Percutaneous Feeding Tubes in Individuals with Advanced Dementia: Are Physicians "Choosing Wisely"?

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OBJECTIVES: To evaluate physician knowledge and perceptions about the American Board of Internal Medicine/American Geriatrics Society (ABIM/AGS) *Choosing Wisely* recommendations regarding percutaneous endoscopic gastrostomy (PEG) in individuals with advanced dementia.

DESIGN: Multicenter, mixed-mode, anonymous questionnaire.

SETTING: Three tertiary and four community hospitals in New York.

PARTICIPANTS: Internal medicine physicians (N = 168).

MEASUREMENTS: Physician knowledge and perceptions regarding PEG tubes in individuals with advanced dementia.

RESULTS: Ninety-nine percent of physicians reported having cared for someone with advanced dementia; 95% had been involved in the PEG decision-making process; 38% were unsure whether the ABIM/AGS *Choosing Wisely* recommendations advise for or against PEG tubes in advanced dementia. Physicians who agreed that there is enough evidence to recommend against PEG placement for individuals with advanced dementia were more likely to know the ABIM/AGS *Choosing Wisely* recommendations (71% vs 28%, $P < .001$). Fifty-two percent felt in control of the PEG placement decision, and 27% expressed concerns about potential litigation. The most common factor influencing physicians was patient or decision-maker request (70%); 63% stated that families request PEG placement even when physician would not recommend it. Only 4% of the physicians would choose to have a PEG tube if they had advanced dementia.

CONCLUSION: Despite the scientific evidence supporting the ABIM/AGS *Choosing Wisely* recommendations against the use of PEG tubes in individuals with advanced dementia, numerous incentives for placement complicate the decision for PEG placement. In today's healthcare environment, it is incumbent upon healthcare practitioners to be aware of the available evidence and to provide leadership to guide this complex decision-making process to promote true person-centered care. **J Am Geriatr Soc 66:64–69, 2018.**

Key words: percutaneous endoscopic gastrostomy; physician knowledge and perceptions; ABIM/AGS *Choosing Wisely* recommendations

Gauderer, a pediatric surgeon, initially developed the percutaneous endoscopic gastrostomy (PEG) procedure as a means of establishing a route for enteral alimentation while avoiding the risks of a formal laparotomy in select babies unable to swallow.[1,2] The procedure was first performed in 1979 on a 4.5-month-old child with bronchopulmonary dysplasia who had been born prematurely.[3] The technique was then successfully adapted for neurologically impaired adults.[4] PEG tube use has since expanded to individuals with various conditions affecting oral intake such as oropharyngeal cancer, stroke, amyotrophic lateral sclerosis, and Parkinson's disease.[5–8] It has also become commonly used in individuals with advanced dementia when the natural and irreversible progression of the disease leads to suboptimal nutritional intake.[9–14]

By 2003, more than one-third of residents with severe cognitive impairment in U.S. nursing homes were reported to have feeding tubes.[15] One recent study reported that the national rate of feeding tube use in individuals with advanced dementia declined between 2000 and 2014, previous studies showed rates from 5.7% to 35%, and overall tube feeding in this population is still common.[10,11,16]

The decision for PEG placement in individuals with advanced dementia is a complex process involving knowledge, perceptions, emotions, and expectations of physicians, the individuals with dementia, and surrogate decision-makers. One study found lower tube-feeding rates

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in nursing homes where physicians are cognizant that PEG tubes have no effect on nutritional status or pressure ulcer healing and perceive dementia to be a terminal illness.[17] A separate study conducted in the nursing home setting reported that approximately half of physicians had a request for PEG tube placement, leading them to recommend PEG.[18]

Some individuals, surrogate decision-makers, and doctors believe that PEG placement improves overall survival and quality of life.[18–21] A 2003 study reported that physicians believed that PEG tubes in advanced dementia improve aspiration pneumonia, pressure ulcer healing, survival, and nutritional and functional status.[18] Furthermore, physicians commonly underestimate 30-day mortality in individuals with advanced dementia undergoing PEG placement and have been shown to believe placement to be the standard of care.[18]

