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# Speech-Language Pathologists' Content Knowledge and Recommendation Practices Regarding Tube Feeding Use For Persons with Advanced Dementia

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**SPEECH-LANGUAGE PATHOLOGISTS' CONTENT KNOWLEDGE AND  
RECOMMENDATION PRACTICES REGARDING TUBE FEEDING USE FOR  
PERSONS WITH ADVANCED DEMENTIA**

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For Cora Blanche Stevens Craig who told me...

"Everybody's life is different.....put on your lipstick and go to work!"

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## **Abstract**

### **Introduction**

Speech-language pathologists are often consulted by physicians to evaluate the swallowing ability of persons with advanced dementia. These cases become complex as feeding and swallowing abilities decline in the end of life and complex decisions regarding artificial nutrition and hydration arise. The purpose of this exploratory study was to describe content knowledge and recommendation practices of speech-language pathologists' (SLPs) regarding use of tube feeding for persons with advanced dementia. Content knowledge related to SLPs' practice setting was also explored.

### **Subjects**

Eighty seven speech-language pathologists responded to this online survey regarding content knowledge and recommendation practices for persons with advanced dementia. Subjects were recruited through online listserves for speech-language pathologists who specialize in swallowing disorders.

### **Methods**

An online survey tool was used to explore speech-language pathologists' perceptions of their content knowledge and recommendation practices.

## **Results**

Although the majority of respondents demonstrated content knowledge consistent with current medical literature gaps in knowledge regarding nutrition and the terminal nature of advanced dementia persist. Only 9% of speech-language pathologists surveyed reported frequently recommending tube feeding for this population. Respondents described medical reasoning that is consistent with models cited in the literature by Jonsen et al. (1992) and Kenny et al. (2010).

## **Conclusion**

Experienced SLPs do not recommend tube feeding for persons with advanced dementia. Gaps in specific content knowledge areas regarding outcomes of tube feeding this population may persist for speech-language pathologists. This is consistent with Sharp and Shega (2009) as well as Vitale et al. (2011). Speech-language pathologists are willing to discuss ethical reasoning used for this complex population and as such this area should be further explored.

## **Chapter I**

### **INTRODUCTION**

#### **Background of the Problem**

Tube feeding use for persons with advanced dementia raises both medical and ethical concerns. The controversy over its use as a medical treatment, basic care procedure or life sustaining technology has been debated in the literature and is now considered ineffective for this population (Finucane, Christmas & Travis, 1999). When patients with advanced dementia become so debilitated that they are unable to eat by mouth, the physician and medical team become involved in difficult feeding decisions. Often the physician will consult the speech-language pathologist (SLP) to evaluate the patient's swallowing ability as well as provide recommendations for safest method of feeding (ASHA, 2001). The clinical decision to use tube feeding for this population often becomes a complex ethical decision (Hughes, Jolley, Jordon & Sampson, 2007). Tube feeding use in the elderly has increased in recent years and although, many physicians and other healthcare professionals disagree with its use for persons with advanced dementia, the practice continues. Kuo, Rhodes, Mitchell, Mor, and Teno (2009), report an incidence of 54/1000 residents in skilled nursing facilities are tube fed. Other literature has reported as high as thirty-four percent of

nursing home residents with advanced dementia are tube fed in the United States (Mitchell, Teno, Roy, Kabamoto, & Mor, 2003). The argument supporting tube feeding use in this population is that it is generally well tolerated, complications are minimal, and it is better to provide nutrition rather than have the patient die from dehydration (Buff, 2006). However, there is no evidence in the medical literature supporting any of these benefits. Tube feeding does not increase life expectancy, prevent aspiration, improve skin integrity or assist in weight gain for persons with advanced dementia (Finucane et al., 1999). From an ethical standpoint tube feeding use for this population is controversial as the patient is unable to participate in the tube feeding decision making process due to advanced cognitive deficits. It is generally considered an ineffective attempt as a life sustaining procedure for those with advanced dementia because tube feeding cannot be realized as metabolic function declines. The body is essentially unable to use this hydration and nutrition. (Henderson, Trumbore, Mobarhan, Benya & Miles, 1992; Plonk, 2005; Finucane et al., 1999; American Academy of Hospice and Palliative Medicine, 2001).

Initially, the benefits of tube feeding this population were assumed to be; increased life expectancy, increased hydration as well as improved nutrition and skin integrity. Unfortunately, there is no evidence to support these outcomes. Potential risks and burdens include death, aspiration, and increased need for the use of restraints resulting in increased pressure sores

(Finucane et al., 1999). Although there have been many publications that indicate there are no benefits to providing tube feeding to patients with dementia, this practice continues (Kuo et al., 2009; Teno, Mitchell, Kuo, Gozalo, Rhodes, & Lima et al., 2011; Mitchell, Kiely, & Gillick, 2003; Gillick, 2000).

### **Factors Influencing Tube Feeding Use**

There are many factors associated with the decision to begin tube feeding in persons with advanced dementia. Clinical characteristics are the factors that are considered intrinsic to the patient. Some examples of intrinsic factors include: age, race, medical diagnosis and presence of dysphagia. Extrinsic characteristics are the factors not directly associated with the patient. Examples of extrinsic characteristics include: type of living facility, geographic location of facility, profit status of facility, staffing, and financial considerations (Mitchell, Kiely, & Gillick, 2003).

Stakeholder perceptions and recommendation practices influencing tube feeding decisions are also important factors. Who are these stakeholders who are involved in the clinical decision making process? The physician, speech- language pathologist (SLP), nurse, social worker, dietician, and most importantly the caregiver or surrogate decision maker, all play important roles in planning the best course of providing nutrition for persons with advanced dementia. Two primary professionals involved in this

decision making are the physician who ultimately orders the tube feeding procedure and the SLP who evaluates swallowing ability and makes feeding recommendations.

### **Physicians' Role**

The physician is the healthcare professional responsible for ordering placement of a feeding tube. Of all the stakeholders, their perceptions have been the most widely explored. Shega, Hougham, Stocking, Cox-Hayley, and Sachs (2003), reported that 74% of physicians indicated that feeding tube placement should not be the standard of care for this population and most believed dementia to be a "terminal diagnosis". However, they reported to continue to order this procedure for persons with advanced dementia. The physicians indicated speech- language pathologists (SLPs) strongly influence their decision to choose feeding tube use for persons with advanced dementia and that hospital nutrition teams are routinely recommending the same. It is unclear why SLPs and others on the healthcare team continue to recommend tube feeding for this population. What influences healthcare professionals to recommend tube feeding? There appears to be a disconnect between what is published in the medical literature and what is done in practice with this population.

### **Speech-Language Pathologists' Role**

Persons with advanced dementia demonstrate progressive decline in memory and communication as well as self-feeding and swallowing. Typically physicians will consult the SLP for swallowing evaluation and recommendations regarding diet safety (ASHA, 2001). Consequently, SLPs become involved in the complex decision-making process regarding artificial nutrition and hydration (ANH) for patients with significant swallowing deficits (dysphagia). SLPs function as an integral part of the healthcare team. Physicians report that the SLP has significant influence during this decision making process (Shega et al., 2003; Hanson, Garrett, Lewis, Phifer, Jackman & Carey, 2008). The American Speech- Language- Hearing Association clearly outlines the SLP's scope of practice to include identification and diagnosis of swallowing deficits and acknowledges SLPs' assistance in localization and diagnosis of diseases and conditions of human communication and swallowing (ASHA, 2011).

Multiple studies in the literature indicate that physicians feel significantly influenced by SLPs to order tube feeding for persons with advanced dementia (Vitale, Hiner, Ury, Berkman, & Ahronheim, 2006; Hanson et al., 2008; Shega et al., 2003). Procedures conducted by the SLP including; bedside swallowing evaluations, videofluoroscopic swallowing studies and aspiration risk reports have all been cited as indicators for the

physician to order tube feeding (Vitale et al., 2006). Mitchell & Teno et al. (2003) investigated nursing facilities characteristics associated with high tube feeding use for persons with advanced dementia. This study revealed that the variable most associated with high tube feeding use was having a staff SLP employed at the facility. Although the investigators are unsure why this relationship exists, it warrants further explanation.

Literature regarding physicians' perceptions regarding tube feeding persons with advanced dementia indicate that there is a disconnect between physicians' expected patient outcomes and actual patient outcomes reported in the medical literature. Physicians report that they are heavily influenced by the SLP to choose tube feeding for their patients even when believe prognosis to be poor. They report ordering tube feeding even though they do not believe it is the standard of care for persons with advanced dementia. (Hanson et al., 2008; Shega et al., 2003). Sharp and Shega (2009) surveyed SLPs regarding their beliefs and practice patterns for tube feeding persons with advanced dementia. Fifty-six percent indicated that they would recommend tube feeding for this population. This study also revealed that many SLPs believed that tube feeding persons with advanced dementia was the standard of care. However when asked if they would choose tube feeding for themselves if they were in a similar position most SLPs indicated that they would refuse. SLPs in this study also reported that they believed patients would experience improved nutrition and increase survival. These authors



concluded that there is a disconnect in SLPs' believed outcomes for use of tube feeding in this population and the current medical literature. Vitale, Berkman, Monteleoni, and Ahronheim (2011), also explored SLPs' perceptions about using tube feeding for persons with advanced dementia. Their results supported Sharp and Shega (2009), concluding SLPs lacked content knowledge regarding the effectiveness of tube feeding for this population. Vitale et al. (2011) reported 55% of respondents indicated that they continue to recommend tube feeding for this population even though over 50% believed that it would increase life expectancy or improve quality of life. 78% of respondents inaccurately believed tube feeding would reduce the risk of aspiration. Although there is no body of literature that explores knowledge and practice of SLPs' recommendations of tube feeding for persons with advanced dementia, these two studies support the physicians' literature indicating that there are misperceptions regarding patient outcomes. They also indicate that SLPs may be an important influence in this decision making process.

