

**FEEDING TUBE INTERVENTION:
FACTORS INFLUENCING DECISION MAKING IN PATIENTS WITH ALS**

by

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Eating and drinking are necessary and pleasurable events that take place every day in a person's life. Individuals with a swallowing disorder, known as dysphagia, have difficulty swallowing food and drinks. This impairment can result in an unpleasant swallowing process or an inability to swallow and associated health issues. Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease which inhibits, and eventually destroys, motor nerve cells in the brainstem and/or spinal cord that control voluntary muscle movement. Patients with ALS will develop dysphagia at some point in the disease process. Some patients opt to use artificial feeding tubes to supplement intake when they cannot obtain adequate nutrition/hydration orally. There are many factors that could affect this decision. This study aims to identify these factors through patient interviews.

Six participants who attended an ALS specialty clinic were interviewed by a third party investigator. The question set used in the interview was based on six main topic areas (background, information, values, outside pressures, support, and reflection), which were also used in a "sister study" by Vesey, Leslie, and Exley in 2008. The de-identified interview transcripts were analyzed using a coding method. The transcripts were coded by the primary investigator based on themes generated in the participants' responses. A second coder was used to check the primary coder's interpretations and to confirm that the conclusions from the transcripts were reasonable.

Patient-generated themes and individual factors were derived from the interview transcripts. Major themes found across patients include information, influences, support, and independence. Some unique personal factors found include how the feeding tube affects an individual's appearance, social restrictions, and weighing the risks and benefits of timing of feeding tube placement. Clinicians need to understand factors patients consider when making the decision to accept or to decline a feeding tube.

For clarity, male pronouns such as he/him/his will be used when discussing a patient or client. Female pronouns such as she/her/hers will be used when discussing the clinician.

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PREFACE

I would to acknowledge and thank my thesis committee for their continuing support and guidance throughout this project. I would also like to thank Siobhan Vesey, Paula Leslie, and Catherine Exley for their work on the sister study which led to my current work.

1.0 INTRODUCTION

Eating and drinking are both necessary and pleasurable everyday events. Daily schedules are dictated by meal times, formal events revolve around food and drink, and social gatherings often take place at restaurants or bars. An individual's daily intake provides nourishment to stay healthy and strong. Food and drink also provide the pleasures of taste and the enjoyable sensations of fullness and satisfaction. Satisfaction and nourishment from eating and drinking are not attainable for all people, especially those with a swallowing disorder.

Swallowing is defined by Mosby's Medical Dictionary as:

The process that usually involves movement of food from the mouth to the stomach via the esophagus. Coordination of muscles is needed from the tongue to the esophageal sphincter. ("Mosby's Medical Dictionary," 2009).

This simple definition provides a general overview of what swallowing entails but does not give a complete description. The "food or drink" referred to in the definition is called a bolus that is formed/controlled during the swallow. Swallowing as a process involves a continuum of movement of the bolus as it is taken into the mouth, passes through the pharynx and enters the stomach. The bolus is prepared in the oral cavity by mastication involving the tongue and teeth.

It is then sent to the back of the oral cavity and is transferred by way of the pharynx through the esophagus and into the stomach.

Swallowing is a vital component of eating and drinking for most people. It is the physical action that allows the substance to enter the stomach in order to fulfill daily nutritional needs. Individuals with a swallowing disorder, known as dysphagia, have difficulty swallowing food or drinks. This impairment can result in an unpleasant swallowing process or inability to swallow, leading to malnutrition and dehydration. Most people do not need to think about swallowing as they eat and drink, since it is a natural and automatic process. Though many people are not aware of their swallow, the ability to swallow safely allows for participation in events and enjoyment of food and drink. Since swallowing is such an integral part of daily life, the results of deterioration or loss of this function are dramatic and devastating (Vesey, 2013).

Research shows that sucking behaviors occur in utero (Poore, Barlow, Wang, Estep, & Lee, 2008), which is why typically developing infants already have sucking and swallowing abilities from the moment they are born. At the other end of the continuum, the aging process does not account for the deterioration of swallowing function seen in some elderly people. The common misconception that aging has a direct effect on swallowing issues is due to the fact that there is a connection between aging and dysphagia. This is mainly in relation to the higher incidence of declined cognition, disease, or injuries which can cause a swallowing disorder to occur as a person ages (Ney, Weiss, Kind, & Robbins, 2009; White, O'Rourke, Ong, Cordato, & Chan, 2008). The correlation between aging and swallowing differences can also be attributed to the normal atrophy that occurs in aging adults. Parameters such as muscle activity, motor-unit density, and somatosensory perception, are found to differ between healthy young adults and

healthy older individuals. This difference is referred to as presbyphagia and is characterized by a *change* in swallowing, not a swallowing impairment (Humbert & Robbins, 2008).

Many conditions can cause a swallowing disorder, including direct injury to parts of the swallowing anatomy: lips, tongue, palate pharynx, larynx, or esophagus. Swallowing impairments can also be caused by congenital disorders, neurologic events such as a traumatic brain injury or stroke, or neurodegenerative diseases.

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease that affects the brain and brainstem nerve cells, the lateral columns of the spinal cord, and the lower motor neurons that arise from the spinal and cranial nuclei. The affected areas are those that control the movement of the voluntary muscles. As the nerve cells degenerate and die, the muscles they control begin to weaken and waste away. Since the muscles of the head, face, and neck can be affected early on in the disease process of ALS, speaking and swallowing become progressively more difficult. Swallowing may eventually become dangerous since the weakened muscles are unable to perform a safe swallow. A patient with weakened muscle function may not be able to completely protect his airway during a swallow, causing him to choke when attempting to eat or drink. This weakness also affects the amount of food/drink the person will be able to eat or drink, resulting in decreased nutrition and hydration. The decrease in nutrition and hydration then further weakens the patient and a cyclical pattern ensues (Veldee & Peth, 1992).

Dysphagia treatment approaches for patients with degenerative diseases vary and include the use of compensatory strategies, diet modification, and surgical intervention such as the insertion of a feeding tube. Treatment should be chosen based on the individual being treated. In patients with ALS, feeding tubes are put into place in an attempt to compensate for the

degeneration of the head and neck muscles needed for swallowing. A feeding tube allows nutrition/hydration to bypass the head and neck structures of swallowing that are impaired.

From a longevity viewpoint, a feeding tube can be an appropriate and necessary tool that serves the primary purpose of providing nourishment to a patient who is not able to receive nourishment orally (Sharp & Shega, 2009). From a patient's view, the use of a feeding tube is not always the best option for a comfortable life or end of life. This study provides information about which factors participants considered when making their decision to have a feeding tube or not. These factors will be unique to each individual patient. The themes will provide preliminary information on what topics related to feeding tubes and ALS are important to a group of patients. A detailed explanation of how people make decisions is beyond the scope of this study.

Factors that may influence a patient's decision making in this particular scenario are explored with the goal of providing practicing clinicians with support when working with these patients. This information may also be of use to clinicians working with other populations. Such clinicians can then work more effectively with similar populations when assisting with making decisions about feeding tubes.

1.1 DYSPHAGIA

Dysphagia is a symptom of another disorder which may be structural or functional in origin. The term is used to describe impaired swallowing and is always found secondary to a main underlying issue, such as ALS. Some common signs of dysphagia are coughing, wet vocal quality (occurs when material is in the larynx during phonation), and complaint of pressure/pain in the throat.

Consequences of dysphagia include the passage of bolus material or saliva into the lungs. If this material contains bacteria then chest infections may occur, resulting in pneumonia. In addition to pneumonia, the most serious life threatening consequences of dysphagia are dehydration and/or malnutrition. Dysphagia also increases risk of choking, though everyone has this risk. The human body stays hydrated and nourished by absorbing nutrients and calories from the daily intake of fluids and solid food. The life-sustaining act of eating and drinking is simple and enjoyable for a healthy individual. For a patient with dysphagia, this task may be physically and emotionally demanding.

1.1.1 Classification

Dysphagia can be classified in many ways, as there are multiple swallowing difficulties that can occur. Each variation can be as serious, as uncomfortable, and as disruptive to life as another. Inability to keep food in the mouth (oral containment), difficulty initiating bolus propulsion, difficulty triggering the swallowing reflex, decreased hyolaryngeal elevation, and weakened pharyngeal compression are just a few of the many swallowing difficulties that a patient may encounter. Swallowing occurs as a continuum of events but clinicians and researchers use a framework which refers to “stages” within a swallow. Typically healthcare professionals refer to an oral preparatory stage, an oral transit stage, a pharyngeal stage, and an esophageal stage. These stages are described by Groher and Crary as follows:

(1) The oral preparatory stage, in which food is masticated in preparation for transfer; (2) the oral stage, which entails the transfer of material from the mouth to the oropharynx; (3) the pharyngeal stage, in which material is transported away from the

oropharynx, ... and (4) the esophageal stage, in which material is transported through the esophagus into the gastric cardi. (Groher & Crary, 2010), p. 20).

1.1.2 Assessment

Dysphagia can occur at any one point in isolation, or in combination with impairments at multiple points along the continuum of swallowing. It is important for the speech-language pathologist or other professionals responsible for diagnosing a swallowing disorder to know exactly where and why the dysphagia is occurring when beginning treatment with a patient with dysphagia. When diagnosing a swallowing disorder, a clinical swallow exam often does not always provide enough information. During the clinical evaluation, the speech-language pathologist is not able to see exactly what is happening physiologically inside the patient's oral cavity, pharynx, or larynx; only overt signs of dysphagia are observed. Some patients with dysphagia may not exhibit any obvious signs during an evaluation.