One study described several factors that appear to influence physician decisions regarding PEG tube use, including "abhorrence of death by 'starvation'; cultural values that promote family-oriented end-of-life decision making; and reimbursement-related factors involved in the choice of PEG."[22]

PEG in individuals with advanced dementia is associated with several serious complications—including in-hospital mortality, recurrent aspiration pneumonia, worsening pressure ulcers, and overall poor survival.[7,13,23–31] Overall, research has failed to show that PEG placement in individuals with advanced dementia fulfills physicians' and families' perceived goals and expectations.[9,13,14,20,21,23–27,29–36] Thirty-day mortality for individuals with advanced dementia who receive a PEG tube ranges from 20% to 54%, with 1-year mortality reaching 90%.[18,20,37–40] Reported 1-year postinsertion mortality was 64% in one study, with half of individuals dying within 2 months.[27] PEG in individuals with advanced dementia usually takes place during acute care hospitalization for pneumonia, dehydration, or dysphagia.[7,25,27] Research shows that individuals who receive a PEG tube during hospitalization have higher 30-day mortality than those who receive one 30 days after hospital discharge, and PEG tube insertion in itself is associated with higher odds of in-hospital mortality.[7,25] Several studies have reported on physicians' poor or lack of communication with individuals and their surrogate decision-makers about procedures such as PEG tube placement.[16,41,42]

Beyond morbidity and mortality outcomes, the cost implications of PEG placement are thought provoking. Research shows that tube-fed nursing home residents yield a higher reimbursement rate from Medicaid while reducing actual expenses incurred by the nursing home.[43] A study comparing the cost of tube-feeding with that of hand-feeding in nursing home residents with advanced dementia found that that the daily costs of hand-fed individuals were significantly higher ($4,219 vs $2,379), whereas total costs to Medicare were greater for the tube-fed residents ($6,994 vs $959).[43]

With "a goal of advancing a national dialogue and avoiding wasteful or unnecessary medical tests, treatments and procedures," the American Board of Internal Medicine (ABIM) Foundation launched the *Choosing Wisely* campaign in 2012.[44] As part of the initiative, the American Geriatrics Society (AGS) released an evidence-based recommendation in 2013 stating, "Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral assisted feeding."[44–45] Despite evidence that "careful hand feeding for patients with severe dementia is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort," PEG tubes are still commonly offered, requested, and used in this population.[13,26]

METHODS

We conducted an anonymous mixed-mode survey using the tailored design method (TDM)[46] in three tertiary care hospitals and four community hospitals in the New York metropolitan area during November 2016 after receiving institutional review board approval. Given the documented low response rates for physician surveys, we used a TDM approach consisting of providing respondents with mixed-mode surveys (paper and online), designing the questionnaires to be brief and personalized, and indicating the sponsor of the study to legitimize the objectives of the research.[46,47] These TDM strategies have been shown to increase response rates of physicians.[46,47] In the absence of validated PEG questionnaires, the survey was developed based on a comprehensive literature review and iterative item modifications based on subject matter expert (geriatricians, psychologists, psychometricians) agreement. Subject matter experts assessed the survey for appearance, relevance, and representativeness of the items, ensuring face and content validity. After subject matter expert review and pilot testing, the survey consisted of 36 items in four main categories: level of involvement in care of individuals with advanced dementia, perceptions about PEG tube placement in individuals with advanced dementia, knowledge about the ABIM/AGS *Choosing Wisely* recommendations, and respondent demographic characteristics.

The survey included 12 questions designed to assess respondents' knowledge of the ABIM/AGS recommendations. This assessment consisted of 12 true-false statements. For each question, respondents were offered the choice of true, false, or not sure. A response of "not sure" was considered an incorrect response, and a nonresponse was not considered correct or incorrect. The percentage answered correctly was calculated for all physicians who answered at least 10 of the 12 questions.