### **Pilot Project**

There are only a handful of articles in the literature addressing stakeholders' perceptions of their practices for persons with advanced dementia. In order to add to this body of literature and explore SLPs' feeding practices for persons with advanced dementia, a pilot project using focus

groups was completed (unpublished paper Remshifski, 2005). The purpose of this qualitative project was to identify general themes in regard to the SLPs' swallowing recommendations and practices for patients with advanced dementia in acute care medical centers. Acute care facilities were targeted as tube feeding procedures are primarily conducted in the hospital setting for persons with advanced dementia (Kuo et al., 2009). Twelve SLPs from three different hospitals in New Jersey and Pennsylvania participated in the study. Focus group interviews were conducted using an inpatient case study about a hypothetical patient with advanced dementia and dysphagia. Group discussions were audiotaped and transcribed by the investigator. Transcripts were reviewed and coded into semantic categories post hoc. Four general themes including; recommendation comments, physician related comments, perceived barriers to care, and practice pattern comments were identified. Specific recommendations included; diet level changes, hand feeding suggestions, as well as recommendations for videofluoroscopy and tube feeding. Practice pattern comments included reports of increased team decision making and discussions with physicians about tube feeding. SLPs reported few discussions regarding hospice or palliative care. SLPs comments also focused on the lack of alternatives to tube feeding and patient placement issues as each contributing to initiation of tube feeding in the acute care centers. They indicated that SLPs were active participants in the conversation and reported being more included by physicians indicating they

were stakeholders in the decision making process. Most SLPs reported that they had not participated in or initiated conversations about hospice or palliative care for patients with advanced dementia. One facility had a newly formed palliative care team and reported that future involvement of the SLP department may impact tube feeding decisions for persons with advanced dementia. Patient placement issues were also identified as a factor contributing to initiation of tube feeding in the acute care setting. SLPs reported that patients with advanced dementia were being admitted into acute care hospitals from skilled nursing facilities and were not able to return to their long term care facility until a feeding tube was placed. Perceived barriers included lack of staff support for hand feeding recommendations and lack of adherence to living wills. Shega et al. (2003) also concluded that 36% of physicians reported that they adhere to the family or caretaker wishes and not those that were previously described by the patient. Conclusions from this project indicated that SLPs considered themselves stakeholders in making feeding decisions for this population however they did not always feel their recommendations were followed by acute care staff.

### **Problem Statement**

Tube feeding is not considered standard of care for persons with advanced dementia however its use continues. To date there are only two studies that have explored speech-language pathologists' perceptions of

content knowledge and recommendation practices. This is an important topic as we move toward a palliative care framework for this terminal population.

### **Purpose of the Study**

To further explore SLPs' content knowledge and feeding recommendation practices for persons with advanced dementia this author designed a survey tool and distributed it through online listserves. The following research questions guided this investigation.

### **Research Questions**

1. What is the content knowledge of SLPs regarding tube feeding persons with advanced dementia?
2. What are the feeding recommendation practices of SLPs for persons with advanced dementia?
3. Is there a relationship between SLPs' practice setting and content knowledge/recommendation practices?

### **Hypotheses**

1. The majority of SLPs' responses to each content knowledge statement will be incorrect relevant to current medical literature regarding tube feeding use in persons with advanced dementia.

2. The majority of SLPs will report they frequently recommend tube feeding for persons with advanced dementia.
3. There will be a relationship between practice setting and individual responses to content knowledge/ recommendation practice statements.
4. There will be a relationship between total content knowledge score and practice settings; experience and, frequency of working with persons with advanced dementia.

## **Chapter II**

### **LITERATURE REVIEW**

#### **Introduction**

The following literature review will include current information regarding the use of artificial nutrition and hydration (ANH) in persons with advanced dementia. This review begins by defining the common types of tube feeding used for this population as well as an introduction to advanced dementia. This information will then be related to factors influencing tube feeding use for persons with advanced dementia as well as some common decision making models. The literature review will conclude by addressing the perceptions of stakeholders involved in this complex decision making process.

The primary rationale of using ANH for any patient is to improve nutritional status or prevent aspiration pneumonia (Logemann, 1998). This decision becomes complex for end of life populations like those with advanced dementia, especially if their preferences are unknown. Persons with advanced dementia are unable to advocate for themselves due to significant cognitive decline. Ethical decision making models demonstrate that when medical indications such as diagnosis and prognosis are known and patient preferences are communicated then ethical decisions are less complex (Jonsen, Seigler & Winslade, 1992). This is not typically the case in

persons with advanced dementia who can no longer communicate their wants and needs.

### **Artificial Nutrition and Hydration**

Feeding tubes are often used to deliver ANH to patients who have significant dysphagia or have difficulty meeting their nutritional needs by mouth. Three common types of feeding tubes are; nasogastric tubes (NGT), percutaneous endoscopic gastrostomy tubes (PEG-tube) and jejunostomy tubes (J-tube).

The NGT is passed transnasally through the hypopharynx and esophagus until it reaches the stomach. NGTs are typically viewed as temporary and traditionally reserved for patients with short term feeding needs. In contrast PEG tubes and J-tubes are considered for more long-term use. PEG tube feeding requires the surgical opening into the abdominal wall through which the tube is inserted into the stomach by endoscopic guidance. PEG tubes are appropriate for a patient who has a functional gastrointestinal tract as the tube passes directly into the stomach (Eisen, Baron, Dominitz, Faigel, Goldstein & Johanson et al., 2002). PEG tubes are commonly used because the surgical risk is generally considered to be low and they are tolerated well by most patients. However, little research has been conducted on patient's safety and outcomes especially for persons with advanced dementia (Plonk, 2005). Similar to a PEG tube the J-tube requires surgical

placement. The J- tube is inserted into the jejunum, a portion of the small intestine. It is typically used instead of the PEG tube for patients with stomach difficulties or gastroesophageal reflux (Eisen et al., 2002; Crary & Groher, 2003). When used in the context of this study, the term "tube feeding" refers to the long term use tubes such as the PEG tube or J-Tube which are often used for persons with advanced dementia.

### **Advanced Dementia**

Persons with dementia and associated communication and swallowing problems are the fastest growing clinical population in the field of speech-language pathology (ASHA, 2005). Speech-language pathologists working in healthcare centers are frequently consulted by physicians to treat communication and swallowing deficits for this population (ASHA Healthcare Survey, 2011). Dementia is a progressive form of cortical impairment that causes severe global cognitive deficits impairing a person's ability to perform most activities of daily living. Dementia is typically a staged condition with a recognized Early, Middle, and Advanced Stage. Advanced dementia is commonly accepted as the terminal stage of dementia. Dementia is a syndrome resulting from one of the following primary diagnoses: Alzheimer's disease, multi-infarct disease or cerebrovascular disease, Lewy body dementia or fronto- temporal dementia. Alzheimer's disease is the most common cause of dementia (Focht, 2009). Dementia is generally



characterized by a deterioration of cognitive functions such as memory, perceptual deficits, apraxia, communication, and executive functioning. Difficulties such as agitation and depression are also present.

Early stage dementia is characterized by memory loss with mild or no difficulties with activities of daily living. Persons with Middle Stage Dementia demonstrate increased memory deficits and increasing difficulties with activities of daily living. Advanced dementia is most clearly marked by significant feeding deficits and or dysphagia (Peck, 1990; Focht, 2009).

Memory problems may cause the patient to lose track of eating during the meal or cause them to forget to eat meals. Patients may also present with agnosia, the inability recognize food. Apraxia, a motor programming deficit, impairs the ability to self feed and language deficits impede the patient's ability to understand directions and communicate during mealtime.

Decreased executive function results in rapid intake of food and inappropriate behaviors during meals. Any of these characteristics combined with agitation and depression usually results in poor appetite or inability to take food orally (Kindell, 2002). Early symptoms of dysphagia or swallowing deficits include slow oral transit of food and delayed initiation of the pharyngeal swallow. As dementia progresses, dysphagia worsens with significant oral and pharyngeal problems characterized by increased holding of food in the oral cavity, inability to recognize food, coughing and choking as well as overt aspiration of food into the lungs. When patients present with apraxia and agnosia, they

have difficulty manipulating utensils and recognizing food items (Volcier, 2005). Eventually, patients are unable to feed themselves and must be hand fed by others (Crary & Groher, 2003). Persons with advanced dementia who can no longer independently participate in mealtime activities eventually become dependent for all activities of daily living. At this stage, patients generally receive a cognitive performance scale score of six or below on the Minimum Data Set and are dependent on others for all daily needs (Mitchell & Teno et al., 2003).

### **Tube Feeding Use in Advanced Dementia: Risks and Outcomes**

The risks of tube feeding persons with advanced dementia have been well documented in the medical literature. Frequently cited risks include aspiration pneumonia, death, pressure sores, and infections (Plonk, 2005; Volcier, 2005; Finucane et al., 1999). Aspiration pneumonia may be caused by reflux of tube feeding fluid as well as aspiration of oral secretions. There is no evidence of prolonged life as a result of feeding tube use for persons with advanced dementia. Some argue there may even be a slightly higher death rate when using tube feeding for this population. In a retrospective cohort analysis of patients who received feeding tubes, the patients with dementia, demonstrated a mortality rate of 54% at 1 month and 90% at 1 year. In this study persons with dementia demonstrated a higher mortality rate than those with other diagnoses who also received PEG tubes (Sanders, Carter, D'Silva,

James, Bolton & Bardhan, 2000). Similarly, Mitchell, Kiely and Lipsitz (1998), examined survival rates for persons with advanced dementia and swallowing difficulties. This retrospective study examined survival rates for persons with advanced dementia and dysphagia who were tube fed and compared them to a matched group who did not use tube feeding. Results indicated that there was no improved survival rate for patients who were tube fed. Murphy and Lipman (2003) examined survival rates of 41 patients with advanced dementia. Group one consisted of 23 patients whose surrogate decision makers (SDM) opted for tube feeding for the patient and the second group consisted of 18 patients with advanced directives prohibiting tube feeding. Survival rate for the tube feeding group was 59 days and survival rate for the group without feeding tube was 60 days thus demonstrating no significant difference.