In many situations, the speech-language pathologist may decide that an instrumental swallowing exam may be necessary to obtain more information on the anatomy or biomechanics. Two common instrumental swallowing exams are the videofluoroscopic swallow study and the endoscopic swallow study. Both studies provide information about a patient's swallow (Langmore, 2003). The studies allow for views of the anatomy and physiology at rest and during swallowing, as well as the effects of possible interventions such as bolus modifications or postural changes.

A videofluoroscopic study is a dynamic x-ray image which captures the oral cavity, pharynx, larynx, and upper esophagus. In this study the patient is instructed to swallow different consistencies of radiopaque material. The clinician is able to observe the anatomy and

physiology during the swallow. Movement of the bolus from the oral cavity to the upper esophagus can be seen together with entry of material into the airway.

An endoscopic swallow study is performed by a clinician passing an endoscope through a patient's nasal cavity and into the pharynx. Once the scope is in place, the clinician is able to see the pharyngeal and laryngeal anatomy at rest and during movements of laryngeal structures. This view is limited to the pharynx and larynx. The clinician is not able to see oral or esophageal structures and, during the pharyngeal stage, the endoscope view is obscured by pharyngeal wall contraction.

1.1.3 Treatment

There is no single treatment for patients with dysphagia, and treatment and prognosis depend on the individual and the cause of the dysphagia. There are three different types of intervention a patient may receive: rehabilitation, compensation, or environmental control. The goal of each of these treatment methods is for the patient to take supplemental or full oral nutrition as safely as possible in order to achieve adequate nutrition and hydration.

Rehabilitative or restorative treatment for dysphagia involves working towards repairing or regaining function of structures involved in swallowing, which have lost strength or precision of movement. This approach may involve strengthening exercises, such as base of tongue (BOT) strengthening, depending on the cause of the dysphagia (Ney, Weiss, Kind, & Robbins, 2009). The Iowa Oral Performance Instrument (IOPI) can be used as a valid and reliable means of assessing and tracking tongue strength and endurance (Adams, Mathisen, Baines, Lazarus, & Callister, 2013). Other rehabilitative treatments could include options such as electrical or

sensory stimulation. A change in diet may be necessary for other patients, as specific textures and consistencies may be easier and/or safer than others to swallow (Goulding & Bakheit, 2000).

Some patients will not benefit from the rehabilitative approach, and they will not be able to regain the muscle strength and coordination needed for a naturally safe swallow. For these patients, compensatory strategies may be beneficial. Compensatory strategies include postural or procedural techniques a patient can use in order to make his swallow as safe as possible. One example of a compensatory strategy is the “chin-tuck” method. This method would be used for a patient who demonstrates poor posterior oral containment or a delayed onset of the pharyngeal stage of swallowing. The patient is instructed to put his chin down towards his chest before he initiates a swallow. The act of flexing his head down prior to swallowing should allow the patient to more easily control the bolus during the swallow which will result in adequate oral containment. The method reduces the distance between both the thyroid cartilage and the hyoid bone and between the hyoid and the mandible. This inhibits a misguided bolus from deeply penetrating into the larynx (Bulöw, Olsson, & Ekberg, 2001), and reduces the hypopharyngeal pressure, allowing for ease of bolus passage. The “chin-tuck” is just one of many different possible compensatory strategies that may be used, though the evidence base for their effectiveness is small (Bulow, Olsson, & Ekberg, 2002).

Environmental management strategies can be beneficial for all patients with dysphagia. These strategies can be used in combination with rehabilitative or compensatory treatment. Environmental management includes any type of environmental structuring, such as a sign in a patient’s room reminding clear his throat after swallowing. Environmental management often includes other caregivers working with the patient during mealtime to ensure that he has the best

posture while eating or that his tray is positioned in a way that enables him to most effectively access his food and drink.

A patient who is unable to safely swallow may also need to have some type of diet modification. Diet modifications can include measures such as thickening liquids, softening solids, or avoiding certain types of food altogether, such as those with crumbly textures. These modifications may be used in combination with a compensatory strategy or with strengthening exercises. The speech-language pathologist works closely with the patient and his caregivers to assess the benefits of the diet modifications. The benefits of the diet modification should be continuously assessed and modified as the patient progresses.

Patient factors must be taken into consideration when deciding on an intervention type. First, a patient must be able to follow directions in order to participate in behavioral treatment. Next, factors such as the patient's presenting diagnosis, his current overall health status, his medical history, or his prognosis for improvement are reviewed. Exercises are contraindicated in certain patient populations. There is emerging evidence that moderate limb exercise is not harmful for patients with ALS, though this is conflicting with evidence for other patient populations. For example, it would not be beneficial to use muscle exercises for a patient with myasthenia gravis, a neuromuscular disease characterized by fluctuating muscle weakness (Cantor, 2010). Excess muscle movement or attempts at "strengthening" in these patients will result in increased muscle fatigue and may result in degeneration of muscle function. For some patients with myasthenia gravis, the act of chewing or swallowing independently or with assistance is exercise enough to cause this fatigue. Similarly, strengthening exercises are not recommended for patients with degenerative diseases, including ALS. The goal for dysphagia

treatment with this patient population is to optimize function for as long as possible, rather than restore or repair (Bello-Haas et al., 2007).

In dysphagia treatment, each patient may or may not benefit from the various treatment options. Each individual's dysphagia is different and each individual will respond differently to various treatments. This is why it is necessary to work with each patient to find the best possible treatment.

1.2 TUBE FEEDING

In serious cases of dysphagia, the use of compensatory strategies, strengthening exercises, or diet modifications may not ensure adequate nutrition or hydration orally. In these cases, it may be necessary to bypass the oropharyngeal passage by means of a feeding tube. A feeding tube is designed to deliver necessary nutrition/hydration to the body of a person who is not able to fulfill his complete nutritional needs by route of oral intake.

Supplemental enteral nutrition was first delivered by enema, recorded by ancient Greeks and Egyptians as far back as 3000 B.C. The introduction of surgically placed feeding tubes did not occur until the mid to late 1800s (Minard, 2006). Since then, the surgical process has improved greatly, particularly within the last 25 years. Improvements have been made in both the physical properties of the tubes being inserted into patients and in the surgical methods of placing tubes used for non-oral feeding.

The technology for tube feeding placement began to develop in the 1940s. Researchers began to note the undesirable side effects that patients receiving tube feedings were

experiencing, such as diarrhea and local irritation (Chernoff, 2006). Medical care providers were unclear about what could be done to improve the feeding solutions until a study focusing on the needs of human amino acid led to a better knowledge of protein requirements in adults (Rose, 1949). This study prompted many medical professionals to look into what types of feeding solutions would be best absorbed by patients, leading to the variety of formulas and solutions which are available today (Kang, Lee, Paik, Kim, & Yang, 2010).

As of 2011, there were more than 100 different solutions commercially available for use in feeding tubes in the United States (Dudrick & Palesty, 2011). Dudrick and Palesty discuss the eight classifications of types of tube feeding – natural foods, polymeric solutions, monomeric solutions, special metabolic solutions, modular solutions, hydration solutions, medical foods, and nutritional supplements. Each type of tube feeding has its own risks and benefits, some of which include nutritional value, ease of digestion, cost, and ease of feeding administration.

A patient who is relying on a feeding tube will not be using the anatomical areas involved in swallowing. As these areas are less frequently used, the tone and strength of these structures begin to diminish. One such structure that is affected by non-use is the lower esophageal sphincter (LES). During a swallow in a normal healthy adult, the LES is relaxed only as the bolus travels through, remaining tight/contracted in areas where the bolus is not present. This contrast of contraction and relaxation produces adequate pressure for bolus propulsion. In a patient who is not adequately using his swallowing musculature, the LES is not relaxing properly or regularly. This results in a low or absent LES pressure at resting position (Mizock, 2007). Presence of a feeding tube can also contribute to a lower LES pressure. This lowered pressure can result in an increase of acid reflux which travels up the esophagus and can easily be aspirated by a patient.

1.2.1 Points of Insertion

Feeding tubes have two main points of insertion: via nasal passage or directly into the stomach through the wall of the abdomen. Feeding tubes may also be inserted through the oral cavity in cases when the tube cannot be placed nasally, though this is not a preferred point of insertion (Williams, 2008). The non-surgical route for a feeding tube is through the nasal or oral cavity, passing into the stomach or small intestine. This type of feeding tube placement is categorized as nasogastric, nasoduodenal, nasojejunal, or ileal, as shown in figure 1.

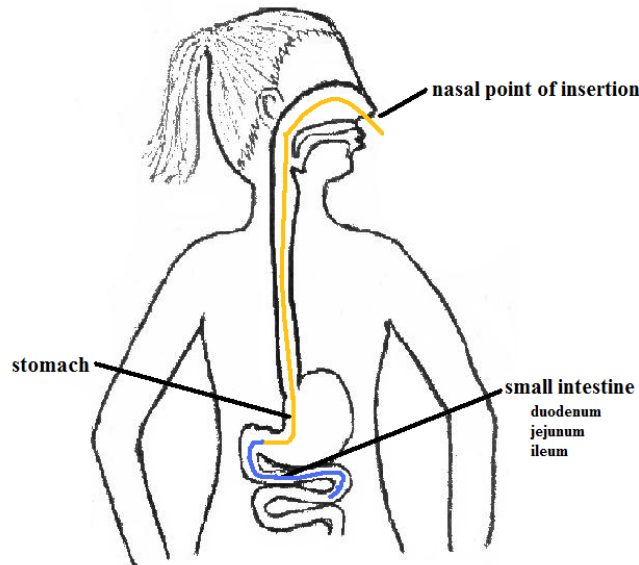


Figure 1: Nasal Feeding Tube Paths (Martin, 2013a)

A nasogastric feeding tube is placed through the nose, runs down the throat and esophagus, and into the stomach. A nasoduodenal, nasojejunal or ileal tube passes through the stomach and ends in the duodenum, jejunum, or ileum sections of the small intestine. The feeding tube may need to pass through the stomach and into the small intestine if the patient is at risk for gastroesophageal reflux. Bypassing the stomach can decrease this risk. The small intestine is not able to digest nutritional components in the same way that the stomach does. As

the feeding tube travels further down through the small intestine, a more complex feeding solution is necessary. Nasal feeding tubes carry food and medicine into the stomachs of patients who are unable to take in the necessary daily nutrients orally. They may also be used in a patient who is still able to consume some food or drink orally but is unable to obtain the necessary calories or hydration for the day.

