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Decision-Making and Outcomes of Feeding Tube Insertion: A Five-State Study

Joan M. Teno, MD, MS^{*}, Susan L. Mitchell, MD, MPH[†], Sylvia K. Kuo, PhD^{*}, Pedro L. Gozalo, PhD^{*}, Ramona L. Rhodes, MD, MPH[‡], Julie C. Lima, PhD, MPH^{*}, and Vincent Mor, PhD^{*}

*Health Services, Policy, and Practice, Warren Alpert School of Medicine, Brown University, Providence, Rhode Island [†]Hebrew Senior Life Institute for Aging Research, Roslindale, Massachusetts [‡]Department of Geriatric Medicine, University of Texas Southwestern Medical Center, Dallas, Texas.

Abstract

OBJECTIVES—To examine family member's perceptions of decision-making and outcomes of feeding tubes.

DESIGN—Mortality follow-back survey. Sample weights were used to account for oversampling and survey design. A multivariate model examined the association between feeding tube use and overall quality of care rating regarding the last week of life.

SETTING—Nursing homes, hospitals, and assisted living facilities.

PARTICIPANTS—Respondents whose relative had died from dementia in five states with varying feeding tube use.

MEASUREMENTS—Respondents were asked about discussions, decision-making, and outcomes related to their loved ones' feeding problems.

RESULTS—Of 486 family members surveyed, representing 9,652 relatives dying from dementia, 10.8% reported that the decedent had a feeding tube, 17.6% made a decision not to use a feeding tube, and 71.6% reported that there was no decision about feeding tubes. Of respondents for decedents with a feeding tube, 13.7% stated that there was no discussion about feeding tube insertion, and 41.6% reported a discussion that was shorter than 15 minutes. The risks associated with feeding tube insertion were not discussed in one-third of the cases, 51.8% felt that the healthcare provider was strongly in favor of feeding tube insertion, and 12.6% felt pressured by the physician to insert a feeding tube. The decedent was often physically (25.9%) or pharmacologically restrained (29.2%). Respondents whose loved ones died with a feeding tube were less likely to report excellent end-of-life care (adjusted odds ratio = 0.42, 95% confidence interval = 0.18-0.97) than those who were not.

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Address correspondence to Joan M. Teno, Professor of Community Health and Medicine and Associate Medical Director, Home and Hospice Care of RI, 121 South Main Street, Providence, RI 02912. joan_teno@brown.edu.

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CONCLUSION—Based on the perceptions of bereaved family members, important opportunities exist to improve decision-making in feeding tube insertion.

Keywords

decision-making; outcomes; feeding tube insertion; dementia

Dementia is a leading cause of death for persons aged 65 and older and is projected to affect 16 million people in the United States by 2050.¹ Problems with eating and swallowing, aspiration pneumonia, and recurrent infections can herald the final stages of dementia.² Over an 18-month period in the trajectory of the illness, eating problems afflict 86% of persons with advanced dementia, and 38.6% of die within 6 months of developing eating problems. The majority of family members of nursing home residents with dementia will need to participate in a decisions with a healthcare provider about management of feeding problems.³

Few studies have examined decision-making in the use of feeding tubes.^{3–7} Between 2000 and 2007, the rate of feeding tube insertion in acute care hospitals declined from 7.9% to 6.2%, but there was substantial variation in hospital rate of feeding tube insertions. A survey of 421 nursing home residents found that nearly two-thirds did not want a feeding tube. One-fourth of those who wanted a feeding tube changed their minds after being informed that one risk of tube-feeding is being physically restrained.⁴ In a sample of nursing home residents in long-term care facilities in Florida, Maryland, North Carolina, and New Jersey, 82% of family members reported that a decision was made regarding the insertion of a feeding tube, with only 1.9% electing to insert a feeding tube.⁷ One study described surrogate decision-makers sampled from Ottawa and Boston nursing homes and found that nearly half did not understand the risks of feeding tubes.⁸ The study further found that the surrogate decision-makers' two most common reasons for feeding tube insertion were prolonging life and prevention of aspiration pneumonia, yet the best available evidence suggests that insertion of feeding tubes is not associated with longer survival, prevention of aspiration pneumonia, healing of pressure ulcers, or better quality of life.^{9,10}

The incidence rate of percutaneous endoscopic gastrostomy tube insertion is 53.6 per 1,000 nursing home residents with advanced dementia; the majority of these insertions occur during an acute care hospitalization.¹¹ There is substantial variation in surgical placement of feeding tubes, with 12% of U.S. hospitals not inserting any feeding tubes over an 8-year period and some hospitals inserting feeding tubes in one in three people with advanced cognitive impairment admitted to that hospital.¹² No study has examined the feeding tube decision-making process in regions of the United States with varying feeding tube use.