Skin integrity is always a concern for all elderly persons with decreased mobility and participation in self-care. Persons with advanced dementia are also at risk for skin breakdown and pressure sores. Tube feeding does not improve skin integrity or prevent the "wasting-away" phenomena that is often observed in persons with advanced dementia (Henderson et al., 1992). Tube feeding this population also carries the risk of aspiration as tube feeding formula can be refluxed into the laryngeal area and aspirated into the lungs resulting in pneumonia. Persons with advanced dementia experience confusion and agitation and often pull or dislodge the

feeding tube. As a result, there is an increased need for restraints. This puts the patient at risk for infection and hospitalization for tube re-insertion (Finucane et al., 1999; Volcier, 2005).

Tube feeding formulas commonly cause increase urine and stool production increasing the risk of poor skin integrity and increased occurrence of pressure ulcers (Volcier, 2005). Patients may experience agitation and restraints may be necessary in order to prevent the patient from harming themselves. Persons with advanced dementia who are tube fed typically are at higher risk for increased use of restraints as the patient attempts to pull at and remove their tube. This use of restraints reduces the patient's ability to move thus increases the risk of developing pressure ulcers. Paradoxically, the very complications that healthcare professionals are attempting to avoid by using tube feeding such as, aspiration and pressure ulcers are also caused by tube feeding. Although it is generally accepted that there is no benefit to providing artificial nutrition to persons with advanced dementia the practice continues (Teno et al., 2010; Gillick, 2009; Plonk, 2005; Mitchell, Kiely, & Gillick, 2003; Gillick, 2000).

### **Intrinsic Factors Influencing Tube Feeding**

The most heavily weighted intrinsic factor in the decision to use tube feeding is dysphagia. Dementia impacts both feeding and swallowing. Feeding deficits are demonstrated when the patient is unable to self-feed or

recognize food. Swallowing deficits impact the patient's ability to orally manipulate and transfer the food bolus and trigger the pharyngeal swallow. Although there are no studies that associate the type of swallowing disorder with the type or stage of dementia it is generally accepted that persons with advanced dementia demonstrate significant difficulty in any of the four stages of the swallow (Logemann, 1998; Mitchell, Teno, Keily, & Shaffer et al., 2009). Oral preparatory problems may exist if the person loses their ability to manipulate food utensils due to apraxia, causing self-feeding problems. Persons with dementia typically develop agnosia, an inability to recognize food. This causes significant difficulty initiating the oral stage of the swallow, as the person no longer recognizes that there is food in the mouth, resulting in holding of the food bolus. They often have difficulty triggering the pharyngeal swallow. Delayed initiation of the reflexive pharyngeal swallow may result in coughing, choking, or aspiration. These swallowing deficits place the person at risk for developing aspiration pneumonia and nutritional compromise with significant weight loss. (Logemann, 1998; Crary & Groher, 2003). Persons with dementia are eventually unable to eat triggering the last stages of advanced dementia (Plonk, 2005).

Ethnicity is an intrinsic factor that appears to be associated with choosing tube feeding (Gessert, Mosier, Brown, & Frey, 2000). Non-white persons are twice as likely as white persons to receive feeding tubes (Ahronheim, Mulvihill, Sieger, Park & Fries, 2001). Welch, Teno, and Mor

(2005) discovered African Americans were more likely to use life-sustaining treatment when compared to Caucasians. The demographic profile commonly associated with tube feeding includes: nonwhite race, males, younger age, and divorced persons (Mitchell & Teno et al, 2003).

### **Extrinsic Factors Influencing Tube Feeding**

Financial incentive is an important extrinsic factor that may influence the decision to recommend tube feeding. Costs of hand feeding residents and reimbursement rates have important financial implications for skilled nursing facilities (SNF).

In a retrospective study conducted by Mitchell, Buchanan, Littlehale, and Hamel (2003), the authors compared the costs of hand feeding versus tube feeding residents with advanced dementia in a long term care facility. This study examined 11 patients who had been tube fed for at least 6 months and matched them with a group of residents who also had a dysphagia but had declined tube feeding. Groups were matched for diagnoses of dementia and dysphagia. The authors analyzed feeding costs for the two groups over a 6-month period of time. The authors included: nursing time for hand feeding and tube feeding, food costs, and all physician and hospital costs associated with tube feeding. Nursing staff reported that it took approximately 20 minutes to hand feed a resident. Costs for hand feeding were determined by multiplying the number of nursing hours by the average hourly pay of either

the nurse or the nursing assistant. Individual hand feeding accounted for the greatest cost difference between residents with and without feeding tubes. This study concluded that daily costs for the skilled nursing facility (SNF) were higher for residents without feeding tubes. They also reported that residents who are tube fed take less nursing time yet generate a higher reimbursement rate from Medicaid. Other literature reports hand feeding residents with severe dementia takes between 45-90 minutes per day. In contrast, tube-feeding a resident is estimated to take 15-20 minutes per day (Mitchell, Buchanan, Littlehale, & Hamel, 2003). Thus, for a SNF, it may be more cost effective to tube feed residents because it takes less staffing time while generating more Medicaid dollars.

Financial benefits are also seen in disproportionate reimbursement schemes. Most long-term care residents eventually use Medicaid to pay for SNF placement. Most states use the Resource Utilization Groups (RUGS) to determine the Medicaid reimbursement rate for care. Upon admission to a facility the resident is placed in a "group" based on their diagnosis, medical status, and need for therapies. Some of these reimbursements may appear disproportionate according to the RUGS system. An example of a disproportionate pay reimbursement is a dependent resident who receives nutrients by tube is categorized as "Special Care". A similar resident who is not tube fed is categorized as "Reduced Physical Functions". Residents grouped as "Special Care" receive a higher Medicaid reimbursement rate

than residents "Reduced Physical Functions". Medicare is essentially a fee-for-service program. Medicare covers the cost of the surgical insertion of the tube, which takes place in an acute care facility. Medicare also covers the cost for treating and for hospital re-admissions for problems related to tube feeding (Mitchell & Buchanan et al., 2003). Complications that may cause re-admission include aspiration, bowel obstruction, wound infection, and ileus (Plonk, 2005; Eisen et al., 2002; Finucane et al., 1999). Skilled nursing facility residents in Medicaid funded beds who are hospitalized for at least 3 days and then return to the SNF typically qualify for an additional 100 days of skilled Medicare services. The Medicare reimbursement for the additional days is at a higher rate than the resident's initial Medicaid reimbursement. If a Medicaid bed resident is returned to a SNF from an acute care facility with tube feeding, the SNF will spend less for staff as they will no longer need to pay a staff member to hand feed the resident and at the same time they will collect more money as the resident now qualifies for the 100 days of Medicare. This is another example of how a SNF may financially benefit from caring for a resident with a feeding tube (Mitchell, Keily, & Gillick, 2003).

### **Patient Placement Issues**

Another important consideration is patient placement. Placement practices may influence the likelihood of a resident receiving a feeding tube. In an unpublished pilot project (unpublished paper Remshifski, 2005), a focus



group of acute care SLPs, identified two distinct populations of persons with advanced dementia who may be considered candidates for tube feeding; those with a documented dysphagia and those with decreased food intake without documented dysphagia. They all reported the practice of using tube feeding for the group who did not present with a specific dysphagia or swallowing deficits. These patients were described as showing the natural signs of end stage dementia including “decreased intake”. SLPs linked this group to problems with patient placement issues after the acute care stay. Some clinicians reported that a patient with dementia, poor nutritional intake, and no dysphagia will receive a PEG tube before being transferred back to a skilled nursing facility or long term care facility. These patients are “unable” to return to facilities unless they can manage an oral diet or have a feeding tube. As a result, patients may receive PEG tubes before returning to their facilities (unpublished paper, Remshifski 2005). Physicians have also reported that they feel pressure from skilled and long term nursing facilities to recommend feeding tubes for persons with advanced dementia (Shega et al., 2003). These patient placement and transfer challenges may impact the decision to use tube feeding for this population.

### **Institution Characteristics**

Characteristics of a SNF or acute care facility may influence feeding decisions. Mitchell, Kiely, and Gillick (2003), investigated extrinsic factors

including staffing patterns, demographic patterns, presence of Medicaid beds and absence of Alzheimer's units in SNFs. They determined that geographic location of a SNF may also play a role in tube feeding use. For example, Mississippi has a high rate of tube feeding use while Maine, Wisconsin, South Dakota, and Nebraska have lower rates of tube feeding use. The extrinsic factors most highly associated with high tube feeding use in SNFs included: urban location, no dementia special care unit, "for-profit" status, and employment of a staff SLP. SLP employment influence has not been replicated in the literature however it is an interesting point as this is one of the studies that calls attention to the SLPs role in this decision making process.

Many factors may influence the decision to use tube feeding for persons with advanced dementia. Intrinsic and extrinsic influences associated with tube feeding use in persons with advanced dementia have been summarized. The higher prevalence of persons being tube fed when a staff SLP is employed at a facility is puzzling and presents as an interesting place to start further investigation. Exploring the SLP's content knowledge and recommendation practices may provide more detailed information about tube feeding in persons with advanced dementia.

