Original Article

Tube Feeding in Patients with Advanced Dementia: Knowledge and Practice of Speech-Language Pathologists

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Abstract

Context. Speech-language pathologists (SLP) are often called on to evaluate eating difficulties in patients with dementia.

Objectives. To assess factors associated with SLPs’ knowledge and recommendations about feeding tubes in patients with advanced dementia.

Methods. A mail survey was administered to a probability sample of 1500 SLPs from the American Speech-Language-Hearing Association mailing list; 731 usable surveys were received (response rate = 53.7%). Self-perceived preparedness, knowledge, and care recommendations were measured. Knowledge items were scored as “evidence based” or not according to the best evidence in the literature.

Results. Only 42.1% of SLP respondents felt moderately/well prepared to manage dysphagia. Only 22.0% of respondents recognized that tube feeding is unlikely to reduce risk of aspiration pneumonia whereas a slight majority understood that tube feeding would not likely prevent an uncomfortable death (50.2%), improve functional status (54.5%), or enhance quality of life (QOL) (63.2%). A majority (70.0%) was willing to consider recommending oral feeding despite high risk of aspiration. Logistic regression analyses indicated that those willing to consider this recommendation gave the most evidence-based responses to knowledge questions about tube feeding outcomes: aspiration pneumonia (odds ratio [OR] = 1.75, 95% confidence interval [CI] = 1.07–2.87), functional status (OR = 1.43, 95% CI = 1.0–2.06), QOL (OR = 2.19, 95% CI = 1.52–3.17), and prevent uncomfortable death (OR = 1.97, 95% CI = 1.37–2.88). Logistic regression analyses also indicated that those with more experience evaluating patients with dementia gave the most evidence-based responses to knowledge questions about tube feeding outcomes: aspiration pneumonia (OR = 2.64, 95% CI = 1.48–4.72) and prevent uncomfortable death (OR = 2.03, 95% CI = 1.35–3.05) whereas those with higher

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self-perceived preparedness in managing dysphagia in dementia had less knowledge in two areas: aspiration pneumonia (OR = 0.57, 95% CI = 0.38–0.84) and QOL (OR = 0.72, 95% CI = 0.51–1.01).

**Conclusion.** Misperceptions among SLPs about tube feeding in advanced dementia are common, especially in relation to risk of aspiration. Knowledge about tube feeding outcomes was positively associated with experience and inversely associated with self-perceived higher preparedness in evaluating patients with dementia. 

**Key Words**
End of life, advanced dementia, feeding tube, dysphagia, speech-language pathologist, enteral nutrition, ethics, artificial nutrition and hydration

**Introduction**
Despite the absence of evidence for clear benefits of feeding tubes for patients with advanced dementia and eating problems, the use of feeding tubes for the administration of artificial nutrition and hydration (ANH) remains commonplace. Feeding tube use for this purpose, however, has been called into question. The catalyst for this challenge includes emerging evidence of the failure of this intervention to improve quality or duration of life and an increased recognition of the high treatment burden associated with tube feeding, often amid efforts to shift to more comfort-focused care.

Although patients with advanced dementia and eating problems are often evaluated by interdisciplinary team members, including speech-language pathologists (SLPs), physicians are ultimately responsible for implementing an appropriate medical work-up and making treatment recommendations, including recommendations about ANH. However, in making clinical decisions about whether to use ANH, physicians often rely on the input of SLPs because of their experience, training, and perceived expertise in feeding and swallowing disorders. In one survey of primary care physicians, 70% of respondents stated that SLPs often make recommendations about feeding tubes in patients with advanced dementia and 66% stated that SLPs’ recommendations influenced their decision about feeding tube placement. Such reliance exists despite potential discrepancies between some SLP recommendations and evidence from the medical literature. For example, certain methods of dysphagia evaluation lack standardization, such as the degree of aspiration used by SLPs to determine whether oral feeding would be safe for a patient. Other methods, such as videofluoroscopic examination, might be inappropriate or misleading in patients with advanced dementia, most of whom would probably be unable to cooperate with the examination. Finally, a bedside evaluation may fail to capture the actual ability of patients to eat when fed small amounts throughout the day, and would supplement, although not replace, a comprehensive evaluation.