Paper surveys were distributed during medical grand rounds, and emailed surveys were sent to medicine physicians and medicine subspecialists; the combined response rate was 17%. The Mann-Whitney test was used to compare groups according to continuous dependent variables. The Kruskal-Wallis test was used for comparisons in which the variable of interest had three levels. Upon finding a significant difference, pairwise comparisons were made using the Mann–Whitney test using a Bonferroni adjustment such that $P < .0167$ was considered significant (0.05/3). Categorical variables were compared using the chi-square test or Fisher exact test, as appropriate.

RESULTS

Of the 168 surveys received, attending physicians completed 56%, residents 34%, and fellows 8%; 76% of the physicians practiced primarily in a hospital setting

Table 1. Respondent Demographic Characteristics

Characteristic	Value
Survey type, n (%)	
Paper	119 (71)
On-line	49 (29)
Profession, n (%)	
Attending physician	82 (56)
Resident physician	50 (34)
Fellow	11 (8)
Nurse practitioner, other	3 (2)
Age, median (interquartile range)	35 (29–49)
Sex n (%)	
Male	82 (56)
Female	64 (44)
Ethnicity, n (%)	
Hispanic	12 (8)
Not Hispanic	132 (92)
Race, n (%)	
American Indian or Alaskan Native	2 (1)
Asian	48 (34)
Black	7 (5)
White	83 (59)
Religious affiliation, n (%)	
Atheist	8 (6)
Agnostic	13 (9)
Catholic	34 (24)
Jewish	35 (25)
Muslim	12 (9)
Protestant	8 (6)
Other	30 (21)
Experience, years, n (%)	
0–5	86 (59)
6–10	13 (9)
11–15	9 (6)
16–20	8 (5)
>20	30 (21)
Primary practice setting, n (%)	
Hospital	111 (76)
Outpatient	27 (18)
Other	9 (7)

(Table 1). The median age was 35, and 44% of the physicians were female. Ninety-nine percent of the physicians stated that they had cared for individuals with advanced dementia (with 76% reporting frequency as often or very often), and 95% reported being involved in PEG decision-making for those individuals. Of the responding physicians, 20% "had a personal experience with someone who had a [PEG] tube outside of [their] work."

Knowledge

Thirty-eight percent of physicians were not sure whether the ABIM/AGS recommendation is for or against PEG tubes in individuals with advanced dementia, and 6% believed that ABIM/AGS recommends PEG tube placement in this population.

With regard to complications, 85% knew that PEG placement does not reduce the risk of aspiration pneumonia, 81% that it does not increase survival, 61% that it does not improve pressure ulcer healing, and 49% that it does not improve nutritional status. When comparing careful hand feeding of individuals with severe dementia with tube feeding, most physicians reported that careful hand feeding is at least as good as tube feeding for the outcomes of comfort (71%), functional status (61%), death (60%), and aspiration pneumonia (58%).

There was a difference in knowledge assessment scores between attending physicians (median 75% correct), fellows (75% correct), and residents (50% correct) ($P < .001$). Pairwise comparisons showed a significant difference in scores between attending and resident physicians, but fellows did not differ significantly from either group. For residents, there was a significant difference according to postgraduate year (PGY) level ($P = .005$), with senior residents (PGY-3) scoring 67% correct, junior residents (PGY-2) 50% correct, and interns (PGY-1) 42% correct. Pairwise comparisons found a significant difference between PGY-1 and PGY-3, but PGY-2 did not differ significantly from either group. Attending physicians and fellows who reported a specialty in geriatric or palliative care scored significantly higher on the knowledge assessment than those without those specialties (median 92% vs 75%; $P = .01$).