### **Team Decision- Making**

Many healthcare professionals find themselves either directly or indirectly involved in team decision- making for persons with advanced dementia. These cases become complex as patients are nearing the end of life and are unable to make palliative care decisions and remain dependent on family members or loved ones to make decisions for them. The following healthcare professional roles will be explored; family or surrogate decision maker (SDM), dietician, nurse, social worker, physician, and speech-language pathologist (SLP).

### **Families' or Surrogate Decision Makers' Perceptions**

The family or surrogate decision maker (SDM) becomes the primary decision maker when the person with dementia can no longer self-advocate. When the patient's self-determination cannot be conclusively identified, decision making becomes complex and is typically turned over to a family member or SDM. Mitchell and Lawson (1999) interviewed SDMs regarding their experiences in choosing tube feeding for their designee with advanced dementia. SDMs reported choosing tube feeding for their dependent family member because they believed tube feeding would prolong life, prevent aspiration, and provide better nutrition. Family members did not believe quality of life was improved and they reported poor communication with the physician regarding the decision to use tube feeding. Teno et al. (2011)

replicated Mitchell and Lawson's (1999) study. This 2011 study revealed that the same perceptions exist today. These respondents also indicated that they felt pressured by the physician to choose tube feeding for their loved ones and that this choice was made in part to make it easier for staff. This study also concludes that there is poor communication between healthcare professionals and families regarding this important decision.

### **Nurses' Perceptions**

Nurses' perceptions of using tube feeding for persons with advanced dementia were explored by Todd et al. (2004). Nurses in this survey revealed that they felt uncomfortable participating in tube feeding decisions when a patient had a poor prognosis although they acknowledged their role in the process. They also indicated that they felt family members were ill informed regarding the risks of tube feeding. Lopez et al. (2010) discovered three themes in their qualitative study based on interviews with nurses in skilled nursing facilities. These themes revealed that nurses lacked knowledge regarding tube feeding use for this population, they reported feeling an ambiguous role in the decision making process and that there was little discussion of moral implications of the decision.

### **Social Workers' Perceptions**

There appears to be paucity in the literature regarding social worker's perceptions regarding this topic. Lacey et al. (2004) conducted a survey of social workers. Fifty percent of social workers reported they were uncomfortable working with a patient with advanced dementia who did not have a living will. This group of respondents also felt that social workers needed more training regarding tube feeding decisions for persons with advanced dementia.

### **Dieticians' Perceptions**

The registered dietitian's role in tube feeding is addressed in a position statement released by the American Dietetic Association (ADA). The ADA supports the dietitian's role as a participant in decision- making for artificial nutrition in people with end stage illnesses. In general the ADA supports the notion of "when in doubt feed" however adds that the dietitian and team need to consider withholding tube feeding if it appears that its use would be considered burdensome in end stage illnesses (ADA, 2002). Healy and McNamara (2002) surveyed dieticians and discovered that 67% felt that families were given insufficient information about tube feeding and less than 50% of respondents favored tube feeding for persons with advanced dementia.

### **Physicians' Perceptions**

The physician is the healthcare professional ultimately responsible for ordering placement of a feeding tube. In a survey 74% of physicians reported that tube feeding placement should not be the standard of care for this population and most believe dementia to be a "terminal diagnosis", however they continue to report using this procedure for persons with advanced dementia. Physicians also indicated SLPs strongly influence their decision to choose a PEG tube for persons with advanced dementia and hospital nutrition teams are routinely recommending the same (Shega et al., 2003). Vitale et al. (2006) supported these findings as physicians in this study indicated that they anticipated better outcomes for persons with advanced dementia such as increased survival, improved nutrition, and decreased aspiration. Physicians in this study also indicated that they were greatly influenced by SLPs to use tube feeding for persons with advanced dementia, citing that they felt SLPs' reports of aspiration risk, bedside swallowing studies, and videofluoroscopic studies were common factors considered. Hanson et al. (2008) confirmed these findings when physicians in their study also anticipated improved outcomes for their patients. There appears to be a disconnect between current medical evidence on tube feeding for persons with advanced dementia and the recommendation practices of physicians. There also appears to be a strong relationship between physician orders and swallowing recommendations from the SLPs.

### **Speech Language Pathologists' Perceptions**

Speech-language pathologists (SLPs) are frequently consulted by physicians for assessment and intervention of dementia related cognitive communication disorders as well as dysphagia and feeding evaluations and treatment (ASHA 2005). Consequently, SLPs become involved in the complex process of determining how to best manage a patient's feeding in order to optimize nutritional outcomes. The SLPs' role for persons with suspected swallowing disorder includes; diagnosing swallowing deficits, making recommendations regarding safe meal choices and feeding safety as well as designing and implementing swallowing treatment programs. SLPs are an integral part of the team and as such they do not make independent decisions about tube feeding for their patients. For persons with dementia there is not only decline in cognitive functions such as memory and communication but also in other areas such as self- feeding and swallowing. Advanced dementia is associated with aspiration and poor nutritional intake. When persons reach this advanced stage of dementia they are no longer able to feed themselves and are in need of hand feeding. They are eventually unable to participate in oral feeding due to severe cognitive deterioration. This is one of the hallmark signs of end stage/advanced dementia (Peck, 1990). As the physician considers percutaneous endoscopic gastrostomy (PEG) tube feeding in acute care and skilled nursing facilities they frequently

consult the SLP for feeding and swallowing recommendations prior to making a final decision.

SLPs typically conduct both swallowing screenings at the bedside as well as instrumental swallowing evaluations such as the videofluoroscopic swallowing study (VFSS) and Fiberoptic Endoscopic Evaluation of Swallowing (FEES). SLPs are trained to make swallowing recommendations based on these objective swallowing evaluations as well as clinical examination. The VFSS is a procedure that requires the patient to swallow barium coated food while undergoing fluoroscopy in the radiology suite thus allowing the SLP to not only determine the etiology of swallowing disorder but also visualize any potential food entry into the airway in real-time. The FEES study is another procedure used by SLPs to objectively assess swallowing using a fiberoptic scope passed transnasally in order to view the pharynx and upper airway during the swallow. These types of instrumentation assist the SLPs in identifying the physiological disorder of the swallowing mechanism. The oral, pharyngeal, and esophageal phases of the swallow can be screened at the bedside however physiologic swallowing deficit is determined by VFSS or FEES studies. Based on the etiology of the swallowing deficit a patient may be asked to modify or eliminate certain liquid or food choices and be enrolled in treatment in order to improve swallowing abilities (ASHA 2001). However persons with advanced dementia are confused and their limited cognitive abilities make it difficult for them to participate in these instrumental studies,



decision making, and subsequent treatment (Brodsky, 2005). Many times they are managed at the skilled nursing facility (SNF) bedside by the SLP with compensatory strategies such as diet modifications and recommendations for posture and instruction to staff regarding safe hand feeding. SLPs may also at this point become involved in team decision making regarding best method of nutritional intake. Sharp and Shega (2009) investigated the beliefs and practices of SLPs in regard to tube feeding this population. This survey consisted of likert scale statements as well as a hypothetical case study with questions regarding how the respondent would manage the case. Fifty-five percent of respondents believed tube feeding is or should be the standard of care for this population. Vitale et al. (2011) also surveyed speech-language pathologists and indicated that respondents believed tube feeding would reduce aspiration risk in this population. They also report that SLP misperceptions in content knowledge exist and perhaps influence decision making. Interesting, Mitchell et al. (2003) discovered that having an SLP on staff at a SNF resulted in residents with dementia being more likely to receive tube feeding. It is clear that the SLP plays a role in tube feeding decisions for this population however their content knowledge, training, and recommendation practices have been underexplored.

## **Ethical Decision Making Models**

Complex medical ethical decisions should be well thought out within the context of an existing framework. As advanced dementia is a terminal condition, The Palliative Care Framework, can be useful (NQF Framework for Preferred Practice Consensus Report, 2009). There are eight domains of the Palliative Care Framework that include the following aspects of care; Structure and Process of Care, Physical Aspects of Care, Psychological Aspects of Care, Social Aspects of Care, Spiritual, Religious and Existential Aspects, Cultural Aspects, Care of Dying, and Ethical and Legal Aspects of Care. The foundation of the framework is on patient centered quality of life. The first domain of "Structure and Process of Care" addresses the importance of the therapeutic disciplines including speech-language pathology, occupational therapy, physical therapy, nursing assistants, chaplains, nurses and physicians as taking an interdisciplinary approach and infusing their skills in a coordinated manner throughout all aspects of care (National Consensus Project for Quality Hospice and Palliative Care, 2009). Literature in the SLP field regarding ethical decision making focuses on living wills and the patient's right to self- determination. There have also been tutorials published by SLPs proposing decision- making models for complex medical cases (Landes, 1999; Sharp & Geneson, 1996). These models primarily focus on ethical issues surrounding a patient's right to consciously refuse nutrition and hydration. However, no controlled studies exist demonstrating the use and

value of these decision-making models. One model described by Jonsen, Seigler and Winslade (1992), presents four basic aspects relating to the patient including: medical indications (diagnosis/prognosis), patient preferences (advanced directives), quality of life (subjective judgment of benefits and burdens) and contextual features (family preferences/economic issues). This model advocates balancing medical indications with patient preference (Sharp & Genesen, 1996). Unfortunately, this model becomes difficult to implement for persons with advanced dementia as they are unable to communicate their wants and needs and are dependent on the surrogate decision maker even when they have an advanced directive. Persons with advanced directives may on the surface appear to be medically less complex to manage however extrinsic factors mentioned above continue to make tube feeding issues difficult even with a living will in place. As discussed earlier, physicians report they do not always adhere to the living will of a person once they are no longer autonomous (Shega et al., 2003).