The current study sought to characterize feeding tube decision-making based on interviews with family members of people with dementia who had died. The goal was to examine how often tube feeding is discussed, whether a decision was made, the quality of that discussion based on the perceptions of the family member, whether they were informed of risks and benefits and received enough information, and the outcomes of feeding tube insertion.

METHODS

A mortality follow-back survey was conducted. Potential respondents were the next-of-kin listed as the contact on the death certificates for decedents whose recorded cause of death was dementia. Death certificates from 2006/07 were sampled, with the interview conducted on average 23.8 months after the nursing home resident's death. States were sampled based on the following criteria: prevalence of feeding tube use, inclusion of different geographic

regions, variety of minority representation, and lack of restriction in access to death certificates for research purposes. Based on previous work,¹¹ states were purposely sampled based on the prevalence of feeding tubes in nursing homes. Two states were selected for their lower rates (MN and MA), and three were selected for having higher feeding tube prevalence (AL, FL, TX). In Texas and Florida, only hospital referral regions with the highest rates of feeding tube prevalence were sampled.

Family members were interviewed only if they stated that they were the person who knew the decedent best and that they were or would have been involved in medical decisionmaking. To qualify for this survey, the family member reported that a feeding tube was inserted, a decision was made not to insert a feeding tube, or the family member reported at least one of three risk factors: an eating problem that resulted in the patient not taking enough nourishment, choking on food, and visible weight loss from not eating enough food.

A total of 1,111 death certificates were sampled. Four hundred fifty cases were excluded because the next-of-kin could not be contacted (n = 277), the next-of-kin was ineligible because they could not communicate in English or Spanish (n = 50), or the next-of-kin stated that the decedent did not need assistance in eating (n = 64) or did not have at least one of the risk factors noted above (n = 59). Of the remaining 661 next-of-kin, 486 (73.5%) agreed to participate in the survey. The survey was conducted by telephone and took on average of 39.1 ± 20.6 minutes.

The survey asked about feeding tube decision-making, the outcomes of feeding tubes, and bereaved family members' perceptions of the quality of end-of-life care. Decision-making regarding feeding tube insertion was based on modified questions from a previously developed survey of feeding tube decision-making⁸ and from the Toolkit of Instruments to Measure End of Life Care.¹³ The outcomes of feeding tube insertion focused on whether the feeding tube bothered the patient, whether physical and pharmacological restraints were used, whether artificial feedings stopped without any other nourishment or fluids, the family members were asked how long the patient survived after feedings were stopped and about the family's distress in the patient's last days of life. For the purpose of this analysis, a single item was used to examine the quality of end-of-life care that asked the respondent to rate the overall quality of care (excellent, very good, good, fair, and poor.

Analytical Approach

The frequency of decisions, quality of decision-making, and outcome of feeding tube insertions are described. Analyses were weighted to account for the oversampling of minorities and nonresponse bias. To examine whether respondents of dementia decedents with a feeding tube reported higher ratings of quality of care, a multivariate logistic model used the weighted data to examine this association after adjustments for age, sex, race, education, use of hospice services, and nursing home organizational characteristics (whether the nursing home was hospital based, had an Alzheimer's unit or special dementia unit, and had disproportionate share of Medicaid patients). Analyses were completed in Stata 10.0 (Stata Corp, College Station, TX).

RESULTS

Patient and Respondent Demographics

The final study cohort represented 9,652 deaths from dementia in the five states. All percentages in this manuscript refer to analyses completed with weighted data that account for the sampling design and nonresponse. Decedents' mean age was 87.9, 71.5% were female, and 85.7% were white (black, 6.3%; Hispanic, 5.6%). As shown in the first column

of Table 1, the majority had more than one of the risk factors that were used to determine whether the decedent had experienced signs and symptoms suggesting an eating problem. A total of 76.4% of decedents died in a nursing home, and 15.6% died in a hospital. The respondent was the child of the decedent in 66.6% of the cases.