Input from the SLP may be more valuable if the physician has already ruled out potentially reversible causes of eating problems that do not fall within the SLP’s expertise, such as anorexia because of medical illness, and consults the SLP for conditions that do. An important example is oral dyspraxia, a progressive failure of the preparatory phase of swallowing that occurs in the late stages of neurodegenerative dementias. In such a case, benefit would be derived from the SLP’s ongoing guidance on ways to optimize assisted oral feeding. This comprehensive approach differs greatly from that applied to stroke patients, whose dysphagia may be reversible, who often can cooperate with the swallowing evaluation and may have substantial rehabilitation potential, and might benefit from ANH while recovering the ability to swallow.

A number of investigators have discussed the need for improved, evidence-based education for SLPs and other allied health care professionals involved in evaluating dysphagia. In contrast, another author, while noting gaps...
in SLP dysphagia training, has argued that SLPs cannot be expected to know the medical ramifications of treatment recommendations in patients with complex medical conditions and that perhaps physicians are inappropriately relying on them to make treatment decisions, including decisions about ANH. In addition, physicians themselves may misunderstand the limitations of tube feeding in advanced dementia. In short, the swallowing evaluation, although appropriate to diagnose conditions such as oral dyspraxia or oropharyngeal dysphagia, cannot be expected to rule out the broad array of clinical problems that could account for an acutely or chronically ill patient’s failure to eat. Furthermore, an accurate diagnosis of irreversible eating problems, whether made by an SLP, a nurse practitioner, or a physician, does not answer the medical or ethical question of whether a patient should have a feeding tube.

We have explored the question of how the SLP evaluation might influence the physician’s treatment recommendations in patients with advanced dementia and eating problems. The objectives of the study were to:

- assess the knowledge and attitudes of SLPs about dysphagia, feeding tubes, and palliative considerations in patients with advanced dementia;
- determine the nature and frequency of physician consultation requests and SLP recommendations in patients with advanced dementia and eating problems;
- identify factors associated with SLP knowledge, attitudes, and willingness to consider alternatives to tube feeding in patients with advanced dementia and eating problems.

**Methods**

**Design**

A survey of SLPs was administered by mail, eliciting knowledge and recommendations related to the care of patients with advanced dementia and concomitant dysphagia.

**Sample**

The target population was SLPs practicing in the United States who work with adults in the medical/health care field. The study population was American Speech-Language-Hearing Association (ASHA) members. A systematic random sample of 1500 eligible members from the 2006 ASHA mailing list was selected. Inclusion criteria for selection of names from the ASHA sampling frame were the following: having certification as an SLP (audiologists and students were excluded); being listed as a clinical service provider; having place of employment listed as a general medical hospital, nursing home, or home health agency; and being listed as working with patients 18 years of age and older. Although information in the ASHA database was used for sample selection, final determination of eligibility was based on responses to the questionnaire. Additional inclusion criteria based on responses to the questionnaire were 1) currently in direct practice and 2) had evaluated a patient with advanced dementia for dysphagia in the last two years. Institutional review board approval was obtained before the initiation of the study. The cover letter sent with the questionnaire included all information necessary to provide informed consent, which was indicated by mailing back a completed survey.

Selected SLPs received a cover letter, questionnaire, self-addressed stamped envelope, and self-addressed stamped postcard. Respondents were asked not to write their name or any other identifying information on the completed questionnaire or return envelope to assure their anonymity. The postcard included the recipient’s name and address and a place to indicate whether a completed questionnaire was sent to the researcher or whether the recipient preferred not to participate. A second mailing was sent to those for whom a postcard was not received. Respondents who sent back a postcard stating that they had returned a questionnaire were entered into a raffle to win a portable MP3 player or a $25 gift certificate to a national bookstore chain.

Of the 1379 potentially eligible respondents (based on removing the 121 names deemed ineligible based on the postcard response), 749 respondents returned a questionnaire. Eighteen of these 749 were deemed ineligible because they indicated on the survey that they were not currently in direct practice and had not evaluated any patients with advanced dementia for dysphagia in the last two years, resulting in a sample size of 731 of 1361 eligible respondents and a response rate of 53.7%.
Measures

Professional and Demographic Characteristics. Gender, race/ethnicity, year in which speech pathology degree was received, and current professional role (direct service provider, director, or supervisor in a clinical program, administrator in a clinical program, college/university professor, researcher, or other) were elicited. Type of practice was assessed by asking the age range of patients and the locus of care (hospital, outpatient setting, nursing home, home, or other). Respondents were asked to estimate the number of patients with advanced dementia they had evaluated for dysphagia in the last two years. The response categories were none, 1–10, 11–25, or more than 25 (see Appendix).