Nasal feeding tubes are initially inserted by a nurse or other trained professional. In some cases the nasogastric tube can be inserted by a caregiver or even by the patient himself after much training and practice (Reimers, Vance, & Young, 1995). It is important that the feeding tube is secured during feedings. An x-ray may also be needed in order to ensure that any feeding tube with a nasal point of insertion does not pass through the larynx and into the lungs instead of down the esophagus and into the stomach or small intestine. It is not uncommon for tubes to be displaced, especially in high-risk patients such as those who are sedated (Kawati & Rubertsson, 2005). Patients who are sedated may not be aware of their environment or may not understand why they have a feeding tube. This lack of awareness or understanding could result in these patients becoming agitated or scared. Either emotion could cause the patients to attempt to remove the tube. In patients who are unsuccessful in complete removal of the feeding tube, it is common that the tubes are displaced.

A feeding tube may also be placed endoscopically. This procedure is performed by first inserting an endoscope through the oral cavity, down the pharynx and esophagus, into the stomach. A small incision is made in the skin on the left side of the abdomen and stomach or intestine (jejunum or ileum) and a flexible tube is inserted, the specific location depending on the anatomy of the patient's digestive system. A jejunal feeding tube may be inserted instead of a gastric tube if the patient has an obstruction in the stomach or any gastric resection (Machella &

Ravdin, 2013). Both procedural results may also need to be checked radiologically, as with the nasogastric tube placement, in order to ensure correct tube placement (see Figure 2).

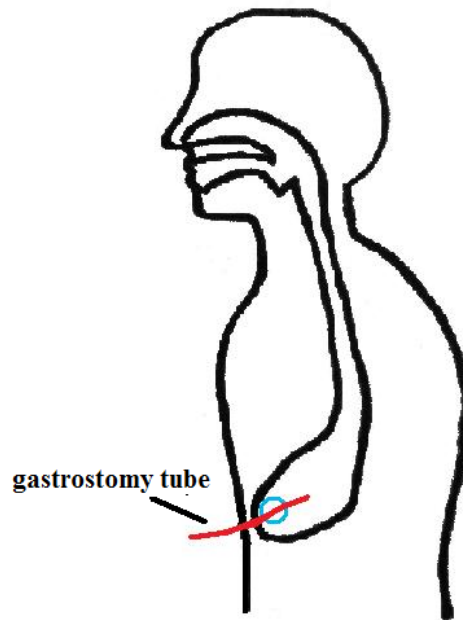


Figure 2: Gastrostomy Feeding Tube (Martin, 2013b)

The gastric feeding tube enters through the skin and the abdominal and stomach walls to allow tube feeding solution to enter directly into the stomach. A jejunal feeding tube passes through the skin and stomach into the small intestine, allowing tube feed to enter directly into the small intestine. This procedure usually has a good surgical prognostic outcome as most patients' stomach and abdomen completely heal in as little as five days (U.S. National Library of Medicine, 2012).

Training is required for the patient and/or caregivers to ensure that they do not harm the patient's stomach or intestines, or dislodge the feeding tube. Along with learning to properly clean and disinfect the area in the days following surgery, the patient and/or caregiver will need to be educated on the correct way to administer feedings (Dennis, Lewis, Warlow, & Collaboration, 2005), how to recognize infection, and what to do if the tube should dislodge. Hospitals and medical centers should provide patients with information regarding care of their

feeding tubes. One example of such information pamphlets from the University of Pittsburgh Medical Center can be found online. This information can be accessed for patients who need a reference for care of the feeding tube (UPMC, 2013a, 2013b). The patient will be informed of activities in which he can and cannot participate and clothing that can be worn for maximum comfort. Contact information on self-help groups, where people can offer first-hand information can be helpful for these patients.

1.2.2 Contraindications and Complications

There are some patients for whom a feeding tube is contraindicated. Examples include patients with certain co-occurring diseases or disorders, patients with a declining or altered mental status, or patients who have overall irreversibly declining health. In these cases the risk of inserting and managing a feeding tube outweigh the potential benefits.

Complications can arise after feeding tube insertion. These include simple complications such as soreness or infection around the feeding tube. There are also serious complications, such as bleeding, respiratory difficulties, allergic reaction to medication or anesthesia in surgery, and surgical errors. In some cases, these serious complications can result in death.

Feeding tubes are placed for the purpose of bypassing the oropharyngeal system used in swallowing. This is reportedly done to decrease the patient's risk of aspiration while eating and drinking. The risk of aspiration from oral intake does decrease once a patient has a feeding tube. Unfortunately these patients are now at a higher risk for aspiration of stomach contents (Mizock, 2007). This risk is present with the use of any gastric tubes. Aspiration of stomach contents occurs when reflux of tube feed from the stomach travels up the esophagus, enters the airway, and then travels into the lungs. This can result in pneumonitis (Marik, 2001). Pneumonia is an

infection that can be community acquired or that can occur as a result of a patient aspirating any bacteria-laden material. Pneumonitis is an infection that occurs as a result of a patient aspirating gastric contents. Each infection can result in severe illness or death if left undiagnosed and untreated.

Due to its manner of placement, a nasogastric feeding tube causes the esophagus to remain slightly open. It is inaccurately assumed that, with a gastric or jejunal feeding tube, the risk of aspiration of stomach contents is decreased. Research suggests that there is no significant difference in aspiration rates between patients with a nasogastric feeding tube and those with gastrojejunal feeding tubes placed percutaneously (Esparza, Boivin, Hartshorne, & Levy, 2001; Hamidon et al., 2006).

1.2.3 Total Parenteral Nutrition

Total Parenteral Nutrition is a method of delivering necessary nutrition and hydration to patients who are unable to use their digestive tract (Fletcher, 2013). Nutrition is delivered via a central venous catheter, and is placed using ultrasound-guided venepuncture (Pittiruti et al., 2009). The delivery of nutrition directly into the veins is typically a last resort and is used only if a patient is unable to independently digest any type of enteral nutrition. Total or parenteral nutrition is not the preferred route of access as it is significantly more expensive than enteral nutrition (Ziegler, 2009) and there are various risks involved, such as infection at the insertion site (Braunschweig, Levy, Sheean, & Wang, 2001).

1.3 AMYOTROPHIC LATERAL SCLEROSIS

Amyotrophic lateral sclerosis, also called Lou Gehrig's disease or motor neuron disease, is a progressive neurodegenerative disease. ALS causes weakness in voluntary, smooth muscles such as those needed for movement of speech articulators. The cause of the disease is unknown, though links in genetics are currently being researched (Orr, 2011). The disease is most prevalent in males between the ages of 40 and 60 years. ALS inhibits and eventually destroys the motor nerve cells in the brainstem and/or spinal cord that control voluntary muscle movement.

Patients with ALS suffer from degeneration of both upper motor neurons (including corticobulbar and/or corticospinal tracts) and lower motor neurons (Britton, Cleary, & Miller, 2013). These two variations of motor neuron loss may result in different primary symptoms. Patients with primarily lower motor neuron loss will exhibit symptoms such as diminished muscle reflexes, fasciculations, or atrophy, while patients with upper motor neuron loss will show signs of spasticity and present with pathological reflexes (Paris et al., 2013). The disease most often presents with a combination of corticobulbar (head/pharynx) and corticospinal (limb) neuron loss, resulting in mixed clinical features, which may fluctuate daily.

ALS causes muscle deterioration over the course of a few years until the muscles in the chest area, including the diaphragm, become progressively paralyzed. Eventually it becomes difficult to breathe on one's own and a ventilator is required to assist in respiration. It is important to track a patient's pulmonary status in order to plan if and when mechanical ventilation will be initiated. Pulmonary function tests can be completed after a diagnosis of ALS in order to assist in prediction of the disease progress (Chandrasoma et al., 2012).

There are several pulmonary function tests. Spirometry tests measure how much air the patient can exhale (Forced Vital Capacity) and how fast the patient can exhale (Forced

Expiratory Volume). Volume tests measure air inhaled and exhaled during normal breathing (Tidal Volume), the maximum amount of air exhaled after maximum inspiration (Vital Capacity), and the air remaining in the lungs after maximal exhalation (Residual Volume). The total volume of air in the patient's lungs after maximal inspiration is known as Total Lung Capacity (Ruppel & Enright, 2012).

For patients with ALS, a decline in these tested pulmonary functions can mark a turning point in the disease progress. A person's predicted vital capacity is derived from equations Goldman and Becklake (1959), which are based on age, height, and sex. The equations for a predicted vital capacity (VC) are as follows:

$$VC = 0.1626 \times \text{Height (inches)} - 0.031 \times \text{Age (years)} - 5.335 \text{ (Male)}$$

$$VC = 0.1321 \times \text{Height (inches)} - 0.018 \times \text{Age (years)} - 4.360 \text{ (Female)}$$

According to the American Academy of Neurology, a decrease to 50% of this predicted vital capacity indicates that steps should be taken to plan for mechanical respiration, while a decrease to less than 30% indicates significant risk of respiratory failure resulting in death (Miller et al., 1999). Without ventilator support, most patients with ALS die of respiratory failure within three to five years of their initial diagnosis (National Institutes of Health, 2012). A person who has ventilator support could continue to live past this five year mark, though he would be completely dependent on the ventilator.