Rate of Feeding Tube Insertion, Decisions, and Communication

Nearly 11% of decedents with dementia had a feeding tube inserted; 30.3% family members stated that there was a discussion about how to manage the eating problem, a decision made to forgo a feeding tube, or both. Thus, for 58.9% of decedents, there was no discussion about managing eating problems between family members and a healthcare provider. Table 1 characterizes the association between sociodemographic factors and each of these categories. Decedents who had a feeding tube were more likely to be black or Hispanic. Massachusetts had the highest rate of discussions and decisions to forgo feeding tubes, and Texas had the highest rate of feeding tubes. Massachusetts and Minnesota had low rates of feeding tubes. Unlike Massachusetts, Minnesota had a low rate of decisions and discussions to forgo feeding tubes. Residents with a feeding tube were more likely to die in a hospital and less likely to rate the quality of end-of-life care as excellent.

For decedents who had a feeding tube insertion or a decision made not to insert a feeding tube, the healthcare provider who participated in the discussion, the amount of time spent on the discussion before the decision, and the quality of the discussion are described (Table 2). For decedents with a feeding tube, 13.7% of the respondents stated that there was no discussion with a healthcare provider before the insertion of that feeding tube. For those without discussion, 91.1% of respondents believed that a discussion should have occurred. The primary care physician was involved in discussions in only approximately one-third of the cases in both groups.

Of respondents who had a discussion about feeding tube insertion, 41.6% reported that the conversation lasted less than 15 minutes. Discussion of the risks of feeding tube insertion occurred in 49.7% of the cases. The option of hand-feeding was not discussed in nearly one-third of the cases. A physician was "strongly in favor" of inserting a feeding tube in 38.2% of the cases, with 11.1% of respondents stating that the physician pressured them to put in a feeding tube. The religious beliefs of the decedent and family played a role in the feeding tube decision in 13.6% of cases in which a feeding tube was inserted. One-quarter of persons (25.7%) stated that a feeding tube was inserted to make it easier for staff to feed the patient.

Outcomes of Feeding Tube Insertion

Respondents reported important adverse outcomes of feeding tube insertion (Table 3). Onequarter (25.9%) of decedents with a feeding tube were physically restrained. Medications to calm patients to prevent them from pulling out the tube were used in 29.2% of the cases, and 39.8% of respondents stated that the feeding tube seemed to bother the patient. Only 32.9% of the respondents believed the feeding tube improved the patent's quality of life, and 23.4% stated that they regretted the decision to insert the feeding tube. After multivariate adjustment, family members whose loved one died with a feeding tube were less likely to state that the quality of end-of-life care was excellent in the last week of life (adjusted odds ratio = 0.42, 95% confidence interval = 0.18–0.97). At the time of death, 38.5% of the feeding tubes had been stopped or withdrawn, with death occurring within 1 week in 66.3% of these cases. One-quarter of respondents (25.5%) stated that they were distressed during this period.

DISCUSSION

Multiple studies report variation in feeding tube insertions according to state, nursing home, or hospital.^{11,14,15} Such variation is ethically defensible if it is based on decision-making that elicits and respects patient's choice. Based on interviews with bereaved family members, the current study presents important concerns about feeding tube decision-making. The majority of such decisions are made in an acute care hospital, with nursing homes playing a limited role in the decision. For those with a feeding tube insertion, 13.7% of the family reported no discussion with a health-care provider before the feeding tube insertion. More than one in 10 felt pressured by the physician to put in a feeding tube. Approximately one in three family members reported that the risks of feeding tubes were not discussed, yet family members reported important risks, including that the tube bothered 39% of the nursing home residents with a feeding tube inserted and that approximately one in three were physically or pharmacologically restrained. These results suggest a process of communication that falls short of the goals of shared decision-making. Ensuring that patient preferences are elicited and respected is an important target for improving the quality of care of persons with advanced dementia.

Few studies have characterized the decision-making process regarding feeding tube insertion.^{3,6,7,16,17} Similar to a previous study in two hospitals with a high rate of feeding tube use,⁷ the results of the current study suggest that physicians play an important role in feeding tube decision-making. Nearly 40% of the surveyed family members reported that a physician was strongly in favor of a feeding tube, with 11.1% reporting feeling pressured by the physician to insert a feeding tube. In 2000, it was reported that 26.1% of Canadian decision-makers and 10.4% of U.S. decision-makers of tube-fed patients with dementia did not discuss feeding tube insertion.¹⁸ The current study, conducted nearly a decade later, shows that this lack of communication has persisted, given that 13.7% did not have a discussion and that approximately one in three persons reported that the risks of feeding tube insertion were not explained to them.