Knowledge About Tube Feeding in Advanced Dementia. Knowledge about the impact of tube feeding for patients with advanced dementia and feeding problems was assessed with four questions addressing common assumptions9 that are not supported by the best available evidence, including the notion that tube feeding: 1) reduces the risk of aspiration pneumonia, 2) improves functional status, 3) enhances quality of life (QOL), and 4) prevents an uncomfortable death. Questions about these potential outcomes were adapted from a previous instrument used to survey primary care physicians on this subject and that had been developed by expert consensus.17 Face and content validity of the indications for tube feeding were assessed by obtaining feedback on the instrument from local SLPs with expertise in this subject.

Each of the knowledge questions had five response categories: 1) no or very unlikely, 2) possibly, 3) probably, 4) definitely, and 5) not sure/no opinion. A dichotomized version of each of the four knowledge questions was created by coding as “evidence based” and “not evidence based” according to the best evidence in the literature. For these questions, “no or very unlikely” was considered the best evidence-based answer. The rationale was based on review of the literature on outcomes associated with tube feeding use in patients with advanced dementia including risk of aspiration pneumonia,2,18 functional status,1,19 QOL,1,5,9 and preventing an uncomfortable death.15,20–26

Relevant Clinical Experience. Respondents were asked how often in the last two years they were asked to evaluate dysphagia in patients who were too lethargic or ill to cooperate and how often in the last two years they were asked by a physician to determine whether a patient with advanced dementia needed a feeding tube. The response categories for these items were the following: frequently (>10 patients), sometimes (3–10 patients), infrequently (1 or 2 patients), and never. To explore SLPs’ willingness to entertain a palliative approach in patients with advanced dementia and eating problems, respondents were asked how often they had recommended a nonoral feeding method for patients with advanced dementia after performing a dysphagia evaluation, and when they did recommend nonoral feeding in such patients, how often they specified the type of feeding method (e.g., percutaneous endoscopic gastrostomy [PEG] or nasogastric [NG] tube) that they were recommending. The response categories ranged from frequently to never. They also were asked whether there were circumstances in which they would recommend oral feeding even though their evaluation identified a high risk of aspiration.

Relevant Training and Education. Respondents were asked whether they had taken a continuing education course covering dysphagia in the last 10 years, and if so, whether the course(s) included information on dysphagia and aging, dementia, end-of-life care, or other (specify). Respondents were asked how well they felt their speech pathology training (including classroom, clinical practicum, and clinical fellowship year) had prepared them to manage dysphagia in patients with severe Alzheimer’s disease or other dementia, stroke, other progressive neurologic disease, or who had a tracheostomy or were ventilator dependent. The response categories were the following: very well prepared, moderately prepared, minimally prepared, and not at all prepared.

Data Analysis Plan

Univariate analyses were used to describe the knowledge and attitudes of SLPs about dysphagia, feeding tubes, palliative considerations, and physician requests for consultations in caring for patients with advanced dementia. Underlying assumptions for multivariable analyses were assessed. Response categories of
categorical variables were collapsed when necessary to correct for small cell sizes.

Bivariate analyses were used to test the associations between knowledge and other study variables. Logistic regression analyses were used to test which variables were associated with each of the four knowledge measures. The final model for each of the knowledge variables included all the variables that were significant (α ≤ 0.05) in any of the models for each to facilitate comparison across all four knowledge variables. Logistic regression models also were estimated, regressing whether a recommendation for oral feeding would be made despite an identified high risk of aspiration on knowledge, clinical experience, and training.

Results

Demographic characteristics, training, and self-assessed level of preparedness for caring for a patient with dysphagia characteristics are shown in Table 1. The vast majority of respondents was female and had non-Hispanic white ethnicity. The year in which respondents received their speech pathology degree was fairly evenly distributed throughout the range, based on analyses of the continuous version of this variable. Hospitals and nursing homes were the most common settings in which respondents provided care. Most respondents were direct service providers, the majority reported that most of their patients were aged 65 years and older, and most had evaluated more than 10 patients with advanced dementia in the past two years.