1.3.1 How ALS Affects Swallowing

In bulbar onset ALS, dysphagia usually occurs early on in the disease. Some patients opt to use artificial feeding tubes to supplement intake when they cannot obtain adequate nutrition/hydration orally. A patient may completely lose the ability to initiate a swallow, or

could retain the ability to initiate a swallow but, due to weakened muscle function, may not be able to adequately open his esophagus to transfer food to his stomach and/or adequately close off his airway to prevent food or liquid from passing into trachea and lungs.

If contaminated material such as material containing pathogens enters the lungs, this could lead to pneumonia. For a person with an impaired swallow, the chance of material entering the lungs is higher. Good oral hygiene can reduce the risk of the aspirated material containing pathogens. Feeding tubes do not eliminate dysphagia-related aspiration of oral secretions, and may sometimes even increase the risk of aspiration from the digestive system, as this may reduce the muscle tone of esophageal sphincter. Feeding tubes are not always a good choice for patients with ALS. To determine if a feeding tube is an appropriate option there are obviously medical and physiological factors to consider. There are also personal and emotional factors that the patient will think about. Data in this area are limited. This project aims to address the gap in this literature.

1.4 DECISION MAKING

People constantly weigh factors in decision making. Decisions such as moving to a new job, getting a new pet or even crossing on a red light require a complex decision-making process. To fully analyze *how* people make decisions is beyond the scope of this project. The aim of this study is to identify *what* factors a particular group of people thought about when making a particular decision. This section briefly outlines some concepts in decision making.

1.4.1 How People Make Decisions

The process of decision making is complex, and it is often difficult for an outsider to understand the driving force behind a decision made by another. This complex process involves multiple factors, although two common factors are classified as:

- logic of risks and benefits; and
- personal beliefs in the form of emotion or intuition (Aarhun & Akerjordet, 2012).

A person thinking that he uses logic in decision making believes that he is aware of all the possible options: he knows the number and types of choices available. Once all possible options have been identified, the individual will weigh benefits and risks of each of the options separately in order to see which has the best possible outcome. This step involves thinking of mini-scenarios in which each option is chosen and mentally carried out. This allows the decision maker to hypothetically walk through what would happen in each scenario. In most situations, there is not simply one bad and one good choice. There may be several “bad” choices and the person must choose the best of these. In these situations, a person uses logical means of decision making by a rank-order method. In this method, a pros and cons list (written or mental) will be made for each situation. The person will then rank his options based on this pro/con analysis.

Making a decision using only logic seems a very easy thing to do. However, most people use logic integrated with emotion and intuition. Neurologist António Damásio argues in his book *Descartes' Error* that there are not two separate factors in the decision making process, but that logic and rationality are directly influenced by emotion (Damasio, 1994). Emotional and intuitive factors play a role in decision making by including personal beliefs. Such beliefs can be based on previous experiences in making similar decisions or can be without any logical reason. Although

they may seem irrational or insignificant to outsiders, personal factors such as stress, anger, or optimism usually play the largest role in an individual's decision making process.

The following is an example of a decision and the possible steps taken to make a choice. A student decides to put off studying for an exam until the last minute. This student may have approached past experiences with procrastination in which everything worked out fine in the end. He may also have personal reasons for leaving the studying until the last minute such as a family emergency, work schedule, or other obligations that take precedence.

This situation could also be influenced by intuition, if the student has a "gut feeling" that the test will not be difficult or that he will not need to study extensively in order to do well on the exam. This student will think of the potential risks and benefits of procrastinating and use his personal beliefs to aid in his decision making. He will use logical components such as having other assignments due or prior commitments/time restraints. He will also use emotional intuitions such as feeling confident about the project or that he works best under pressure. Most people do not usually think about the process of decision making, but it is important to keep in mind two major factors – logic of risks and benefits and personal beliefs and emotions – that play a role when making a decision.

1.4.2 Healthcare Decision Making

Healthcare decisions involve the major components of general decision making. Patients use logic, emotion, and intuition to help guide their decisions. Healthcare decisions are difficult to make because they are potentially emotionally laden and can involve life-or-death decisions.

Some people know all possible choices and outcomes of surgery or therapy before making a choice about which one would work for them. In a healthcare setting, it is usually the

role of the primary physician or nurse to give the patient information about all possible choices and outcomes and to ensure patient understanding. The average person does not have extensive knowledge about medical procedures and treatments, and would not be able to make a decision simply based on hearing the names of the choices of medical treatments. The healthcare professional must be continuously educated on the most current and effective treatments in order to provide the patient with all possible options.

Evidence-based practice (EBP) is a term used by practicing clinicians. It is one framework within which a clinician may make any decisions or recommendations. A knowledgeable clinician who uses the appropriate research in a specific area in order to provide the best possible treatment for her client is using evidence-based practice. This clinician is also able to best inform her patient about possible outcomes of different treatment choices, along with the research supporting these interventions. Informed decision making allows a patient to use the logical thinking measure of weighing risks and benefits of each possible choice.

Clinicians need to research and learn about available treatment options and outcomes for a variety of medical conditions. EBP has three cornerstone components (Sackett, Rosenber, Gray, Haynes, & Richardson, 1996). Clinicians need to be aware of the evidence for current best practice for a variety of treatment possibilities. Clinicians should also use their best judgment in implementing clinical measures, and incorporate patient/client beliefs and preferences. Incorporating these EBP components can help ensure that clinicians provide patients with the best possible care.

The “ethical grid” by David Seedhouse (2008) (Figure 3) is a framework to explore the different factors involved in providing care for a patient. This grid takes many factors into

consideration, including available resources, evidence/facts, codes of practice, wishes of others, telling the truth, and giving the client autonomy, among many others (Seedhouse, 2008).

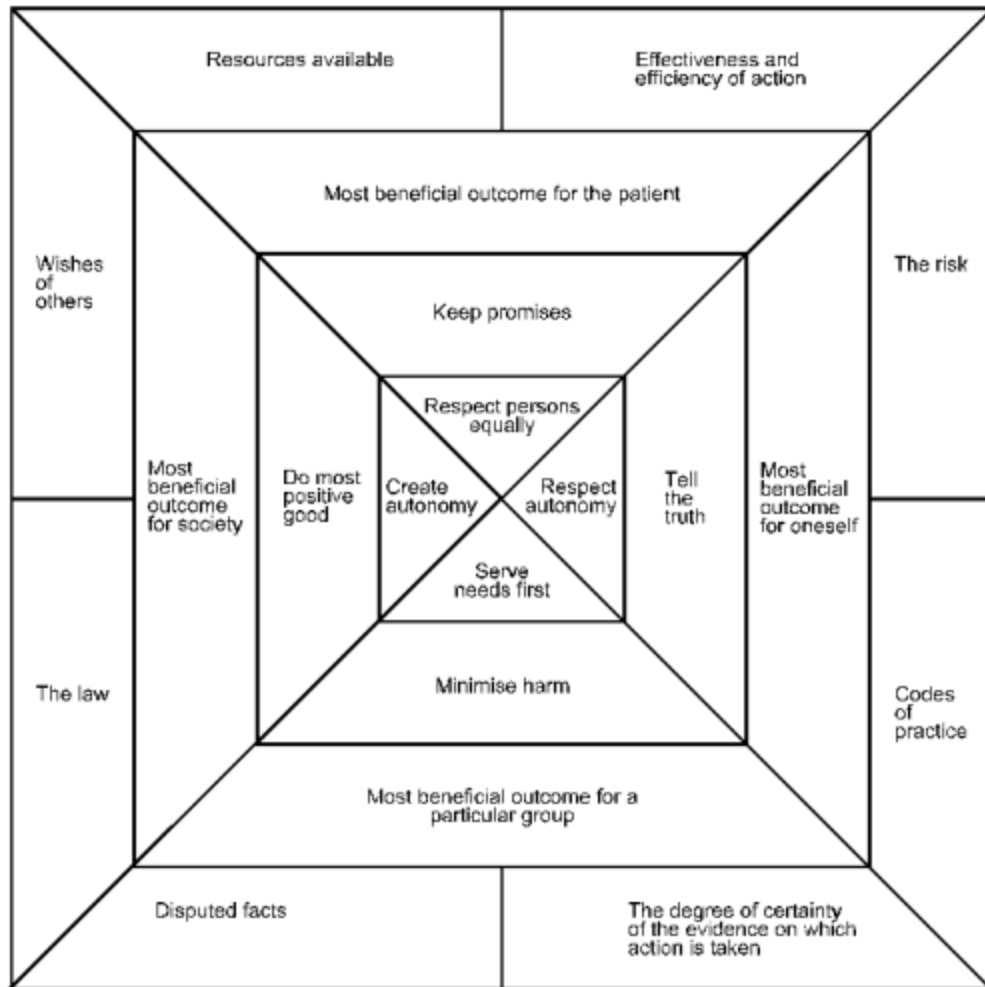


Figure 3: "Ethical Grid." By Seedhouse, D. 2009. Reprinted with permission.

The ethical grid is composed of four layers, illustrated by the layered boxes, with several components in each layer. From the outermost layer the aspects are: practicalities, outcomes and priorities, moral duties, and basic purpose. The boxes are meant to be chosen by clinicians and patients using the grid. A clinician would start with the outermost layer, having an open discussion about each box. Any boxes that do not apply to the clinical case are “discarded” and only the relevant boxes are left to help in the decision of care. With this approach people think of

different factors than a principle medical ethical approach. It allows for people to think about some practicalities involved such as who is involved or resource availability.