An important finding of this research is that there are important risks to feeding tube insertion that previous research had not adequately quantified. More than one-third of people with dementia with a feeding tube were physically or pharmacologically restrained to prevent the patient from pulling out the tube. Two small studies reported the use of restraints in persons with a feeding tube,^{19,20} with a study of nursing home residents in Singapore finding that a feeding tube was the reason given for restraint use in one in five nursing home residents. Another study found that 44% of persons with a feeding tube developed agitation in the ensuing 11 months.²¹ Some family members perceived benefits of feeding tubes. Nearly one-third of the families believed the feeding tube improved the quality of life, and only 23.4% regretted the decision to put in a feeding tube.

The two states with the lowest rate of feeding tube use have different patterns regarding discussion and decisions made to forgo feeding tubes. Massachusetts had the highest rate of discussions and explicit decisions made to forgo feeding tubes, whereas Minnesota, which had an equally low rate of feeding tube use, had substantially fewer discussions and decisions, yet in both states, family members reported similarly higher ratings of the quality of end-of-life care. These results deserve further research and may reflect physicians who believe that the standard of medical care should be to not offer (and therefore not discuss) a feeding tube, given the existing observational data that suggest limited benefits of inserting feeding tubes in persons with advanced dementia.²²

One in three family members believed that the feeding tube improved the quality of life. Nearly 14% stated that their religious beliefs influenced the decision to insert a feeding tube.

Further qualitative research is needed to better understand this finding, as well as the finding that only about one in four regretted the feeding tube decision.

There are important limitations to this research. First, the results reflect the perception of family members whose perceptions may be an inaccurate recall of events or level of nursing home resident level of distress. Additionally, these perceptions may have changed over time. Second, decision-making was studied in only five states. Furthermore, it was not possible to locate 277 family members, and 70.8% of the contacted respondents agreed to participate in the survey. Third, the case-finding depended on the accuracy of physician completion of the death certificate. A previous study has found that physicians often fail to report dementia as the cause of death.²³ Thus, the current study could be underestimating the true rate of concerns with decision-making, because the data would be biased toward including only cases in which the physician recognized that dementia was a terminal condition. Fourth, the analyses of the sociodemographic association with feeding tube insertion are subject to type II error based on small sample size. Despite these limitations, this work is the first multistate study to examine feeding tube decision-making for persons with advanced dementia based on interviews with family members.

CONCLUSION

The current public policy debate regarding healthcare reform focuses on the examination of the validity and meaning of striking variations in healthcare utilization. Several studies have found significant variation in the use of feeding tubes. The current results suggest that there are important opportunities to improve the decision-making process, in that family members reported not being informed of the risks of feeding tube insertion and that nearly 14% felt coerced by a physician to insert a feeding tube. Furthermore, there are important long-term risks of feeding tubes, with nearly 40% of tube fed people being physically or pharmacologically restrained. Based on these findings, there is need for improving decision-making in the use of feeding tubes in persons with dementia.

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Table 1

Characteristics of Decedents and Respondents According to Feeding Tube Decision-Making Status