Most respondents reported having taken continuing education courses covering dysphagia in the last 10 years. The vast majority of courses that covered dysphagia included information on aging and dementia, and a majority included information on end-of-life care. Respondents’ reported that preparedness in managing dysphagia varied depending on the underlying medical condition of the patient. Although the majority (74.4%) felt moderately or well prepared to manage dysphagia in patients with stroke, only 42.1% felt prepared to manage dysphagia in patients with severe dementia.

Table 2 presents characteristics of consultations requested of the SLP for patients and the care recommendations the SLP made. Almost 60% reported that physicians “sometimes” or “frequently” asked whether a patient needs a feeding tube, and a large majority (80.9%) reported receiving requests to
evaluate dysphagia in patients who were too lethargic or ill to cooperate. Over half reported recommending a nonoral feeding method in patients with advanced dementia; of these, almost half indicated that they specify the type of nonoral feeding method they are recommending. Furthermore, 70% reported that there are circumstances in which they would recommend oral feeding even if their evaluation indicated a high risk of aspiration. Respondents were asked to describe these circumstances in an open-ended question. Analyses of these qualitative data are beyond the scope of this study; however, the following represent typical responses to this question.

If there is a living will and family also refuses tube feeds, I would recommend the safest alternative p.o. diet.

If family decides on hospice then I’d make a recommendation. Sometimes if the patient and family sign a waiver I’d make a recommendation for the safest diet possible.

When family, physician, and nursing are aware of the risk of aspiration.

Quality of life issues—family strongly feels patient should be allowed to eat for pleasure and they understand the risks and the MD agrees.

SLPs’ views about the effect of tube feeding in patients with advanced dementia are presented in Table 3. When asked whether tube feeding would reduce the risk of aspiration pneumonia, only 22.0% responded with the most evidence-based answer of “no or very unlikely.” In contrast, when asked whether tube feeding would prevent an uncomfortable death, improve functional status, or enhance QOL, 50.2%, 54.5%, and 63.2%, respectively, responded with the most evidence-based answer (“no or very unlikely”).

Table 4 presents the logistic regression models, indicating higher level of knowledge about feeding tube use on all four measures from SLPs who were willing to recommend oral feeding despite a high risk of aspiration. Those who had evaluated larger numbers of patients with dementia were more likely to give the most evidence-based responses on the tube feeding outcomes of risk of aspiration pneumonia and preventing an uncomfortable death. Those who had taken a course on dysphagia that included content on end-of-life care were more likely to believe that tube feeding was not likely to prevent an uncomfortable death. SLPs who reported feeling well or moderately prepared to manage dysphagia in patients with dementia were actually more likely to give a less evidence-based answer for whether tube feeding reduces the risk of aspiration pneumonia and whether it would likely enhance QOL.

Several factors were independently associated with respondents’ willingness to recommend oral feeding in certain circumstances despite recognition of a high aspiration risk for the patient (Table 5). These included having evaluated more than 10 patients within the

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Reported Characteristics of Consults Received and Recommendations Made by SLPs for Patients with Advanced Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physician Requests</strong></td>
<td><strong>Sometimes or Frequently</strong> (%)</td>
</tr>
<tr>
<td>Frequency in last two years asked by physician to determine whether patient with advanced dementia needed a feeding tube (n = 715)</td>
<td>59.4</td>
</tr>
<tr>
<td>Frequency in last two years asked to evaluate dysphagia in patients who are too lethargic or ill to cooperate (n = 721)</td>
<td>80.9</td>
</tr>
</tbody>
</table>

| **SLP Recommendations** | **Sometimes or Frequently** (%) |
| Frequency recommended a nonoral feeding method after performing a dysphagia evaluation of patients with advanced dementia (n = 719) | 55.2 |
| Among those who made a recommendation: Frequency of specifying type of feeding method when recommending nonoral feeding in patients with advanced dementia (n = 610) | 46.6 |
| Would consider recommending continued oral feeding even if evaluation identifies high risk of aspiration (n = 711) | Yes (%) 70.0 |

*Response categories were the following: frequently (>10 patients), sometimes (three to 10 patients), infrequently (one or two patients), never.

*Response categories were the following: frequently, sometimes, rarely, and never.

*Response categories were yes and no.
last two years, having taken a continuing education course covering end-of-life care in the past 10 years, and believing that tube feeding would not enhance QOL or prevent an uncomfortable death. Respondents whose practice included mostly patients younger than 18 years of age were less likely to express this willingness.