Once a clinician has current knowledge of and rationale for possible treatment options she must provide these details to the patient. Armed with this information, the patient will be able to discuss his informed preferences with the clinician. Keeping the patient's best interest in mind, the clinician will consider the patient's preferences and her own expert knowledge to help the patient make his important healthcare decision (Leslie & Krival, 2010).

Patients making healthcare decisions still rely on their emotions and intuitions to assist in their decision making. For example, a patient may not want to have surgery, even though it is recommended by the physician, because a friend had adverse outcomes after a similar surgery. These factors can be frustrating for the physicians and healthcare team if they have a strong opinion about what the patient should do. Healthcare professionals should try to explore the reasons why a patient may or may not want to get the surgery in order to clear up any misconceptions or clarify any questions the patient may have. Ultimately the professionals must respect the decisions of the patient and not force their own opinions into the decisions which must be made by the individual.

Emotional factors can also be brought into the decision making process by family and close friends of the patient. Usually caregivers believe that they have the patient's best interest in mind, but they also have their own reasons for choosing certain options. They may fear losing their loved one or fear that their loved one will be in too much pain.

1.4.3 Healthcare Decisions Related to ALS and Tube Feeding

ALS differs from many health conditions because death occurs within about three to five years in patients who are not using ventilator support, which is relatively quick (National Institutes of Health, 2012). Therefore the decisions patients need to make with regard to this disease may be some of their last. Most patients want to be comfortable as they near the end of their life. An individual should take into account both the length and quality of his life as he makes decisions about the end of his life.

As muscle function deteriorates, the process of eating and swallowing becomes increasingly difficult. Typically there is no cognitive decline although recent evidence suggests that there may be ties between certain types of ALS with frontotemporal dementia (Giordana et al., 2011). Eventually the process of eating and drinking that used to be enjoyable turns into an excruciating task that consumes much of the person's energy. This patient now faces a choice. His first option is to receive a feeding tube in order to maintain necessary daily nutrition and hydration and to minimize discomfort experienced during swallowing. The patient may believe that his feeding tube will reduce the risk of oropharyngeal aspiration but there will still be pathogens in his saliva that can enter the lungs, which is why proper oral care is necessary.

A patient is made aware of possible risks and benefits of the feeding tube by his physician. The physician should inform the patient that the feeding tube may or may not increase the length of his life. It may also decrease his quality of life due to reduction of pleasurable oral intake, increased care management, discomfort secondary to the feeding tube, or increased risk of acid reflux and aspiration of stomach contents.

The second option a patient has is to decline the offer of a feeding tube. The patient will be able to eat and drink what is comfortable for him, although this still has a risk of malnutrition (due to reduced intake or fatigue), dehydration, aspiration and choking. These risks may increase the possibility of weakness or illness and so shorten his life.

The decision is not a simple one to make. There are many factors to take into account on the part of the patient and the caregivers, such as mental status, prognosis, treatment burdens, risk of aspiration, and patient viewpoints (Segel & Smith, 1995; Sharp & Genesen, 1996). A clinician working with a patient with ALS needs to keep these factors in mind as she works together with the patient and caregivers to make a decision on feeding tube use in order to ensure that the decision is the best fit for the patient. The importance of the patient viewpoint in this decision making process is immeasurable.

1.4.4 Feeding Tubes: Factors Affecting Decisions

There is very little information on what factors people consider when thinking about feeding tubes. A 2008 pilot study involving feeding tube decision making looked at perspectives of patients with progressive dysphagia who had already received feeding tubes (Vesey, Leslie, & Exley, 2008). The study by Vesey, Leslie, and Exley will be referenced as a “sister study” to the current research. The aim of the study by Vesey, Leslie and Exley was:

to explore and understand factors that influence a patient’s decision-making when considering percutaneous endoscopy gastrostomy placement for nonoral nutrition and hydration supplementation” (Vesey, Leslie, & Exley, 2008) p.1).

This study provides evidence that participants were strongly influenced by medical opinion and the status or progression of their physical deterioration at the time the decision was made (Vesey, Leslie, & Exley, 2008). The interview for the study was semi-structured and reflected six topics:

- background (b): details on swallowing difficulties
- information (i): what information the patient received and how he received it
- values (v): religious or social values that impacted decision
- outside pressures (o): anyone who had an influence on the patient's decision
- support (s): encouragement from family, friends, medical team, or caregivers
- reflection (r): how the patient feels about the feeding tube decision

In this 2008 article, these six topics are referred to as themes. For clarity and discrimination between subject-generated themes used in the current study, these six areas will now be referred to as topic areas.

Most patients did not have knowledge of feeding tubes or related procedures before they needed to make their decision. The Vesey, Leslie, and Exley study gave evidence that there is a need for patient education, which is supported by the current study.

1.4.5 Study Aim

The need for further research on the topic of feeding tube decision making is stated in the study by Vesey, Leslie and Exley. This need for information prompted the current study. The aim of

this study is to provide data on factors that may influence patients with ALS as they make the decision to receive a feeding tube or not. This study does not attempt to answer how different patients make the decision to receive a feeding tube or not. Based on patients' reports, this study outlines some of the factors that may influence their decision. This study will identify which factors a specific group of people with ALS considered when deciding about a feeding tube. This is not a complete list of factors for all patients but can be a starting point.

2.0 METHODS

The deidentified data used in this study come from a series of interviews carried out in the United Kingdom (UK). The interviews were conducted with patients attending a specialist ALS clinic. Transcripts of the interviews were provided for this study and analyzed using a qualitative data coding approach. The Institutional Review Board at the University of Pittsburgh granted approval for the current study. The study confirmation number given by the Institutional Review Board is PRO12110377. As the transcripts were analyzed by the primary investigator, a code book was formed around themes in the participants' comments. The coded transcripts and the code book were managed using Microsoft Word © (Microsoft Corporation, WA, USA) software and its "paragraph sort" alphabetizing function for ease of sorting text by assigned code.

2.1 DATA COLLECTION COMPLETED IN ENGLAND

All the patients invited to participate in this study were attending a specialist ALS clinic and needed to make the decision specifically about having a gastrostomy tube (not nasogastric). The study was approved by the Local Research Ethics Board (LREC), a government body independent of the institution for which the researchers worked. The study was also approved by the separate Hospital Trust Research Committee. Studies must be approved by both bodies in the UK. Over the course of two months, six patients were identified by the Consultant Neurologist

(equivalent to an Attending Physician in the USA) as people who had made the decision about a gastrostomy feeding tube within the past 12 months. All six consented to be in the study.

Patients were interviewed by a non-biased third party clinical researcher (i.e., she did not work for the clinical team or the hospital) using a semi-structured interview approach (see Appendix A). This third party clinical researcher is referred to from here on out as “*the reporter*”. The questions were based on several topics, as outlined in the sister study by Vesey, Leslie, and Exley (2008). The interview was semi-structured, meaning that a list of questions was asked of all participants but they were free to expand on subjects or go off topic as they wished.

The questions allowed patients to expand as much on one idea or give as little information about a topic as they wanted, with no set limitations. Interviews were audio-recorded and subsequently transcribed by a medical secretary experienced in transcription. Some patients who presented with severe dysarthria were asked some questions with a yes/no format, and/or used writing, instead of the open-ended format, in order to provide the least stressful environment that would foster communication. To help patients who presented with severe dysarthria, the following two approaches were used: changing the question to a yes/no format or iterative reporter dialogue.

2.1.1 Participants

Participants included one male and five females, who ranged in age from 46-75 years. Time from diagnosis of ALS in this patient population ranges from 6 months to 10 years. Patient phenotypes included four patients with pseudobulbar palsy/bulbar onset, one patient with familial ALS, and one patient who did not have a phenotype classification (see Table 1).

Table 1: Participant Data

Age (at time of study)	Sex	Time from Diagnosis	Phenotype
64	F	1 year	Pseudobulbar Palsy/bulbar onset
71	F	9 months	Pseudobulbar Palsy/bulbar onset
46	F	8 years	Familial ALS, no other information given
70	F	6 months	ALS *this was not further classified by the neurology report
60	M	10 months	Pseudobulbar Palsy/bulbar onset
75	F	1 year	Pseudobulbar Palsy/bulbar onset

Some participants also had family members who assisted with answers and, in some cases, gave additional information during the interview. Four of the six patients interviewed did not have a feeding tube at the time of interview. Of these four, two had decided that they would like to go ahead with the procedure to receive a feeding tube.

2.1.2 Data

The data provided for this thesis were the six interview transcripts. The transcripts were assigned a number 1-6 by the original interviewer. To ensure participant confidentiality, the numbered transcripts were then randomly assigned to a letter A-F by a different third party before giving them to the author, AJM.

2.2 DATA ANALYSIS AND CODE BOOK DEVELOPMENT

2.2.1 Primary data coding

Coding is a common approach to analysis of qualitative data. It is used to analyze any type of data that is text, such as dialogue that come from focus groups, or observations of existing groups, such as groups in a workplace or a sports team (Krueger & Casey, 2000). Transcripts are coded for common themes. A theme is the overarching idea or topic which encompasses an area of text. Themes are used as the base or “root” of a code name, as discussed below.

The method of coding used for this study is as follows. Each transcript is read and themes are noted; themes are put into a new document labeled as the code book (Appendix B). Code names are based on definitions of the important themes noted from the interview. Each code has a unique definition. It is crucial that the definitions for each term are clear and concrete. Hypothetically, with training, any novice independent coder given the definition should be able to apply the codes to the same passages in the transcript as the original coders. As the transcripts are read, codes and their definitions are refined and new codes are added to accommodate new data that do not fit into another category (Taylor-Powell, 2003). Codes are formulated based on the main theme of the comment. The code may have a second or third theme and will have a coding suffix that allows for further classification.