Characteristic	Total	Feeding Tube Inserted	Decision Made for No Feeding Tube	Discussion but No Decision	No Discussion
Sample size, n/weighted N	486/9,652	59/1,038	82/1,701	62/1,227	283/5,686
Age, mean (95% CI)	87.9	85.3 (83.9–86.6)	86.4 (84.9–87.9)	87.9 (86.4–89.5)	89.0 (88.2–89.8)
Decedent female, % (95% CI)	71.5	80.4 (65.6–89.8)	67.0 (54.3–77.6)	78.6 (65.8–87.5)	70.0 (63.5–75.2)
Race or ethnicity, % (95% CI)					
White	85.7	72.0 (58.7–82.4)	86.9 (78.4–92.4)	91.1 (82.4–95.7)	86.7 (83.1–89.5)
Black	6.3	10.3 (5.7–17.9)	2.2 (1.0-4.9)	4.8 (2.0–11.1)	7.2 (5.8–8.8)
Hispanic	5.6	12.0 (4.9–26.6)	6.6 (3.0–13.8)	3.3 (0.8–13.0)	4.6 (2.8–7.6)
Other	2.4	5.7 (2.1–14.2)	4.2 (1.4–12.3)	0.8 (0.01–12.3)	1.6 (0.005–0.05)
Relationship of respondent to decedent, % (95% CI)					
Spouse	8.4	7.4 (3.2–16.0)	9.1 (4.4–17.7)	6.3 (2.7–13.7)	8.8 (6.0–12.7)
Child	66.6	69.1 (56.2–79.6)	66.6 (55.0–76.5)	75.4 (63.2–84.5)	64.3 (58.3–69.8)
Sibling	3.5	5.1 (1.6–15.3)	1.4 (0.2–9.0)	0.0	4.6 (2.5–8.1)
Other	21.5	18.4 (10.5–30.1)	22.9 (14.6-34.0)	18.4 (10.4–30.3)	22.4 (17.8–27.7)
Respondent education, % (95% CI)					
≤8th grade	1.1	0.0	0.0	1.9 (0.4–7.6)	1.5 (0.6–3.7)
Some high school	3.0	2.3 (0.7–7.3)	5.6 (2.3–12.9)	3.4 (1.0–11.1)	2.3 (1.2–4.5)
High school graduate	23.2	23.4 (14.2–36.1)	23.8 (15.2–35.4)	13.4 (7.1–24.0)	25.0 (20.1–30.7)
Technical school	4.9	7.4 (2.9–17.8)	4.1 (1.3–11.7)	1.0 (0.2–6.2)	5.6 (3.4–22.9)
1–3 years college	25.2	25.2 (15.5–38.3)	25.6 (16.9–36.7)	32.3 (21.7–45.1)	23.6 (19.0–29.0)
4 year college graduate	17.2	14.2 (6.4–28.8)	15.8 (9.7–24.7)	20.4 (12.0–36.0)	17.5 (13.2–22.9)
>4 year degree	24.7	22.7 (13.3–35.9)	25.1 (15.9–37.3)	27.7 (17.3–41.1)	24.3 (19.4–20.1)
Respondent female, % (95% CI)	66.6	61.6 (47.9–73.7)	64.8 (53.1–74.5)	61.6 (48.5–73.3)	69.2 (63.2–74.6)
Patient had eating problem where there was concern about nutrition, % (95% CI)	78.3	76.1 (61.2–86.5)	78.3 (67.7–86.1)	89.2 (79.1–94.7)	76.3 (70.7–81.1)
Patient choking on food, % (95% CI)	36.1	33.9 (22.8–47.2)	42.6 (31.6–54.4)	58.2 (45.4–70.1)	29.7 (24.3–35.7)
Patient with visible weight loss from not eating enough food, % (95% CI)	0.69	56.6 (42.8–69.3)	74.1 (63.0–82.7)	67.5 (54.4–78.4)	70.0 (64.2–75.2)
State, % (95% CI)					
Minnesota	19.8	3.5 (0.9–12.5)	14.7 (8.5–24.2)	13.5 (6.7–25.5)	25.7 (21.1–30.8)

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Characteristic	Total	Feeding Tube Inserted	Feeding Tube Inserted Decision Made for No Feeding Discussion but No Decision No Discussion Tube	Discussion but No Decision	No Discussion
Massachusetts	23.0	2.4 (0.4–14.0)	34.3 (24.0–46.3)	37.4 (26.1–50.4)	20.2 (15.8–25.5)
Alabama	12.6	12.3 (7.3–20.0)	11.2 (6.9–17.7)	20.5 (13.5–30.0)	11.3 (8.8–14.4)
Texas	30.7	62.6 (50.2–73.6)	23.7 (15.2–34.9)	24.9 (15.3–37.7)	28.2 (23.5–33.5)
Florida	13.9	19.2 (11.9–29.5)	16.2 (10.8–23.6)	3.6 (1.4–9.1)	14.6 (11.6–18.1)
Site of death, % (95% CI)					
Hospital	15.6	39.2 (26.8–53.3)	13.3 (7.8–21.9)	6.2 (2.4–14.9)	14.0 (10.4–18.6)
Nursing home	76.4	55.5 (41.7–68.5)	82.2 (73.3–88.5)	91.6 (81.9–96.4)	75.2 (69.8–79.8)
Assisted living	4.5	2.3 (0.04–12.9)	3.0 (1.2–7.4)	0.0	6.4 (4.2–9.6)
In-patient hospice	3.5	3.0 (0.5–16.3)	1.5 (0.4–5.3)	2.2 (0.4–12.5)	4.5 (2.4–8.0)
Quality of end of life care excellent, % (95% CI)	43.7	28.4 (16.8–43.7)	40.0 (29.4–51.6)	52.2 (39.5–64.5)	45.7 (39.6–52.0)

CI = confidence interval.