Discussion

Our study builds on and extends research informing the care of patients with advanced dementia and eating problems. This was a national study of SLPs that assessed training, knowledge, self-assessed preparedness, and experience with the care of these patients to further explore factors predicting important care recommendations that minimize risk and maximize QOL for these patients.

Knowledge About Tube Feeding in Advanced Dementia

We found that many SLPs have beliefs about tube feeding in advanced dementia that do not comport with the best available evidence in the scientific literature.1–3,9,15,18–26 The discrepancy with the evidence is particularly marked in relation to aspiration risk: only 22% of SLP respondents believe that tube

Table 4
Factors Associated with Knowledge About Tube Feeding in Patients with Advanced Dementia

<table>
<thead>
<tr>
<th>Measure</th>
<th>Reduce the risk of aspiration pneumonia</th>
<th>Improve functional status</th>
<th>Enhance QOL?</th>
<th>Prevent an uncomfortable death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would consider recommending continued oral feeding even if evaluation identified high risk of aspiration (as compared with would not recommend)</td>
<td>1.75b (1.07, 2.87)</td>
<td>1.43b (1.0, 2.06)</td>
<td>2.19b (1.52, 3.17)</td>
<td>1.97 (1.37, 2.88)</td>
</tr>
<tr>
<td>Evaluated ≥10 patients with dementia in the past two years (as compared with &lt;10)</td>
<td>2.64c (1.48, 4.72)</td>
<td>1.36</td>
<td>0.92, 2.02</td>
<td>1.07</td>
</tr>
<tr>
<td>Took continuing education course on dysphagia that included end-of-life care (as compared with did not take such a course)</td>
<td>1.44d (0.92, 2.45)</td>
<td>0.98</td>
<td>0.69, 1.40</td>
<td>1.00</td>
</tr>
<tr>
<td>Well or moderately prepared to manage dysphagia in patients with dementia (as compared with minimally or not at all prepared)</td>
<td>0.57 (0.38, 0.84)</td>
<td>0.83</td>
<td>0.60, 1.15</td>
<td>0.72d (0.51, 1.01)</td>
</tr>
<tr>
<td>Model X²</td>
<td>48.02c (18.55d</td>
<td>1.010</td>
<td>51.91c</td>
<td></td>
</tr>
</tbody>
</table>

OR = odds ratio; CI = confidence interval.

Logistic regression also controlled for: whether respondent took a continuing education course in last 10 years on dysphagia and aging, a course on dysphagia that included information on dementia, age of most clients, and year in which speech pathology degree was received.

*p ≤ 0.10.

*p ≤ 0.05.

*p ≤ 0.01.

*p ≤ 0.001.
feeding is unlikely to reduce the risk of aspiration pneumonia whereas 76% believe that tube feeding might reduce aspiration risk. Although just over half believe that tube feeding would not help to improve functional status, enhance QOL, or prevent an uncomfortable death, there is still a considerable amount of misperception among SLPs on these parameters.

Our findings on SLP knowledge about tube feeding and aspiration risk, functional status, and comfort are consistent with the findings in a recent study by Sharp and Shega.16 We agree with Campbell-Taylor11 that the SLP swallowing evaluation in patients with dementia has been traditionally focused on the risk of aspiration. Rather than focusing on aspiration risk, the SLP evaluation might be more useful to the primary medical team and to surrogate decision makers if the SLP were to identify a specific feeding disorder related to late-stage dementia, such as oral dyspraxia or oropharyngeal dysphagia, and discuss her/his recommendations within this context. The SLP can be integral to facilitating the development of a palliative plan of care that includes alternatives to tube feeding, such as teaching caregivers and staff optimal strategies to continue oral feeding for comfort as safely as possible. Such participation in team efforts could help to guide decision making and shift to a more palliative plan of care.

To our knowledge, our study is the first to elucidate factors associated with SLP knowledge about tube feeding outcomes in patients with advanced dementia. Having evaluated a larger number patients (10 or more) in the past two years and possessing a willingness to recommend oral food intake despite a high risk of aspiration had the greatest effect with respect to SLP knowledge about the impact of tube feeding on aspiration risk, functional status, QOL, and preventing an uncomfortable death. Interestingly, having this increased experience with patients with dementia and being cognizant of alternative management strategies, including careful continued oral feeding, were both found to have a greater effect on SLP knowledge than did actual formal coursework covering end-of-life care, aging or on dementia, and year in which speech pathology degree was received; all of which were not significant in the model.