In this study the codes consisted of a root and a suffix. The root is based on the main theme derived from the text. For example in sections of text where the code LOG_v is used, the main theme of the text is centered on the logistics of how the tube feeding/cleaning/care will work. Texts with the same basic theme but different aspects were then differentiated with a suffix. For example in the code BURDEN_SELF_v, the text is focused on the theme of feeling

burden, but the person is specifically feeling some type of burden on himself. This differs from the code BURDEN_OTH_v in which the person is specifically feeling as though he is a burden to another person. The suffixes SELF and OTH help to differentiate between these two aspects of the overall theme BURDEN.

Sometimes a further suffix was used to distinguish additional differences. For example the code INFL_PROF_GEN_o is defined as “general influence from professional team,” as compared to INFL_PROF_PART_o defined as “particular professional person of influence mentioned by name or title (e.g. my nurse, Dr. Smith).” The third suffix “GEN” or “PART” identifies further distinctions between professional influences. The final letter suffix provided the primary investigator with a link to a topic area from the Vesey study question section that generated the response. This suffix allowed the codes to be tracked. The following is a participant quote and the corresponding code name, followed by the code definition and explanation:

“I wasn’t aware that would have to happen. I thought once [the feeding tube] was in I wouldn’t have to do anything with it whatsoever until I needed feeding. I didn’t realize that it’s got to be actually flushed out on a daily basis, sometimes every day.”

Code: INFO_SURG_NEG_i

Definition: (in terms of the feeding tube, the procedure, or expected outcomes) the patient reported that he/she was not given enough information from medical team, the information was conflicting between professional, or the information given to the person was not helpful.

The root code INFO was given to this text because the participant discussed information about the feeding tube/procedure or about the disease process of ALS in terms of swallowing difficulties. This quote was given the code suffix of SURG because the information being discussed was related to the feeding tube/procedure. This participant reports that s/he did not receive enough information about this aspect of the feeding tube care, and was assigned another code suffix NEG (comments about receiving good information would be given the code suffix POS). A final letter suffix (i) links the text to the Vesey, Leslie and Exley study topic area “information.”

The code book was expanded as each transcript was reviewed and new themes were identified. The transcripts were reviewed a second time by the original coder, AJM, to ensure that all codes were used in appropriate sections of the transcript. Any irrelevant data – portions of the transcript that did not relate to the decision to have a feeding tube – were not coded (Taylor-Powell, 2003).

The coded transcripts were sorted alphabetically by code. This allowed for ease in locating information on one specific topic. It is important to note that the code definitions used for this data set are specific to this study. They are concrete and absolute for purposes of coding this particular set of transcripts only.

2.2.2 Coding Done by a Second Rater

In this study, a second coder was used to verify the primary coder’s interpretations and that the conclusions from the transcripts are reasonable. The purpose of the second coder was to verify that the primary coder’s interpretations were reasonable and to confirm that the conclusions from the transcripts were reasonable. The second coder [EMD] used in this study was a second year

master's student in the speech-language pathology program at the University of Pittsburgh. She also received her undergraduate degree from the University of Pittsburgh, in Communication Science and Disorders. The second coder had no previous experience with transcript coding.

The typical training process when using a second coder involves pre-training. This requires that the primary coder review the code book with the second coder, pairing sample quotations with each code. In this study the secondary coder was given the code book but did not receive the pre-training. This explains the very low initial inter-rater agreement. If coding by a second rater is used in a study, the second coder is not involved in the making of the code book; this is done solely by the primary coder, in this case, the study PI. Once completed, the finalized code book and uncoded transcripts are given to the second coder. Using the code book, the second coder reads through the original uncoded transcripts and assigns codes. The second coder does not create any new codes, but uses only codes that were already defined. The definition of each code is crucial at this point in the data analysis. The primary investigator ensures that each definition is clear and unique to that code, as any ambiguity could result in confusion for the second coder during the coding process.

In this study, coding was discussed by the primary investigator and the second coder after the second coder completely finished coding all six transcripts. For any discrepancies between the coders, the initial approach was to agree on a code. If the coders did not agree, one of two methods was followed. The first method was to slightly change an existing definition to best fit a coded section. The second method was for the two coders to create a new code that best fit the content in that section. As this did not directly follow the standard approach of pre-training, the following results are expected to be low for the first attempt. The results of these methods are outlined in Tables 2 and 3.

Table 2: Second Rater Agreement by Transcript

Transcript	Number of statements	Initial Agreement
1	150	43% (65)
2	107	53% (57)
3	51	53% (27)
4	69	70% (48)
5	83	58% (48)
6	93	66% (61)

Table 3: Second Rater agreement by Topic Area

Topic	Codes per Topic Area	Initial Agreement	Method 1: minor definition change	Method 2: new code formulation
Background	8	29%	3	2
Information	13	38%	3	5
Values	11	60%	3	1
Outside Pressures	5	80%	1	0
Support	9	67%	1	2
Reflection	4	25%	2	1

When either method was used, sections containing the discrepant codes were reviewed. In cases where a definition was changed slightly: if the newly formed definition still fit the sections using the code, the code was retained. If the new definition did not fit, the definition was further edited, or the section was given a different code. In cases where a new code was created: if the original code still fit the content of the section, this code remained. If the new code more accurately fit, the new code was used.

2.2.3 Data Management

Microsoft Office Word 2007 © software (Microsoft Corporation, WA, USA) was used to sort coded data. Each transcript was essentially put into a two-columned table. In the left column, relevant codes were assigned to the sections of the transcript to which they correlated. The transcript was systematically read and relevant codes continued to be put in the left column. If a quote or part of a transcript fit two codes, the relevant text was copied and pasted immediately below the original text, and the second code was put in the left-hand column. During the process of coding, cutting and pasting, a new document is made. This is separate from the original transcripts and allows the primary investigator to easily view sections of text within the same code. This maintained the integrity of the interview transcripts. Once the transcripts were completely coded, the Paragraph Sort tool in Microsoft Office Word 2007 © software (Microsoft Corporation, WA, USA) was used to alphabetize text by code. This allowed for identification of factors that supported the patient-generated themes and could link to the previous study “topics”. There were 40 codes derived from the six transcripts, as outlined in appendix B.

Computer based data management software, such as ATLAS/ti and NUD-IST © 1996 – 2007 QSR (QSR International, Melbourne, Australia) is sometimes used with data from focus group and other transcript analysis. This software was designed to manage large amounts of data - tens or hundreds of transcripts at a time. Using such software the researcher still has to define the codes, code the text, look for themes, and interpret the data in the same manner as in this study, using Word software. These computer based data management tools also have features such as allowing two researchers to work on a live data set simultaneously and storing their work in real time. Given the limited number of transcripts (n=6) used in this study, the powerful management aspects of computer-based software were not necessary.

2.2.4 Interpretation

The importance of people's feelings on factors influencing decision making cannot be ranked. For example, there could be a low level concern that occurs more often in discussion, or there could be a high level concern that only occurs once or twice within each patient interview. However, as this is a preliminary study in this area, some frequency counts are used as a means of quantifying the data. The patients were permitted to say as little or as much as they wanted. Some participants in this study had dysarthria, which affected the intelligibility of their speech. The participants were offered a pen and paper or the researcher repeated what she thought they said and the participant would indicate whether that was correct or not by nodding or shaking of the head and if it was not correct, the researcher tried other words until the participant indicated that the correct word or phrase had been used.

3.0 RESULTS

Results are displayed in terms of themes and factors. Relations to the six topic areas outlined in the sister study are included. These topic areas are background, information, values, outside pressures, support, and reflection. Topic areas derived from the sister study were used as the final suffix in the code classification of the current study. Themes derived from patient responses were used to form the root of the code name. The 16 themes generated from the patients' responses in this study include Influences, Support, Information, Burden, Surgery, Swallowing difficulties, Emotions, and Independence. The themes are unique to this study and are connected to their correlating factors. Factors are linked to code definitions and provide information about specific aspects that may influence a person's decision-making process.

3.1 THEMES

The themes in the current study were patient-generated and were the root of the code formation. For example, multiple patients made comments about additional burden of care of having a feeding tube. These comments were coded under the patient-generated theme of "burden" and coded with a root code BURDEN. These patient-generated themes are listed below in terms of overall occurrence (see Table 4).

Table 4: Themes and Occurrence

Theme	Occurrence	Theme	Occurrence
Appearance	3	Influences	72
Burden	4	Information	70
Decision Steps	15	Logistics	2
Disease Decline	12	Restrictions	14
Emotions	16	Support	23
Health	9	Surgery	10
Impressions	25	Swallowing difficulties	22
Independence	29	Time	11

3.1.1 Individuals

Data on individual themes used by participants A-F are displayed in pie charts. This display method shows the wide range of themes a person considers as well as the proportionality between each theme. Participant quotes were taken from the theme areas in which the individual had the most comments. These quotes are displayed at the end of each individual section to provide examples of participant responses.

3.1.2 Participant A

Participant A was able to answer all questions independently and elaborated on many of them. Participant A had a higher number of quotes around themes of support, time, and influences (see Figure 4).