Physicians who agreed that "there is enough evidence to recommend against [PEG] placement for individuals with advanced dementia" were more likely to know the ABIM/AGS *Choosing Wisely* recommendation (71% vs 28%, $P < .001$) and scored significantly higher on the knowledge assessment questions than those who did not agree (median correct 80% vs 42%, $P < .001$ (Table 2).

Physicians who correctly answered that the ABIM/AGS *Choosing Wisely* does not advise "recommending percutaneous feeding tubes in patients with advanced dementia instead of offering oral assisted feeding" were

Table 2. Physician Characteristics and American Board of Internal Medicine/American Geriatrics Society *Choosing Wisely* Recommendations Knowledge Assessment Scores

Variable	N[a]	Median (Interquartile Range)	P-Value
Profession			
Attending	81	75 (50–92)	<.001[b]
Fellow	11	75 (58–92)	
Resident	48	50 (33–67)	
PGY of resident physicians			
1	13	42 (18,50)	.005[c]
2	12	50 (33–67)	
3	18	67 (50–83)	
Specialty of attending physicians and fellows			
Geriatric or palliative	12	92 (79–92)	.01
Other or none	55	75 (42–83)	
"There is enough evidence to recommend against [PEG] placement for individuals with advanced dementia."			
Agree, strongly agree	98	80 (58–92)	<.001
Strongly disagree, disagree, neutral	49	42 (17–64)	

[a]Sample sizes vary because of nonresponse.

[b]Results of pairwise comparisons: attending physicians vs fellows, $P = .81$; attending vs resident physicians, $P < .001$; fellows vs resident physicians, $P = .03$.

[c]Results of pairwise comparisons: postgraduate year (PGY) 1 vs PGY 2, $P = .26$; PGY 1 vs PGY 3, $P = .001$; PGY 2 vs PGY 3, $P = .10$.

older than those who answered incorrectly (median age 36 vs 32; $P = .02$). Attending physicians were more likely to know the ABIM/AGS recommendation (71%) than fellows (55%) and residents (33%) ($P < .001$). Among residents, there was no association between PGY and the correct response to this question. Forty-seven percent of PGY-3 residents answered correctly, 25% of PGY-2 residents, and 21% of PGY-1 residents ($P = .30$). The sex of the physician was not associated with knowledge of the ABIM/AGS recommendation ($P = .09$).

Physicians who agreed that "there is enough evidence to recommend against [PEG] placement for patients with advanced dementia" were also more likely to be familiar with knowledge of the implications of PEG placement, including that it does not reduce aspiration pneumonia (96% vs 66%, $P < .001$), increase survival (95% vs 54%, $P < .001$), improve pressure ulcer healing (70% vs 41%, $P < .001$), improve nutritional status (60% vs 28%, $P < .001$), or improve functional status (94% vs 75%, $P = .002$); they were also less likely to be "concerned about legal barriers with regard to limiting treatment" if they did not offer PEG (56% vs 36%, $P = .01$).

Physicians who agreed that "there is enough evidence to recommend against [PEG] placement for patients with advanced dementia" were also more likely to agree that PEG placement decreases overall quality of life (56% vs 16%, $P < .001$) and that "careful hand-feeding of patients with severe dementia is at least as good as tube-feeding for the outcomes of" death (76% vs 29%, $P < .001$), aspiration pneumonia (70% vs 36%, $P < .001$), functional status (70% vs 45%, $P = .004$), and comfort (78% vs 58%, $P = .01$). Only 36% of physicians were able to accurately estimate the 30-day mortality of individuals with severe dementia who receive a PEG tube; 57% underestimated mortality or were not sure.

Perceptions

Based on their experience, 15% of physicians incorrectly stated that tube feeding was not associated with agitation, and an additional 16% were unsure; 20% reported that tube feeding was not associated with worsening pressure ulcers, and 38% were unsure.