The Education for Physicians in End of Life Care (EPEC) is an educational tool designed by a geriatrician with the aim of reducing ineffective end of life measures. This tool was trialed as part of an overall education program designed by an SLP in a hospital setting. The aim of the study was to provide education to doctors, residents, and other stakeholders regarding ineffectiveness of tube feeding for persons with advanced dementia. They measured the program's impact on the use of feeding tubes with a pre and

post study. Results indicated that this program was effective in reducing the number of tube feeding procedures conducted for patients with advanced dementia at this particular hospital (Monteleoni & Clark, 2004).

### **Summary of Literature Review**

Tube feeding use for persons with advanced dementia continues even though evidence suggests that this procedure is ineffective in prolonging life, improving nutrition, or preventing aspiration. Physicians continue this practice although they do not believe it to be the standard of care for this population (Shega et al., 2003; Vitale et al., 2006; Hanson et al., 2008). Extrinsic influences including overall costs and financial incentives, as well as other factors that influence team decision-making were presented. The healthcare community has a responsibility to explore all factors and outcomes associated with this treatment procedure as well as the factors influencing team decision-making for this population. Dysphagia and an inability to take food orally are hallmark signs in the terminal phase of dementia (Peck, 1990). Thus, the SLP becomes involved in this complex decision-making process and physicians report being heavily influenced by the SLP's recommendations. However, it is the physician who ultimately makes the recommendation for tube feeding to the proxy or surrogate decision maker. As the family and healthcare team are responsible for advocating for persons who are no longer able to make their own medical decisions there is a need to fully understand

the influences, actions, and recommendations made by healthcare professionals in regards to using tube feeding for this population. To further explore the SLP's role a survey was designed to investigate the SLP's content knowledge and recommendation practices in the use of tube feeding for persons with advanced dementia.

## **Chapter III**

### **METHODS**

#### **Design**

This study used an exploratory survey design to determine SLPs' content knowledge and recommendation practices regarding tube feeding use for persons with advanced dementia. The Seton Hall Institutional Review Board (IRB) approved the research study.

#### **Survey Development**

An online survey titled "Tube Feeding Use in Persons with Advanced Dementia: Speech-Language Pathologists' Content Knowledge and Recommendation Practices" (Appendix A) was designed to collect exploratory data in regards to speech-language pathologists' content knowledge and recommendation practices. This Likert Scale survey required subjects to respond to 10 statements. A Likert scale is a summative scale often used for measurements of attitudes and perceptions and can be used to make statistical comparisons between groups of respondents (Portney & Watkins, 2009). The survey consisted of three sections: 1) demographic/biographical information 2) content knowledge and practice statements and 3) one open ended question regarding tube feeding practices. In the demographic and

biographical information section respondents were asked to identify themselves by years of experience, geographic area of employment, highest degree earned, geographic area their professional degree was conferred, current credentials, primary place of employment and frequency of working with individuals with advanced dementia. Section 2 consisted of 10 likert scale statements relating to SLPs' content knowledge and recommendation practices regarding tube feeding persons with advanced dementia. Section 3 was the open ended response where respondents could freely type in a description of their recommendation practices.

### **Validity of Instrument**

In order to create the survey and control for content and face validity a two round Delphi technique was used. A panel of four experts assessed content validity. These individuals all had experience working with and treating persons with advanced dementia. Three of the four experts were published in this area. Two members were geriatricians and two were speech- language pathologists from New York and New Jersey.

This panel of experts was asked via e-mail to review the preliminary survey designed by the primary investigator and determine if the likert statements addressed appropriate content knowledge and recommendation practices. They were asked if the statements on the survey were clear and relevant in regards to their area of expertise. The content statements were

pre-coded as correct or incorrect based on current medical literature. Appropriate content revisions included change in ordering of statements, word choice, and omission of bias or repetitive statements. The statements were examined by the group until 80% consensus was achieved for each statement.

### **Subjects**

Respondents consisted of a convenience sample of SLPs from NY, NJ, and CT who had a history of working with persons with advanced dementia. A general solicitation e-mail was sent to members of two listserves whose members specialized in swallowing disorders (Appendix B). This solicitation e-mail described the purpose of the study, and invited interested participants to log on to the URL where the survey was posted. In order to meet inclusion criteria the respondent had to be an SLP who worked with patients with advanced dementia and worked in NY, NJ or CT. The listserves included Division 13 (ASHA Swallowing and Swallowing Disorders special interest division) as well as another dysphagia listserve; [dysphagia-bounces@dysphagia.com](mailto:dysphagia-bounces@dysphagia.com). Permission to post this solicitation was given by the webmasters of each listserve. Informed consent was distributed however subjects were not required to provide formal consent for this survey (Appendix C). Consent was implied by the participant voluntarily completing the on-line survey (Portney & Watkins, 2009).



**Data Collection**

The survey was posted on Seton Hall University's secure server through the ASSET: Academic Survey System and Evaluation Tool project available through the Department of Information Technology. The respondents were asked to log on to the survey web address and log in via password. This password ensured that respondents did not log in multiple times. The ASSET system is an anonymous tool used for collecting survey data.

**Independent Variables**

Independent variables included 9 answers to demographic questions. These included: (1) years of practice; (2) ethnic background; (3) state where SLP employed (NY, NJ, CT); (4) highest degree earned; (5) current credentials; (6) place of primary employment; (7) frequency of working with persons with advanced dementia; (8) location of graduate program where master's degree conferred; (9) how respondent acquired information regarding tube feeding.

**Dependent Variables**

Dependent variables included the responses to the 10 Likert Scale statements regarding content knowledge statements about tube feeding use and recommendation practice statements. Statements required choosing one

of five levels of responses: (1) strongly disagree; (2) disagree; (3) unsure; (4) agree; (5) strongly agree.

### **Statistical Analysis**

Data was obtained from 87 respondents. They were each coded for download into the Statistical Package for Social Sciences (SPSS 16.0). In order to achieve a medium effect size of .30 a minimum of 128 respondents were required in order to obtain a power of .80 at the .05 level (Faul, Erdfelder, Buchner, & Lang, 2009).

The data collected included both nominal and ordinal data as such both descriptive and nonparametric analyses were used. Nominal data analysis included: percentages, standard deviation, mean, and mode. Ordinal data was analyzed using median and mode (Munro, 2001; Portney & Watkins, 2009).

Chi-Square Test of Homogeneity ( $X^2$ ) was used to study the relationships between the independent and dependent variables. Chi-square is typically used for nominal data. One way analysis of variance (ANOVA) was also used to analyze relationship between total content knowledge score and practice setting; years of experience, and frequency of working with persons with advanced dementia.

## **CHAPTER IV**

### **RESULTS**

#### **Characteristics of the Sample**

The on-line survey was completed by 87 respondents. All respondents held either the master's degree (97.7%) which is the minimum requirement to practice in the field of speech-language pathology or a terminal degree of Ed.D. or Ph.D. (2.3%). Most respondents (76, 87.4%) held the Certificate of Clinical Competence (CCC) from ASHA. Seven respondents (8.0%) were currently completing their clinical fellowship (CF) training in order to earn the CCC, and 4 respondents (4.6%) had the CCC and the credential of Board Recognition for Specialist in Swallowing and Swallowing Disorders (BRSS). BRSS is an optional additional swallowing credential available through ASHA.

Twenty-seven (31%) of respondents had more than 20 years of experience. Eight (9.2%) reported 16- 20 years of experience, 15 (17.2%) reported 11-15 years of experience and in the category of 6-10 years and 0-5 years there were 14 (16.1%) and 23 (26.4%) respondents respectively.

The primary place of employment for most respondents was reported as long term care/skilled nursing facility (35, 40.2%), and acute care setting (31, 35.6%). Ten subjects (11.5%) worked in outpatient rehabilitation centers, 2 subjects (2.3%) worked in home care, school districts, and private practice and 5 subjects worked in university settings. These employment based

demographics are consistent with ASHA's 2009 Health Care survey polling 4,000 health care SLPs who indicated 20% work in medical acute care facilities, 23% work in skilled nursing facilities, 16% in home health care and 8% in rehabilitation centers. The remaining 33% reported working in outpatient and pediatric clinics (ASHA, 2009).

More than half of the respondents (48, 55.2%) were from New Jersey, 26 (29.9%) were from New York, and 13 (14.9%) were from Connecticut. Most respondent's master's degrees were conferred in the Northeastern United States, 71 (81.6%), 8 (9.2%) received their degrees in the Southeastern U.S., 5 (5.7%) in the Midwest, 2 (2.3%) in the Northwest, and 1 (1.1%) in the Southwest.

In regards to ethnicity, White not of Hispanic origin was the largest group noted with 76 persons representing 87.4% of respondents. Asian or Pacific Islander was represented by 6 persons representing 6.9% of respondents, and Black not of Hispanic origin there were only 3 respondents or 3.4%. In the Hispanic category there were 2 respondents representing 2.3% of the group. These ethnicity based demographics are also consistent with ASHA Healthcare Survey 2009 which revealed most SLPs working in healthcare settings are white (ASHA, 2009). Table 1 represents a summary of the respondent's demographics.