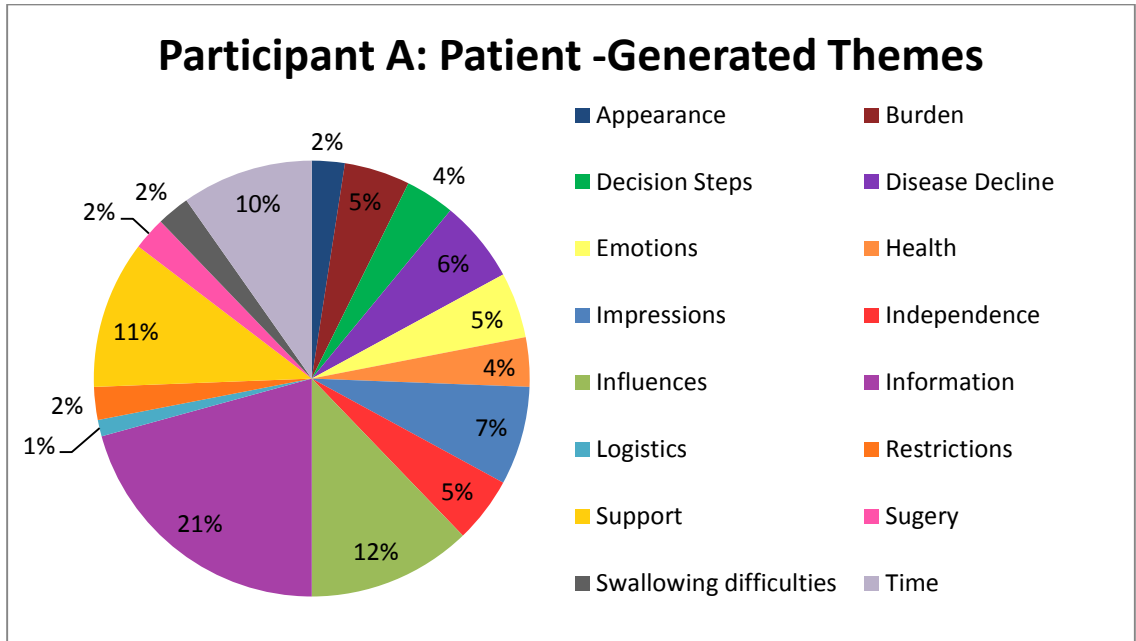


Figure 4: Participant A - Themes

The following quotations are taken verbatim from the interview transcripts to give examples of themes that participant A raised. Theme names are displayed above quotes and are formatted as bold and capitalized (**THEME**).

TIME

I would say better to have it done and not leave it for feeding straight away to give yourself a chance to get used to the procedure. Because just flushing the water

through can sometimes go wrong and I think I would panic I would have panicked had friends not been able to get food in that was my only way of nutrition.

INFORMATION

I thought once it was in I wouldn't have to do anything with it whatsoever until I needed feeding. I didn't realize that it's got to be actually flushed out on a daily basis, sometime every day.

I wasn't aware that I would have a long tube hanging out of me stomach and then I would go back I think six weeks later and have the button fitted.

DISEASE DECLINE

I think [having the surgery] is another reality that the MND's [Equal to ALS] getting worse ... and it's a constant reminder because this thing is there. It has to be used when the doctors say.

3.1.3 Participant B

Participant B gave most responses through the form of reporter iterative dialogue. S/he was able to answer all questions, though some were changed to a yes/no format. Participant B had the largest number of quotes on the patient-generated themes of influences, and a large number of quotes on disease decline and support (See Figure 5).

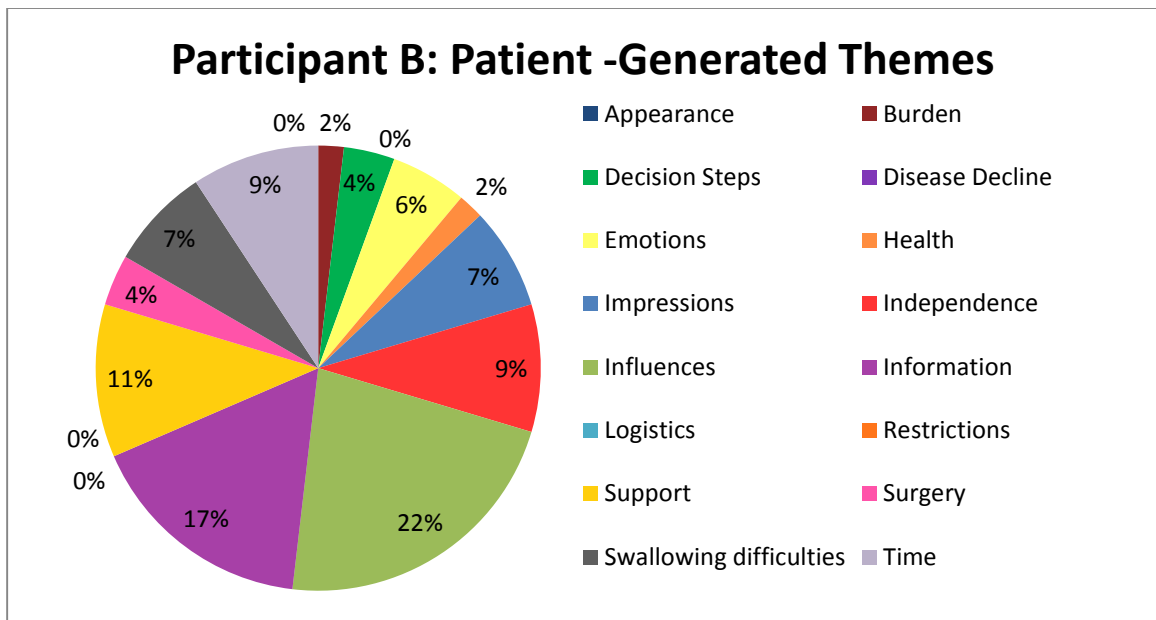


Figure 5: Participant B - Themes

The following quotes are taken from the iterative dialogue in the interview transcripts. These quotes give examples of themes that participant B raised. Theme names are displayed above quotes and are formatted as bold and capitalized (**THEME**).

INFLUENCES

So you felt they supported your decision but you still had control over the decision.

INDEPENDENCE

The decision was left in your [the patient's] hands.

TIME

If information is given too early it's not good because you won't take up that information – it's not applicable.

3.1.4 Participant C

Participant C was not able to answer all questions. The interview for this participant was abbreviated and was completed through mostly yes/no question format. Participant C did not elaborate on any questions. Participant C did not have a feeding tube at the time of interview and so was not asked the questions referring to having a feeding tube. S/he had the largest number of responses on the theme of information, followed by the theme of influences (see Figure 6).

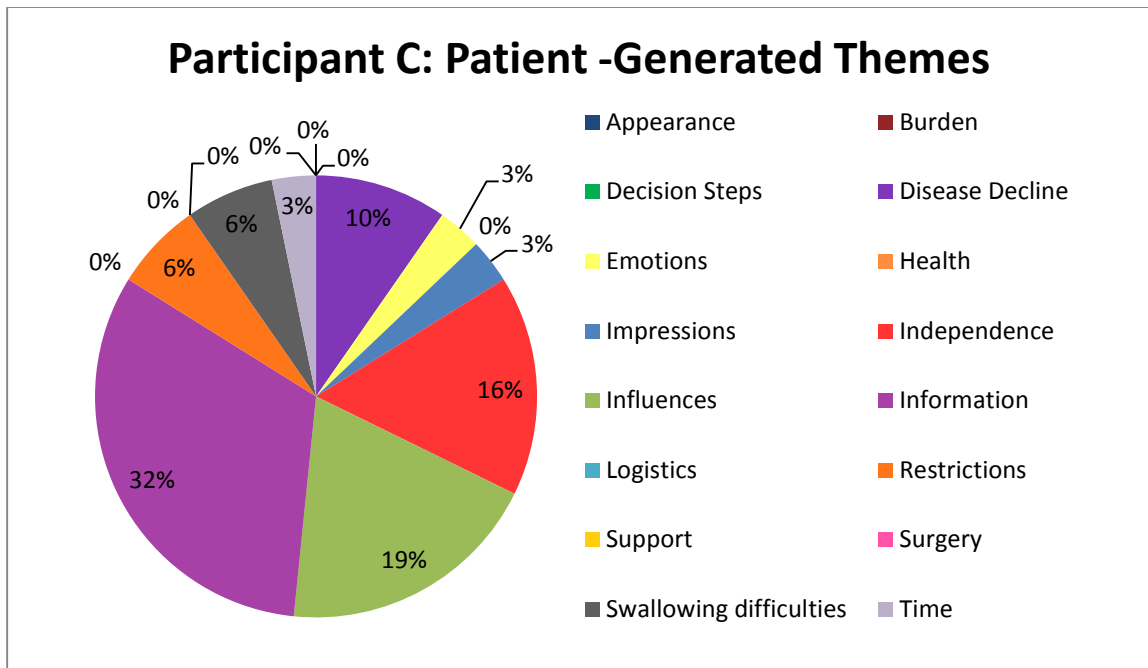


Figure 6: Participant C - Themes

Some comments are directly from the patient, as denoted by (direct quote) following the theme name. Comments below that are not direct quotes were reporter comments that received a response from the participant that indicated a “yes” response in agreement. The following reporter quotations and verbatim patient quotations are taken from the interview transcript to give examples of themes that participant C raised. Theme names are displayed above quotes and are formatted as bold and capitalized (**THEME**).

TIME

You don't want it until it's really necessary.

INDEPENDENCE (direct quote)

Everyone's different, I would know if I needed it.

INFLUENCE (direct quote)

I think the doctors know everything.

INFORMATION

Okay so you've gone to the internet to find out information about MND. You've been able to access people that you might not be able to see but you have been able to access them through the internet.

3.1.5 Participant D

Participant D was not able to answer any questions with full responses. Most responses were obtained through iterative dialogue with the reporter. Some questions were changed to yes/no for ease of response and some questions were answered by the participant's family member. Participant D did not have a feeding tube at the time of interview and so was not asked the questions referring to having a feeding tube. Participant D had the largest number of quotes on the influences theme, and a large amount of quotes on the information theme (see Figure 7).