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Table 5

<table>
<thead>
<tr>
<th>Measure</th>
<th>OR</th>
<th>95% CI</th>
</tr>
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<tbody>
<tr>
<td>Evaluated ≥10 patients in the past two years</td>
<td>1.84b</td>
<td>1.20, 2.85</td>
</tr>
<tr>
<td>Feels it is unlikely that tube feeding prevents uncomfortable death</td>
<td>1.79c</td>
<td>1.04, 2.34</td>
</tr>
<tr>
<td>Continuing education course on dysphagia in the past 10 years that included end-of-life care</td>
<td>1.56d</td>
<td>1.00, 2.23</td>
</tr>
<tr>
<td>Feels it is unlikely that tube feeding enhances QOL</td>
<td>1.27b</td>
<td>1.20, 2.67</td>
</tr>
<tr>
<td>Age of most patients (ref. group = age 65+)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;18 years</td>
<td>0.28d</td>
<td>0.14, 0.59</td>
</tr>
<tr>
<td>18–64 years</td>
<td>0.54</td>
<td>0.22, 1.33</td>
</tr>
<tr>
<td>All ages of adults (age 18+)</td>
<td>1.05</td>
<td>0.64, 1.71</td>
</tr>
<tr>
<td>All ages of adults and younger patients</td>
<td>0.73</td>
<td>0.43, 1.24</td>
</tr>
</tbody>
</table>

Model \( \chi^2 \) 80.0d

OR = odds ratio; CI = confidence interval.

*Logistic regression also controlled for: whether respondent felt that tube feeding would reduce the risk of aspiration pneumonia, how well respondent felt speech pathology training prepared them to manage dysphagia in patients with severe Alzheimer’s disease or other dementia, respondent took a continuing education course on dysphagia in last 10 years that included information on dysphagia and aging or on dementia, and year in which speech pathology degree was received; all of which were not significant in the model.

bP ≤ 0.001.
cP ≤ 0.05.
dP ≤ 0.01.
outcomes is somewhat concerning; however, similar incongruities between self-assessment of knowledge and actual knowledge or competency have been observed in other areas of health professionals’ education.27 SLPs who possess a higher comfort level might be more difficult to reach with traditional educational efforts if they do not perceive dementia and end-of-life care as areas in which they might benefit from further instruction. Furthermore, the fact that our study found that experience with higher numbers of patients predicts knowledge, whereas formal continuing education coursework in general does not, points to the need for further study of mechanisms of optimal SLP education and training in the areas of aging, dementia, palliative care, and related topics.

SLP Feeding Recommendations for Patients with Advanced Dementia

Most (55%) SLP respondents in our study reported recommending a nonoral feeding method either “sometimes” or “frequently” in patients with advanced dementia, with just under half of those (46%) reporting that they specify a method (e.g., NG tube or PEG) in their formal recommendations. Our finding that SLPs may recommend a nonoral feeding method is consistent with the findings of Sharp and Shega16 that indicate SLPs commonly discuss specific methods of nonoral feeding methods with patients and families. It is plausible that the tendency to recommend nonoral feeding methods, and tube feeding in particular, may be a response to requests for consultation made by physicians—nearly 60% of SLPs in our study reported that they had been asked by a physician to determine whether a patient with advanced dementia needs a feeding tube. This practice potentially places the SLP in the uncomfortable position of being asked to make recommendations that may lie outside of the SLP’s area of expertise and that, furthermore, may not be evidence based. This underscores the need for physicians to better appreciate the role of the SLP and improve their own knowledge about the effects of tube feeding in advanced dementia10,17 and the feeding and swallowing disorders in general.