Table 1. Respondent demographics

Variable	Characteristics of sample (N=87)
Years of experience	
0-5 years	26.4%
6-10 years	16.1%
11-15 years	17.2%
16-20 years	9.2%
Over 20 years	31%
Credentials	
CCC	87.4%
CCC BRSS	4.6%
CF	8%
Primary place of employment	
Skilled Nursing facility	40.2%
Acute care	35.6%
Outpatient Rehabilitation	11.5%
Home care	2.3%
School District	5.7%
University Setting	5.7%
State Employed	
Connecticut	14.9%
New Jersey	55.2%
New York	29.9%
Highest Degree Earned	
Ed.D or PhD or SLP.D.	2.3%
Masters	97.7%
Degree conferred	
Northeastern USA	81.6%
Southeastern USA	9.2%
Midwestern USA	5.7%
Northwestern USA	2.3%
Southwestern USA	1.1%
Ethnicity	
White	87.4%
Hispanic	2.3%
Asian	6.9%
Black/African American	3.4%

When asked how frequently they worked with persons who had advanced dementia most respondents reported they worked with this population daily (37, 42.5%) or weekly (31, 35.6%). Nine respondents (10.35%) worked with patients with dementia monthly, and 10 (11.5%) worked with the population less than monthly. When the respondents were asked to identify the methods by which they learned about tube feeding for persons with advanced dementia, respondents were given the following choices: self-directed literature review, continuing education, graduate coursework or none of the above. In the category of self-directed literature review 76 (85.1%) responded, continuing education 74 (85.1%) responded and 41 (47.1%) chose graduate coursework, only 2 (2.3%) chose the category none of the above. Respondents were able to choose more than one category to answer this question.

## **Findings**

To answer Hypothesis 1, that "the majority of SLPs' responses to each content knowledge statement will be incorrect relevant to current literature regarding tube feeding use in persons with advanced dementia", content knowledge questions were scored individually. Upon review of the data 83 of the 87 respondents (95%) answered correctly when asked if tube feeding prevented aspiration in persons with advanced dementia. Table 2 shows the frequency distribution in response to the statement "Persons with advanced dementia will not aspirate if they are tube fed."

**Table 2. Persons with advanced dementia will not aspirate if tube fed**

N	Strongly disagree (%)	Disagree (%)	Unsure (%)	Strongly Agree (%)
87	75.9	19.5	3.4	1.1

**Note: Correct answer is strongly disagree or disagree**

When asked if knowledge of nutrition is necessary to make non-oral feeding recommendations for persons with advanced dementia, 71 (81.6%) respondents answered the question correctly. Table 3 shows the frequency distribution.

**Table 3. Knowledge of nutrition necessary**

N	Strongly disagree (%)	Disagree (%)	Unsure (%)	Agree (%)	Strongly Agree (%)
87	4.6	9.2	4.6	47.1	34.5

**Note: Correct answer is strongly agree or agree**

When asked if pressure sores could be prevented with the use of tube feeding, 54 (62%) respondents answered the question correctly and 33 (37.9%) respondents answered incorrectly. This question generated the greatest amount of variability. Table 4 represents the distribution of responses for this question.

**Table 4. Pressure sores can be prevented with the use of tube feeding**

N	Strongly Disagree (%)	Disagree (%)	Unsure (%)	Agree (%)	Strongly Agree (%)
87	17.2	44.8	18.4	18.4	1.1

**Note: Correct answer is strongly disagree or disagree**

Table 5 presents a frequency distribution for, "My knowledge base of the benefits and risks of tube feeding persons with advanced dementia is adequate in order to make recommendations to physicians about specific non-oral feeding methods." Fifty- nine (67.8%) respondents answered this question correctly. Twenty- eight answered the question incorrectly.

**Table 5. My knowledge of benefits and risks of tube feeding....**

N	Strongly Disagree (%)	Disagree (%)	Unsure (%)	Agree (%)	Strongly Agree (%)
87	6.9	14.9	10.3	48.3	19.5

**Note: Correct answer is strongly agree or agree**

When asked if, advanced dementia is a terminal illness, fifty- nine respondents (67.8%) answered correctly and 28 respondents (32.1%) answered this question incorrectly.



**Table 6. Advanced dementia is a terminal illness**

N	Strongly disagree (%)	Disagree (%)	Unsure (%)	Agree (%)	Strongly Agree (%)
87	3.4	23.0	5.7	33.3	34.5

**Note:** Correct answer is strongly agree or agree

Total score for all content questions, which ranged from 1 to 5, revealed a mean of 3.74 with a standard deviation of 1.05. Twenty three respondents (26.4%) answered all 5 content questions correctly, and 33 respondents (37.9%) answered 4 content questions correctly. Thirty- one respondents (35.6%) answered 3 or fewer questions correctly. The majority of respondents answered 3 or more questions correctly thus not supporting the hypothesis.

**Table 7. Total score: Content knowledge questions**

Number Correct	Frequency correct answers	Percent
1	3	3.4
2	8	12.6
3	20	23.0
4	33	37.9
5	23	26.4

Analysis of the data revealed that Hypothesis 2, that “the majority of SLPs will report they frequently recommend tube feeding for persons with advanced dementia”, was not supported. Only 9% of the respondents reported frequently recommending tube feeding for this population. The frequency distribution in Table 8 shows that most respondents indicated that they disagreed (50, 57.5%) and strongly disagreed (22, 25.3%) with the

statement "I routinely recommend tube feeding for persons with advanced dementia." Only 7 respondents agreed (8.0%) and 1 strongly agreed (1.1%).

**Table 8. Routinely recommend tube feeding for persons with advanced dementia**

N	Strongly disagree (%)	Disagree (%)	Unsure (%)	Agree (%)	Strongly Agree (%)
87	25.3	57.5	8.0	8.0	1.1

To answer Hypothesis 3a, that "there will be a relationship between practice setting and individual responses to recommendation practice statements", and Hypothesis 3b, that "there will be a relationship between practice setting and individual responses to content knowledge statements", chi square analyses were conducted. In order to conduct valid chi square analyses, cells of like categories were collapsed (skilled nursing/long term care, and home care) and some questionnaire choices were withheld from analysis to minimize or eliminate cells with expected values of less than 5 (Downie & Heath, 1974). The strongly disagree category was collapsed with the disagree category, and the strongly agree category was collapsed with the agree category. Also, since so few respondents chose the question option "unsure," respondents who chose this option were withheld from analysis as well. In most cases, these changes resulted in no or few cells having expected values less than 5.

Upon review of the data, recommendation practice questions were not statistically related to practice settings. Chi-square analysis on practice question 1, "I engage in discussions with physicians" revealed a non-significant  $X^2$ , ( $X^2=.031$ ,  $p=.85$ ), indicating that no relationship exists between the practice settings and the responses to practice question 1. When looking at practice question 6, "I routinely recommend tube feeding for persons with advanced dementia" a non-significant  $X^2$ , ( $X^2=2.19$ ,  $p=.13$ ), indicating that no relationship exists between the practice settings and responses to practice question 6. It is important to note that 2 cells had expected values less than 5. Recommendation practice question 7, "Recommend tube feeding is within scope of practice", a non-significant  $X^2$  was obtained, ( $X^2=1.13$ ,  $p=.28$ ), indicating that no relationship exists between the practice settings and the responses to practice question 7. For recommendation practice statement 9, "I use structured guidelines for non-oral feeding recommendations" a non-significant  $X^2$  was obtained, ( $X^2=.16$ ,  $p=.68$ ), indicating that no relationship exists between the practice settings and responses to practice question 9. A non-significant  $X^2$  was also obtained ( $X^2=.45$ ,  $p=.49$ ) for practice statement 10 "I use knowledge of nutritional needs when making recommendations" indicating no statistical relationship exists between practice setting and practice statement. Based upon this data hypothesis 3a was not supported.

The results of chi-square testing for content questions also revealed responses to content statements were not statistically related to practice

settings. When reviewing responses for content question 2, "Persons with advanced dementia will not aspirate if they are tube fed" there was no variability in responses and as such chi-square could not be computed. Practice setting was not statistically related to content questions regarding nutrition, ( $X^2=.01$ ,  $p=.91$ ), pressure sores ( $X^2=.18$ ,  $p=.66$ ), benefits and risks of tube feeding ( $X^2=1.23$ ,  $p=.26$ ), or terminal illness ( $X^2=.63$ ,  $p=.42$ ). Based upon this data hypothesis 3b was not supported.

To answer Hypothesis 4a, "SLPs practicing in long term care facilities will score higher on total content knowledge score as compared to those practicing in acute care facilities", a one way analysis of variance (ANOVA) was conducted. Results did not reveal any significant differences in total content score based on practice setting, [ $F(2,84)=.22$ ,  $p=.80$ ].

Upon reviewing the demographic data, 23 SLPs reported having 5 or fewer years of experience while the remaining 64 respondents indicated that had more than 5 years of experience. The respondents were compared in terms of their overall content knowledge score. A one-way ANOVA did not reveal any significant differences in total content score for the SLPs grouped by years of clinical experience, [ $F(4, 82) = 1.84$ ,  $p=.12$ ]. Thus Hypothesis 4b, "SLPs with greater than 5 years of experience will demonstrate higher total content knowledge score than those with less years of experience" was not supported.

To answer Hypothesis 4c, "SLPs who work daily with persons with advanced dementia will demonstrate higher content knowledge score than those who work less frequently with persons with dementia", a one way analysis of variance was conducted to determine if significant differences exist on the total content score by how often respondents worked with patients with dementia. A significant F was obtained [ $F(3, 83) = 2.71, p = .05$ ]. Scheffe post hoc comparisons were used to identify actual group differences which indicated that the subjects who worked with dementia patients daily (mean=4.02) and monthly (mean =4.11) had significantly higher mean content question scores than subjects who worked with dementia patients weekly (mean = 3.41) and less than monthly (mean = 3.40). Thus Hypothesis 4c was supported. The means and standard deviations are presented in Table 9.