Table 2

Perceptions of Family Members of Decision-Making Process Regarding Feeding Tube Placement

Outcome	Feeding Tube Inserted	Decision Made For No Feeding Tube
Sample size, n/weighted N	59/1,038	82/1,701
Doctor or healthcare provider who spent most time talking about feeding tube decision, % (95% CI)		
Primary care doctor	32.7 (20.8–47.5)	30.8 (21.0-42.8)
Another doctor or consultant	30.8 (20.4–43.7)	9.9 (5.4–17.5)
Another healthcare provider	13.7 (6.7–27.9)	17.3 (9.8–28.5)
Did not discuss	13.7 (6.4–26.8)	41.3 (30.5–52.9)
Time spent discussing feeding tube, % (95% CI)		
No discussion	13.7 (6.4–26.8)	41.3 (20.5–52.9)
<5 minutes	7.6 (2.1–24.0)	7.5 (3.1–17.3)
5–15 minutes	34.0 (22.5–47.8)	16.1 (9.0–27.2)
16 minutes-1 hour	25.6 (15.8–38.6)	20.9 (13.2–31.3)
>1 hour	10.8 (5.1–21.5)	11.5 (5.6–22.3)
Explanation of risks to placing feeding tube, % (95% CI)		
Yes	49.7 (36.4–63.1)	45.5 (34.2–57.2)
No or did not discuss	39.3 (26.7–53.5)	50.8 (39.3-62.2)
Explanation of benefits to placing feeding tube, % (95% CI)		
Yes	60.3 (46.2–72.9)	50.4 (39.0-61.8)
No or not discuss	28.4 (17.3–42.8)	47.2 (35.9–58.7)
Information received on risks and benefits of feeding tube, % (95% CI)		
Less than wanted	14.4 (6.6–28.4)	3.9 (1.2–10.9)
Just the right amount	58.1 (44.2–70.8)	45.0 (33.9–56.7)
More than wanted	2.5 (0.7-8.8)	9.2 (3.9–20.2)
Did not discuss	13.7 (6.4–26.8)	41.3 (30.5–52.9)
Explanation of option of hand feeding as long as patient was comfortable, % (95% CI)		
Yes	22.6 (13.3–35.6)	40.1 (29.4–51.9)
No or did not discuss	30.9 (19.2–45.8)	51.8 (40.3-63.0)
Hand feeding not an option	38.2 (26.3–51.7)	4.6 (1.8–11.1)
Doctor's feeling regarding placement of feeding tube, % (95% CI)		
Strongly against	2.3 (0.4–12.8)	6.4 (2.6–14.8)
Somewhat against	9.4 (3.7–21.9)	13.4 (7.0–23.9)
Neither for or against	15.1 (7.9–27.0)	20.9 (12.9-32.0)
Somewhat in favor of	8.7 (4.3–16.9)	5.3 (2.1–12.5)
Strongly in favor of	38.2 (25.6–52.5)	1.4 (.5–4.2)
Did not discuss with physician	13.7 (6.4–23.4)	41.3 (36.5–52.9)
Decision on use of feeding tube not made free of pressure from physicians or healthcare providers, % (95% CI)	11.2 (5.6–23.4)	1.0 (0.2–6.0)
Religious beliefs play important role whether or not to insert feeding tube, % (95% CI)	13.6 (7.3–23.8)	19.0 (11.2–30.4)

CI = confidence interval.

Table 3

Risks, Benefits, and Regret Regarding Feeding Tube Insertion

Outcome	Value
Benefits	
Feeding tube improve quality of life	32.9
Risks	
Patient seemed bothered by feeding tube	39.8
Patients hands or upper body tied down to prevent them from pulling at feeding tube	25.9
Patient given medications to calm them down to prevent from pulling at feeding tube	29.2
Patient given medication or tied down to prevent them from pulling at feeding tube	34.9
Patient sent to emergency department of hospital because of problem with feeding tube	26.8
Best captures feelings regarding decision-making on use of feeding tube	
Regret	23.4
Right decision	61.9