Only 52% of physicians reported being in control of the decision to place a PEG tube in individuals with advanced dementia. Individual and decision-maker requests (70%) and prognosis (66%) were the most common factors influencing a physician's decision to place a PEG tube, followed by functional status (62%), comorbidities (62%), and cognitive status (52%); age (41%) and evidence of weight loss (19%) were less relevant (Figure 1). Sixty-three percent of physicians stated that families request that PEG tubes be placed for their family member with advanced dementia even when the physician does not recommend it. Eight-two percent of physicians reported that the decision for PEG tube placement in individuals with advanced dementia should be individualized.

Only 16% of physicians believed that the recommendations to avoid placing PEG tubes in individuals with advanced dementia are intended to reduce healthcare costs; 4% indicated cost as a factor influencing their decision about PEG tube placement. Ten percent reported that skilled nursing facility admission requirements for PEG tube placement influenced their decision to proceed. Twenty-seven percent of physicians expressed concerns about potential litigation; an additional 25% neither agreed nor disagreed as to whether they would be concerned about legal barriers with regard to offering PEG tube placement. Only 8% stated that they would feel responsible for hastening death if PEG was not offered. Physicians who were less concerned about legal barriers scored significantly higher on knowledge questions pertaining to the recommendation (75% vs 58%, $P < .001$).

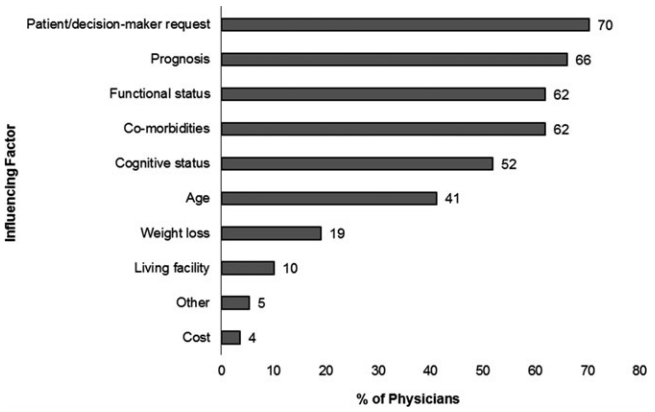

Figure 1. Factors influencing physicians' decision about percutaneous endoscopic gastrostomy tube placement in individuals with advanced dementia.

Thirty-five percent were unsure whether or disagreed that "there is enough evidence to recommend against percutaneous feeding tube placement for patients with advanced dementia." Sixty-eight percent of physicians believed that "the recommendation to avoid [PEG] tubes in patients with advanced dementia is intended to improve the quality of their end of life care," but only 42% of physicians thought that placement of a PEG tube for a individual with advanced dementia decreases overall quality of life.

Only 4% of the responding physicians would choose to have a PEG tube placed if they were to develop advanced dementia themselves.

DISCUSSION

Our study evaluated physician knowledge and perceptions regarding the use of PEG tubes in individuals with advanced dementia. Almost all physicians surveyed had personal experience caring for individuals with advanced dementia. They also reported being involved with the complex challenges of PEG decision-making for these individuals. An overwhelming majority of physicians felt that avoidance of PEG tube placement does not hasten death in individuals with advanced dementia, and almost all physicians admitted that they would not want a PEG tube if they were to develop advanced dementia themselves.

When faced with placing PEG tubes in individuals with advanced dementia, physicians were ambivalent regarding the evidence against their placement. They did not agree that PEG tube placement decreases overall quality of life and stated that the decision should still be individualized, even in individuals with advanced dementia.