Almost 80% of SLPs in our study reported having been consulted to evaluate dysphagia in patients who were too lethargic or ill to cooperate. This finding is consistent with the clinical experience of the authors. We are encouraged that 70% of respondents stated that there are circumstances in which they would recommend oral feeding even though the evaluation identifies a high risk of aspiration, indicating a willingness by most SLPs to consider a more palliative management plan despite aspiration risk in patients with advanced dementia. These results point toward SLPs’ likely support of a recently published proposal to legitimize the option of comfort feeding as a clearly accepted alternative to tube feeding in this population.28

Our interpretation that SLP recommendations for continued oral feeding reflect recognition for the need to consider palliative approaches is supported by our findings that this willingness to consider oral feedings, despite acknowledgment of potential risks, was associated with experience with more patients with advanced dementia, belief that tube feeding was unlikely to enhance QOL or prevent an uncomfortable death, and education about end-of-life care. In contrast, having taken courses covering aging and dementia, but not end-of-life care, was not associated with willingness to recommend oral feedings for these patients. Elucidation of these experiential knowledge and educational predictors is an important beginning in understanding SLP knowledge about palliative management options in patients with advanced dementia and has implications for further palliative education and training of SLPs. This important area deserves further study because SLPs are often directly involved in delineating treatment plans in patients with advanced dementia and eating problems.

Roles of SLPs and Other Health Professionals

So, what should be the role of the SLP on the one hand, and the physician on the other? Or, more broadly, what should be the role of individual health professionals on the team and how should all members work together in developing short- and long-term goals for the patient?

The swallowing evaluation, although appropriate to diagnose conditions such as oral dysphagia or dyspraxia, cannot be expected to rule out the broad array of clinical problems
that could account for an acutely or chronically ill patient’s failure to eat. Such an evaluation would best be performed by a physician, who would then determine if additional diagnostic testing should be done and by whom. The physician, who is typically knowledgeable about the indications for diagnostic testing involving the internal organs, also should have basic knowledge about the place of swallowing evaluations in such a patient’s work-up, so that s/he can determine when, and in particular, if, such an evaluation is appropriate. The best source of that information should be the SLP, who should be educated on this as well.

The interdisciplinary team of physician, gerontological nurse practitioner, nurse,29 social worker,30 and SLP, or other professionals who know the patient, should together establish short- and long-term goals for the patient and determine if tube feeding is medically indicated. Surrogate decision makers who wish to authorize tube feeding must be fully and correctly informed about the risks, including treatment burdens, and benefits (if any). Family meetings with one or more members of the team should be held if needed and ethics consultation provided if there are enduring conflicts.31 We agree with Pollens in including the SLP as an important member of the interdisciplinary team, especially in a palliative model, where the SLP can “…assist in developing strategies that maximize the patient’s ability to enjoy the pleasure of eating in as safe and comfortable a manner as possible.”32

Strengths and Limitations

Selection bias is likely given the response rate for this study. It is possible that SLPs who were more interested in this topic and/or had strong opinions or personal beliefs about tube feeding in patients with advanced dementia completed a questionnaire. In addition, those with minimal experience with tube feeding in dementia may have declined to complete a questionnaire.

Another potential limitation of our study is the possibility of recall problems as a result of measures that are based on self-report over relatively long time periods. Recall bias also is possible if respondents were influenced by experiences with patients with advanced dementia.

We recognize that the lack of a gold standard on which to establish correct responses about indications for and consequences of tube feeding in advanced dementia presents a potential limitation to our study. Nonetheless, our study questions were based on careful review of the literature on feeding tube outcomes in patients with advanced dementia.1–3,9,15,18–26,33 Although these findings are from observational studies and expert opinion, in lieu of a randomized controlled trial (which would be difficult to conduct), these data are relevant in helping to frame the ethical basis on which important clinical decisions in the care of patients with dementia are made.

Lastly, SLP knowledge about tube feeding and palliative considerations in patients with advanced dementia may have improved since the time of the administration of our survey. Educational initiatives aimed at enhancing SLP knowledge about end-of-life care in patients with advanced dementia have been supported by ASHA,34 raising awareness of these issues among SLPs. Despite this, we feel that there is an urgent need to enhance palliative care education of SLPs and all professionals involved in the care of patients with advanced dementia.

Study strengths include having a large national sample with an acceptable response rate and sufficient statistical power to test associations between study measures. We included a wide range of measures on knowledge, attitudes, behaviors, professional education and training, and personal and professional characteristics.

Future Directions

An important area warranting further exploration includes the need to understand the nature of cultural and religious values of SLPs and the potential influence of these values on SLPs’ views of dying, palliative care, and treatment recommendations in patients with dementia and eating problems. Gaining further insight into how these important sociodemographic factors might influence the care of patients with dementia may help in targeting educational efforts and improving palliative approaches to care for this population.

