;79:386–393.

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