**Table 9. Total score content questions by frequency of working with Persons with advanced dementia**

Frequency of working population	N	M	SD
daily	37	4.02	.95
weekly	31	3.41	1.05
monthly	9	4.11	1.05
less than monthly	10	3.40	1.17

### **Open Ended Question**

In order to explore any additional recommendation practices, respondents were asked to complete an open ended question, "Please provide any other feeding recommendation practices for persons with advanced dementia". This allowed the researcher to explore any additional recommendation practices made for this population that were not assessed by the survey's quantitative questions. Although this response was optional, a total of 63 (72%) of respondents answered the open-ended question. Fifty-eight respondent's comments were transcribed post-hoc and coded into themes. Five respondent's comments were withheld from analysis as their responses were either unintelligible due to typographical errors or the comments did not pertain to the question. A total of 124 comments were transcribed and coded. Data was examined using a thematic analysis as described previously in the literature by Braun & Clarke (2006). This method allowed the researcher to use inductive means by coding key semantic terms into discovered categories allowing common themes to emerge. As presented in Table 10, "Open ended recommendations for persons with advanced dementia", two general categories emerged from the individual question data set. These categories included; Ethical Decision Approach (EDA) and Specific Feeding Recommendations (SFR). From these two categories 9 themes emerged. The majority of comments (90) related to Ethical Decision Approaches including, interdisciplinary or multidisciplinary

feeding decisions (29), following advance directive (20), family education/training (19), quality of life issues as driving recommendations (12) and, using palliative care approaches (10) were noted. Thirty-four comments pertained to Specific Feeding Recommendations including; adjusting P.O. diet (15), compensatory treatment strategies (8), advocating tube feeding use (7), and recommending additional instrumentation studies such as Modified Barium Swallow or Fiberoptic Endoscopic Evaluation of Swallowing (4).

**Table 10. Open ended "recommendations for persons with advanced dementia"**

Inductively Developed Thematic Categories

Category	Thematic Category	Key semantic terms	#	Characteristic Response
Q1. Please provide any other feeding recommendations for persons with advanced dementia.				
Ethical Decision Approach (EDA)				
EDA 1	Interdisciplinary Approach	Interdisciplinary, multidisciplinary, team discussion, ethics committee	29	"I discuss options with family, physician and dietician"
EDA 2	Advance Directive	Living will, advance directive, patient wishes, proxy	20	"Always follow patient's written directive first"
EDA 3	Family Education	Provide education to family, family counseling, caregiver education	19	"I talk with families about pros and cons and educate them"
EDA 4	Quality of Life	quality of life	12	"Quality of life is the most important component of the decision"
EDA 5	Palliative Care	Hospice, A.N.D.(allow natural death), palliative care	10	"allow nature to take its course"
Specific Feeding Recommendation (SFR)				
SFR 1	Adjust PO diet	Adjust PO diet level, hand feeding, continue PO feeding	15	"adjust dietary choices and consistency"
SFR 2	Compensatory treatment strategy	Posture, oral care, adaptive feeding equipment	8	"Increase HOB, increase oral care"
SFR 3	Tube feeding	NG, PEG, alternate nutrition, hydration	7	"consider alternate nutrition if unable to meet needs by mouth"
SFR 4	Instrumentation	MBS, FEES study,	4	" I recommend MBS"



## CHAPTER V

### DISCUSSION

The purpose of this study was to explore speech-language pathologists' content knowledge and recommendation practices regarding tube feeding use in persons with advanced dementia. Data was collected through an online survey that was distributed to members of listserves whose participants specialize in swallowing disorders. A total of 87 respondents completed the online survey. The respondents consisted of experienced SLPs who worked with persons with advanced dementia in New Jersey, New York and Connecticut.

Four hypotheses were posed at the start of the study. The first hypothesis predicted that the majority of speech-language pathologists' responses to individual content knowledge statements would be deficient relative to current medical literature. Between 62%-95% of respondents answered content knowledge statements correctly. However, there was some variability in two of the statements that warrant discussion. Only 62% of the respondents understood that pressure sores cannot be prevented by using tube feeding. This statement is directly related to nutrition and how the body metabolizes nutrients during the end of life. It is widely recognized in the medical literature that skin integrity will not be improved for this patient population using of tube feeding (Silverman et al., 2008; Henderson et al., 1992). As one of the primary reasons to use tube feeding is to improve

nutrition (Logemann, 1998) it would seem important that SLPs understand how this artificial nutrition is utilized by a patient in the end stages of their illness.

Recognition of advanced dementia as a terminal illness was another content statement that demonstrated variability in responses. Thirty-two percent indicated that they did not believe or were unsure if advanced dementia was a terminal condition. This is alarming, as it is widely recognized in the medical literature that a diagnosis of advanced dementia is reflective of the end stage of their illness. This staged condition is identified by the physician (Focht, 2009). Therapeutic approach is dependent on accurate medical diagnosis and prognosis (Jonsen et al., 1992). Understanding a patient's phase of illness will influence the philosophical framework used by the speech-language pathologist. If the therapist does not believe the patient to be in the end stage of life then it is unlikely a palliative care framework will be adopted as guiding the swallowing treatment. This could potentially lay the foundation for recommendation practices that may be misaligned with best practice for terminal patients. For example, Mitchell, Teno & Keily et al. (2009), investigated the last month of life in persons with advanced dementia and discovered that patients undergo burdensome care that yield no benefit. Some of these treatments were tube feeding, increased use of antibiotics, and transfers in and out of acute care facilities. These treatments can negatively impact quality of life and place

unnecessary burden on both families and patients. Misinterpreting the patient's prognosis may cause the SLP to recommend treatments that the patient can no longer benefit from. Gaps in content knowledge and misperceptions of these patient outcomes are common in other stakeholders as well and demonstrated throughout the literature (Shega et al., 2003; Vitale et al., 2006; Hanson et al., 2008; Lopez et al., 2010, Lacey et al., 2004; Mitchell & Lawson 1999; Teno et al., 2011).

The second hypothesis predicted respondents would report frequently recommending tube feeding for persons with advanced dementia. Only 9% of respondents in this study reported routinely recommending tube-feeding for persons with advanced dementia. This is consistent with medical literature advising against tube feeding persons with advanced dementia (Volcier, 2005; Finucane et al., 2009) however it is in contradiction to both Sharp & Shega (2009) and Vitale et al. (2011) findings that over 50% of respondents continue to recommend tube feeding for this population. In addition, Sharp & Shega (2009) also identified SLPs from New York and New Jersey as perceiving tube feeding as the standard of care for this population.

Speech-language pathologists work with this population in a number of different settings including acute care and skilled nursing facilities. Tube feeding placement procedures are conducted in the acute care setting (Kuo et al., 2009). Residents are commonly transferred into acute care and feeding tubes are placed prior to their return to skilled nursing facilities. This

researcher suspected that there may be a difference in SLPs' content knowledge based on practice setting. Speech-language pathologists working in long term care have increased exposure to this population in comparison to the therapist working in the acute care center. This survey was unable to determine if any significant relationship existed between SLPs' practice settings and responses to individual content knowledge or responses to individual recommendation practices.

The study also attempted to look for relationships between total content knowledge score and practice setting; experience level; and frequency of working with persons with advanced dementia. No significant differences existed in total content knowledge score based on practice setting or years of experience. Differences did however exist in total content knowledge score based on how often the SLP worked with persons with advanced dementia. For example SLPs who worked daily with persons with advanced dementia demonstrated higher mean total content knowledge score as opposed to those who worked weekly or less than monthly with this population. An unexpected result was that persons who worked monthly with this population also demonstrated a high mean total content score in comparison to persons who worked weekly or less than monthly. However as this was such a small group it is difficult to discern level of significance. Vitale et al. (2011) reported that having increased experience with this population had a greater effect on content knowledge than did actual formal

coursework. In their study, experience working with more numbers of persons with advanced dementia predicted knowledge. Although this current survey did not ask the respondent to indicate the exact number of clients they worked with who were diagnosed with advanced dementia the findings are similar.

Related to content knowledge, SLPs reported how they received information about tube feeding persons with advanced dementia. Respondents were permitted to choose more than one learning method. Most SLPs, over 80%, reported accessing continuing education or self-directed literature review. 47% indicated learning about this population through their graduate curriculum. This is not surprising as this was a group of experienced SLPs who with 16 to 20 years plus experience. It is possible that most graduated before swallowing courses were required in the graduate curriculum explaining why most did not choose graduate curriculum.

Overwhelmingly most SLPs in this study, (95%), correctly agreed that tube feeding does not prevent aspiration in this population. This is consistent with current medical literature that recognizes this patient population continues to demonstrate aspiration pneumonia even after receiving tube feeding (Finucane et al., 1999). However this finding is in contrast to both Sharp and Shega (2009) and Vitale et al. (2011) who report SLPs continue to believe that aspiration can be prevented with tube feeding. This contrast in content knowledge may be reflective of recent successful campaigns for

continuing education on this topic by the American Speech-Language and Hearing Association that focused on the fact that aspiration cannot be prevented for this population by the use of tube feeding (Wagner, Sharp, & Bolster, 2009).

Thematic analysis of an open ended question provided another data source in this study. Respondents were asked to “provide any other feeding recommendations for persons with advanced dementia”. Two general categories emerged; Ethical Decision Approaches and Specific Feeding Recommendations. Ethical Decision Approaches described by respondents in this study are consistent with Kenny et al. (2010) finding that “focusing on the well-being of others” is one of the five aspects central to ethical reasoning used by experienced SLPs. Comments were also consistent with a shift toward a palliative care framework as respondents comments reflected on “quality of life” as being paramount to decision making. Jonsen et al. (1992) ethical reasoning model was supported as comments regarding autonomy and adhering to “patient preferences” were revealed. Respondents also reported specific feeding recommendations to include continuing with oral diet level and promoting hand feeding. These recommendations are reflective of literature directed at decreasing burdensome interventions in end of life (Mitchell & Teno et al., 2009; Kuo et al., 2009).