Furthermore, consistent with a previous study, our results show that physicians tend to underestimate mortality after PEG tube placement.[18]

Previous studies have suggested that nonclinical factors strongly influence feeding tube decisions.[11,12,17,18,48] Although a majority of physicians in our study reported that families inappropriately request PEG tube placement in individuals with advanced dementia, regardless of their demographic background, training, and experience, physicians remain hesitant to advocate strongly against PEG tube placement and allow surrogate decision-makers and fear of litigation to drive the process. The utility of PEG tubes in older adults came into question less than a decade after first being used in this population.[9] Indeed, even Gauderer, when reflecting on 20 years of PEG use, warned against the potential risks of overuse of this simple and otherwise relatively safe procedure and urged that "we as physicians must continuously strive to demonstrate that our interventions truly benefit the patient."[4] Gauderer also stated that the goal of the intervention should be to "provide comfort and hope; to facilitate care and improve the quality of life…to return the patient to oral intake whenever possible… [and] avoid additional problems."[3] As conveyed in the ABIM/AGS *Choosing Wisely* recommendations, the routine ordering of PEG tube placement in individuals with advanced dementia has not only been shown to lack proven benefits, but also may cause pain and suffering at the end of life.[13,23,25–27,32,33]

Poor physician survey response rates generated an anticipated limitation to our study's methodology. Physicians are less likely to respond to surveys than other individuals because of lack of time.[49] Time spent on completing a survey is often tine taken away from providing care for individuals, and physicians prioritize caring for individuals over other activities. To strengthen the study design, we employed a mixed-mode survey including paper and online surveys and collected data from multiple acute care facilities, including tertiary and community hospitals. Moreover, physicians who responded may have been more likely to be caring for individuals with advanced dementia than those who did not. Medicare beneficiaries account for more than half of hospital days. Because we surveyed providers in the hospital setting, we believe that the majority of providers (those who participated in our study and those who did not) routinely take care of individuals with dementia.

Our findings support an urgent need to promulgate the evidence behind the PEG guidelines on a wider scale to better assist physicians and families during the crossroads of this challenging decision. These educational efforts should be first focused on physicians practicing in hospital settings because most PEG tube placements occur during hospitalization and result in higher mortality.[7,25,27] Further research should be conducted to explore the quality and content of discussion between the medical team, the individual with dementia, and his or her family regarding feeding difficulties and options, as well as caregiver perspectives on and motives for PEG tube placement in individuals with advanced dementia—whether emotional, financial, moral, religious, or otherwise. Almost all physicians would choose not to consent to PEG tube placement for themselves if they were to develop dysphagia with advanced dementia. Nonetheless, they struggle when it comes to the decision; the surrogate decision-maker and perhaps other factors, including the ease and availability of the procedure, time constraints for discussion and education, fear of litigation, and persistent incentives for PEG tube placement in this population, overpower the common sentiment and simple knowledge of ultimate poor outcomes.

Although programs designed to increase physician knowledge of evidence-based practice such as *Choosing Wisely* need to continue, greater support and resources are needed to promote efforts to explore surrogate decision-makers' goals and expectations for their loved ones with advanced dementia and allow time to discuss and educate surrogate decision-makers about the natural progression of dementia and the evidence-based recommendations. Although the healthcare team is largely the source of knowledge for surrogate decision-makers, other currently available resources are the ABIM/AGS *Choosing Wisely* recommendations[50] and the Alzheimer's Association.[51] There are also decision aids for caregivers that seek to improve decision-making about feeding alternatives in dementia care.[52] Although decision aids have been shown to improve decision-making about feeding options in individuals with dementia, they are not routinely used in practice.[52] Ultimately, it is not until overall incentives are aligned with the scientific evidence that significant changes to healthcare practice will occur at a national level.

CONCLUSION

Despite the scientific evidence supporting the ABIM/AGS *Choosing Wisely* recommendations against the use of PEG tubes in individuals with advanced dementia, many incentives, whether emotional, cultural, financial, legal, or directed by national and state reimbursement policies, continue to drive PEG tube placement in this population.

There is not a "one size fits all" solution to the issue of decision-making regarding PEG placement in individuals with advanced dementia. In light of the colliding currents of today's economic, social, and moral climates, the wishes of individuals with dementia, family concerns, and evidence-based guidelines must all be respectfully considered and addressed during the decision-making process. In this healthcare environment, it is incumbent upon practitioners to provide the leadership to guide this complex decision-making process to promote true person-centered care.

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