Furthermore, the role of continuing education and its effect on subsequent knowledge, attitudes, and practice outcomes of SLPs deserves further study. Our study showed mixed
results. Although we found no association between SLP knowledge of tube feeding outcomes with general continuing education covering dysphagia in aging and dementia, we found a positive association between continuing education specifically covering palliative care and SLPs’ willingness to recommend continued oral intake despite a high risk of aspiration in patients with advanced dementia. Incorporation of palliative care and dementia content in SLP curricula and continuing education may be important in improving the care of patients with dementia and eating problems. Similarly, efforts to improve SLP head and neck cancer education have already been accomplished through incorporation of oncology content into the curricula of most SLP training programs, providing a useful guide for efforts to include palliative care content in SLP educational curricula. Ultimately, efforts to measure educational outcomes related to SLP curricula and continuing education in the areas of palliative care and advanced dementia are needed.

Health care professionals, SLPs included, encounter difficulty when assessing the experiences of patients with advanced dementia. Although there appears to be professional consensus and indirect evidence that forgoing tube feeding does not create discomfort in dying patients, it is not possible to know with certainty what a patient with advanced dementia experiences. Studies on competent hospice patients who either desire little or no food and water or voluntarily refuse food and fluids to hasten death provide direct evidence of this experience, and it is reasonable to expect that this would apply to patients with dementia. Furthermore, prospective observations of patients with dementia who forgo tube feeding at the end of life suggest that few patients appear to experience discomfort, and the discomfort appearing in a minority of patients can be attributed to comorbidity, which would be amenable to palliative care interventions. Studies that further characterize patient symptoms and caregiver satisfaction in forgoing tube feeding and acceptance of continued oral feeding for comfort are needed.

To garner further support and acceptance of palliative approaches for feeding patients with advanced dementia, further study of SLPs’ and other health care professionals’ acceptance of regionally recognized standards of care that include alternatives to tube feeding in patients with advanced dementia is needed. Furthermore, we believe that it is incredibly important to incorporate palliative feeding strategies into an overall integrated palliative approach for patients with dementia that truly engenders patient-centered care as the standard of care.

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Appendix

Knowledge, Experience, and Preparedness Items from the Questionnaire

KNOWLEDGE

- For a patient with advanced dementia and feeding problems, do you feel that tube feeding will:
  1. reduce the risk of aspiration pneumonia?
  2. improve functional status?
  3. enhance quality of life?
  4. prevent an uncomfortable death?
Response Categories:
- DEFINITELY
- PROBABLY
- POSSIBLY
- NO OR VERY UNLIKELY
- NOT SURE/NO OPINION

EXPERIENCE

- Within the last 2 years, how many patients with advanced dementia have you evaluated for dysphagia?
Response Categories:
- NONE
- 1–10
- 11–25
- MORE THAN 25

- In the last 2 years, how often have you been asked to evaluate dysphagia in patients who are too lethargic or too ill to cooperate?
Response Categories
- NEVER
- INFREQUENTLY (1 OR 2 PATIENTS)
- SOMETIMES (3 TO 10 PATIENTS)
- FREQUENTLY (>10 PATIENTS)
- NOT SURE

- In the last 2 years, how often have you been asked by a physician to determine whether a patient with advanced dementia needs a feeding tube?
Response Categories
- NEVER
- INFREQUENTLY (1 OR 2 PATIENTS)
- SOMETIMES (3 TO 10 PATIENTS)
- FREQUENTLY (>10 PATIENTS)
- NOT SURE

- Are there circumstances in which you would recommend oral feeding even though your evaluation identifies a high risk of aspiration?
Response Categories
- YES
- NO

PREPAREDNESS

- How well do you feel your speech pathology training (including classroom, clinical practicum, and clinical fellowship year) has prepared you to manage dysphagia in patients with the following conditions?
  1. Stroke
  2. Severe Alzheimer’s disease or other dementia
  3. Other progressive neurologic disease
  4. Traumatic brain injury
  5. Tracheostomy/Ventilator dependence
  6. Acute illness with multiple medical problems
  7. Head and neck surgery
Response Categories
- NOT AT ALL PREPARED
- MINIMALLY PREPARED
- MODERATELY PREPARED
- VERY WELL PREPARED
- NOT SURE