The results of the open ended portion of this survey also revealed that 20% of specific feeding recommendations continue to include consideration of

tube feeding for this population. This is in contrast to some of the respondents' likert statement responses. Respondents may have felt more comfortable writing about their recommendations for tube feeding in a narrative format versus a forced choice likert format. In this way they could explain or talk about their recommendations.

Lastly this current study did not attempt to investigate SLPs personal values in relationship to influencing decision making for tube feeding. It may be that personal values or the culture may drive recommendations for this population (Kenny et al., 2010).

### **Limitations**

The primary limitation of this study is its small sample size. It is not possible to generalize these responses to other populations of SLPs as power was not achieved. It is also likely that the states these respondents were employed in differ in population density and financial constraints of health care systems in comparison to SLPs from other geographic regions. As such it is not possible to compare this population of respondents to other populations of SLPs. This was also a sample of convenience, who learned about the survey from a flier distributed on a listserve. When using listserve recruitment it is not possible to confirm how many SLPs saw the recruitment e-mail or viewed the survey. It is also not known how many SLPs belonging to the listserve could have potentially met the inclusion criteria for this study.

For example, is it not possible to know how many persons who belong to the listserve work with persons with advanced dementia. As such it is very possible that this population is not representative of SLPs who work with persons with dementia. Reliability of responses is always a concern in survey research. Respondents may have been unwilling to indicate true recommendations if they felt they were contrary to accepted norms. Respondents may also demonstrate the Hawthorne Effect causing them to respond differently simply because they knew they were taking a survey. The respondent may have answered in a way which they thought was most acceptable to the researcher. The researcher attempted to minimize this bias by phrasing statements in a neutral tone. Also the respondents may have been influenced by self-lifting bias. An example of this would be answering in such a way that would shed a positive light on the responder. The researcher attempted to control for this by posting likert questions first and personal demographic questions at the end of the questionnaire so that the personal demographic information did not affect answers to content knowledge or recommendation practice statements (Portney & Watkins, 2009). The "Habit bias" may also influence responders. Habit bias may take place when a survey respondent falls into the habit of answering statements similarly without considering each statement individually. The researcher attempted to control for this by formatting the content knowledge likert statements differently from one another (Dillman, 1978). The pre-coding of content



statements into correct or incorrect based on current medical literature is a limitation as this was based on best evidence to date and as new evidence emerges this information may change.

Lastly, construction of likert scale statements may be a limitation. It is impossible to measure if categories (strongly agree, agree, unsure, disagree, strongly disagree) have equal intervals between them. The researcher attempted to control for this by collapsing the categories post hoc forcing a yes or no response for content knowledge statements.

## **Chapter VI**

### **SUMMARY AND CONCLUSION**

The results of this study build on the small body of literature that exists regarding perceptions of healthcare professionals regarding tube feeding persons with advanced dementia. One of the most important findings of this study revealed that experienced SLPs do not routinely recommend tube feeding for persons with advanced dementia and most respondents demonstrated content knowledge consistent with current medical literature. However the variability in some responses to content knowledge statements may highlight gaps in SLPs' content knowledge specific to this population. These gaps are consistent with the findings of both Sharp & Shega (2009) and Vitale et al. (2011), as they conclude there are misperceptions held by SLPs about the outcomes of tube feeding for this patient population. This may indicate a need for better training of speech-language pathologists in this area. This lack of knowledge and disconnect regarding outcomes for tube feeding this population has also been reported in the literature for physicians and other healthcare professionals.

In order to examine the usefulness of these findings, a larger scale study with a focus on external influences and ethical decision making approaches used by SLPs should be conducted. Sampling SLPs from a

variety of ethnic and cultural backgrounds could yield more information regarding the influence of personal values on recommendation practices and the decision- making process. Ultimately, this study recognizes the SLPs' role as a stakeholder and participant in this complex ethical decision for this important and vulnerable population.

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## Appendix A

## Survey Tool

**Title: Tube Feeding Use in Persons with Advanced Dementia: Speech Language Pathologist's Content Knowledge and Recommendation Practices**

**1. Please indicate your level of agreement with the following statements.**

**1. I engage in discussions with physicians about hospice and palliative care options for persons with advanced dementia.**

Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
5	4	3	2	1

**2. Persons with advanced dementia will not aspirate if they are tube fed.**

Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
5	4	3	2	1

**3. Knowledge of nutrition is necessary to make non-oral feeding recommendations for persons with advanced dementia.**

Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
5	4	3	2	1

**4. Pressure sores can be prevented with the use of tube feeding in persons with advanced dementia.**

Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
5	4	3	2	1

**5. My knowledge of the benefits and risks of tube feeding persons with advanced dementia is adequate to make recommendations to physicians about specific non-oral feeding methods.**

Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
5	4	3	2	1

**6. I routinely recommend tube feeding for persons with advanced dementia.**

Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
5	4	3	2	1

**7. Recommending methods of tube feeding is within the scope of practice of the speech language pathologist.**

Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
5	4	3	2	1

**8. Advanced dementia is a terminal illness.**

Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
5	4	3	2	1

**9. I use structured guidelines for non-oral feeding recommendations for persons with advanced dementia.**

Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
5	4	3	2	1

**10. I use knowledge of nutritional needs when making recommendations for persons with advanced dementia.**

Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
5	4	3	2	1

**II. Background Information:**

Please respond to the following questions

1. How many years have you worked as a speech- language pathologist?

- ☐ 0-5
- ☐ 6-10
- ☐ 11-15
- ☐ 16-20
- ☐ 20+

2. What is your ethnic background (ASSET program will provide drop down menu).

3. Where do you live?

- ☐ Northeastern United States
- ☐ Southeastern United States
- ☐ Northwestern United States
- ☐ Southwestern United States
- ☐ Midwestern United States
- ☐ Outside the United States

4. What is your highest degree earned?

- ☐ Ed.D. or Ph.D. or SLPD
- ☐ M.S. or M.A

5. What are your credentials?

- ☐ Certificate of Clinical Competence (CCC) from ASHA
- ☐ Certificate of Clinical Competence and Board Recognized Specialist in Swallowing and Swallowing Disorders (CCC-BRS-S)
- ☐ Currently completing my CFY year

6. Which practice setting best describes your primary place of employment as defined by 50% or more of your work hours per week?

- ☐ Skilled Nursing or Long Term Care Facility
- ☐ Acute Care facility
- ☐ Rehabilitation facility
- ☐ Home Care
- ☐ Hospice
- ☐ School District
- ☐ Private Practice
- ☐ University Setting

7. How frequently do you work with persons who have advanced dementia?

- ☐ daily
- ☐ weekly
- ☐ monthly
- ☐ less than monthly

8. Where did you receive your professional degree?

- ☐ Northeastern United States
- ☐ Southeastern United States
- ☐ Northwestern United States
- ☐ Southwestern United States
- ☐ Midwestern United States
- ☐ Outside of the United States

9. Please check all the ways in which you have received information about tube feeding use in persons with advanced dementia (you may check more than one).

- ☐ Graduate coursework
- ☐ Continuing Education
- ☐ Self-directed literature review
- ☐ None of the above

**III. Please describe your recommendation practices for persons with advanced dementia.**

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Appendix B  
Recruitment E-mail

Dear Speech-Language Pathologist,

**Subject: Invitation to Participate in Research about Tube Feeding in Persons with Advanced Dementia**

A research study investigating speech language pathologist's content knowledge and recommendation practices regarding tube feeding for persons with advanced dementia is being conducted. I am seeking speech language pathologists with experience working with persons with advanced dementia who work in Connecticut, New Jersey or New York. Participants will complete an on-line survey about their tube feeding content knowledge and recommendation practices with persons who have advanced dementia.

Consent will be demonstrated by your voluntary completion of the on-line survey. The survey will take approximately 10 minutes to complete.

There will be no cost involved in participating in this research. All responses will be anonymous and confidential.

Data collected from your anonymous survey will be stored on a USB memory key and locked in a secure file cabinet in my office.

To take the on-line survey, log on to:

<http://asset.tlrc.shu.edu/servlets/asset.AssetSurvey?surveyid=1628>

If you have any questions about your participation in this project, please contact Patricia A. Remshifski, principal investigator, at the location below:

Patricia A. Remshifski M.S. CCC SLP  
Assistant Professor  
Department of Speech- Language Pathology  
Seton Hall University  
South Orange NJ 07079

Phone: 973-313-6121  
E-mail: [remshipa@shu.edu](mailto:remshipa@shu.edu)

This research has been approved by the Institutional Review Board of Seton Hall University.

## Appendix C Informed Consent/Invitation to Participate



**Subject: Invitation to Participate in Research about Tube Feeding in Persons with Advanced Dementia**

A research study investigating speech language pathologist's content knowledge and recommendation practices regarding tube feeding for persons with advanced dementia is being conducted. I am seeking speech language pathologists with experience working with persons with advanced dementia. Participants will complete an on-line survey about their tube feeding content knowledge and recommendation practices with persons who have advanced dementia.

Consent will be demonstrated by your voluntary completion of the on-line survey. The survey will take approximately 10 minutes to complete.

There will be no cost involved in participating in this research. All responses will be anonymous and confidential.

Data collected from your anonymous survey will be stored on a USB memory key and locked in a secure file cabinet in my office.

To take the on-line survey, log on to:

(URL will be provided upon IRB approval)

If you have any questions about your participation in this project, please contact Patricia A. Remshifski, principal investigator, at the location below:

Patricia A. Remshifski M.S. CCC SLP  
Assistant Professor  
Department of Speech- Language Pathology  
Seton Hall University  
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Phone: 973-313-6121  
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This research has been approved by the Institutional Review Board of Seton Hall University.

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