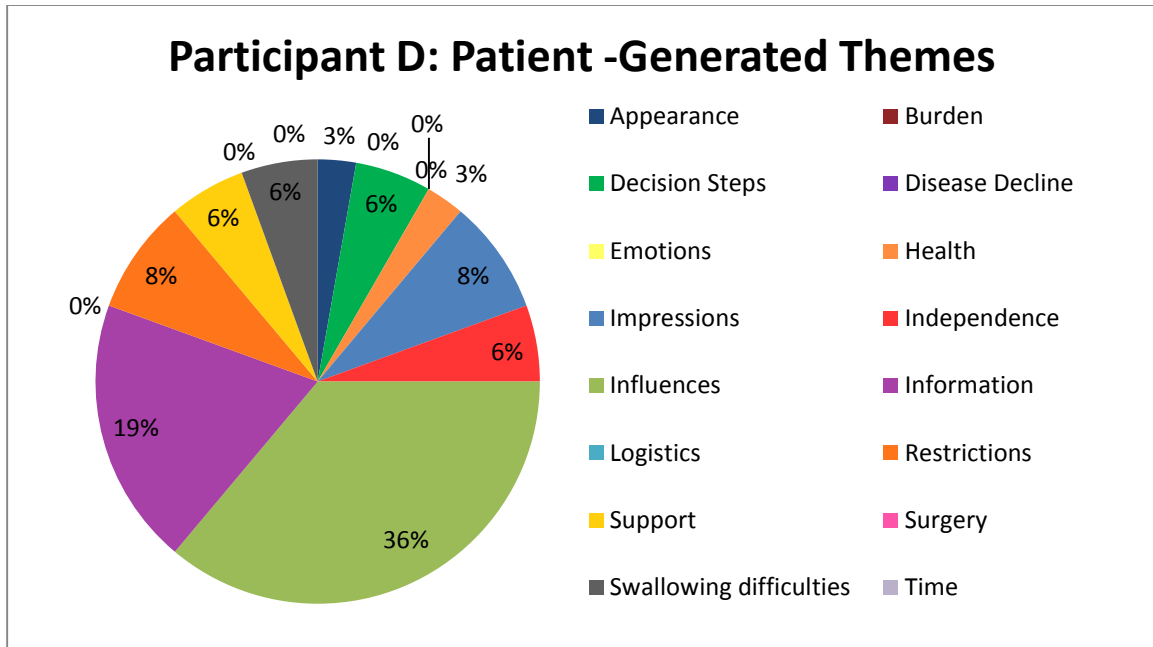


Figure 7: Participant D - Themes

There are quotes directly from participant D, denoted by (direct quote). Comments that are not direct quotes were reporter comments that received a response from the participant that indicated a “yes” response in agreement. The following reporter quotations and verbatim patient quotations are taken from the interview transcripts to give examples of themes that participant D raised. Theme names are displayed above quotes and are formatted as bold and capitalized (**THEME**).

RESTRICTIONS (direct quote)

Embarrassed in company.

DECISION STEPS

At the time it was first mentioned you didn't want it. Now as things have gotten worse you do want it and it might be a good idea. Today you do want to have the PEG.

HEALTH

Your health might improve if you get the tube... you can eat more through the tube.

INFLUENCE

Their opinions were important as well, they understand.

3.1.6 Participant E

Participant E answered questions with an iterative dialogue response or with a full, independent response. Participant E was able to elaborate on many of the questions through researcher interpretation. Participant E did not have a feeding tube at the time of interview and was so not asked the questions referring to having a feeding tube.

Participant E had a large number of quotes focusing on information, as well as a large number of quotes on the topic of influences (see Figure 8).

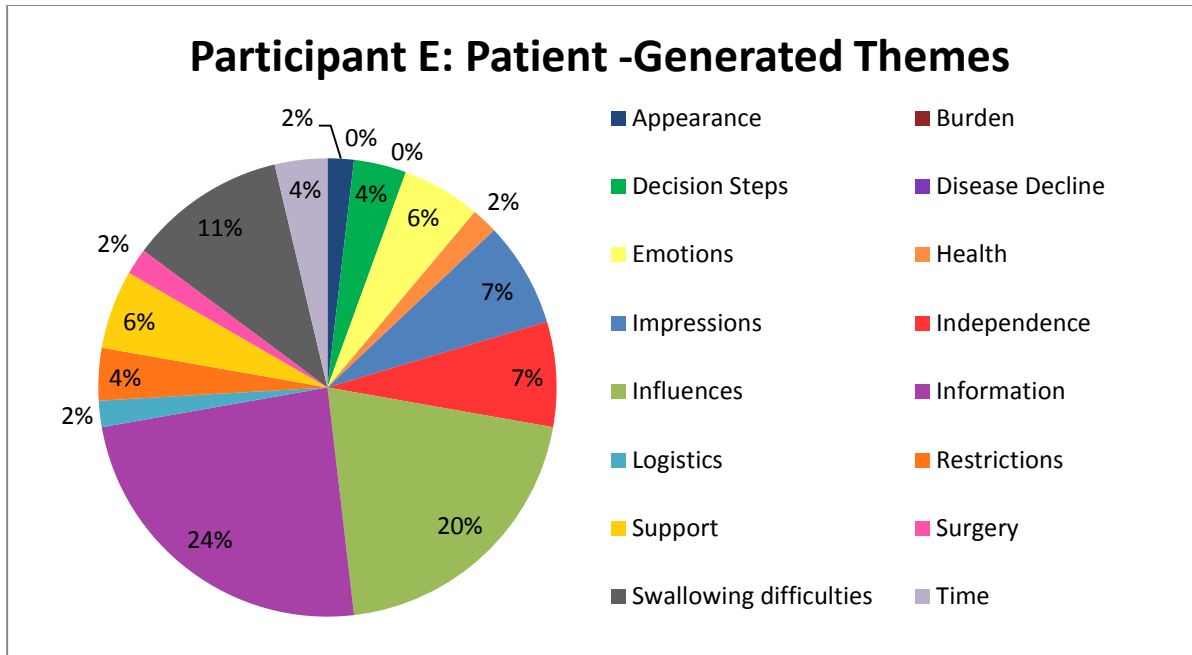


Figure 8: Participant E - Themes

The following quotes are taken from the iterative dialogue in the interview transcripts. These quotes give examples of themes that participant E raised. Theme names are displayed above quotes and are formatted as bold and capitalized (**THEME**).

RESTRICTIONS

You don't like eating in front of people. You are embarrassed.

APPEARANCE

You just didn't want a tube that comes sticking out of you.

SUPPORT

So they didn't push you, they explained it. If you said you wanted it but then backed down that would be fine as well.

3.1.7 Participant F

Participant F was able to answer all questions independently with full responses and elaborated on many of the questions. Participant F did not have a feeding tube at the time of interview and so was not asked the questions referring to having a feeding tube. Participant F had the largest amount of quotes centered around the patient-generated theme influences, as well as a large number of quotes centered on the themes of independence and information (see Figure 9).

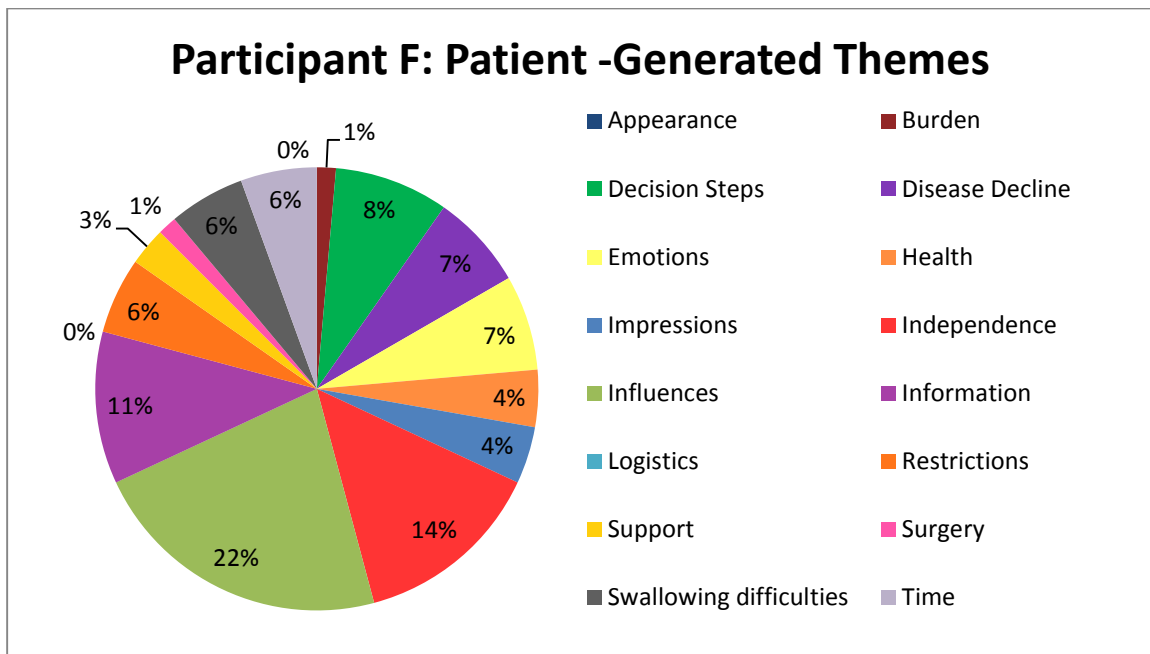


Figure 9: Participant F - Themes

The following quotations were taken verbatim from the interview transcripts. These quotes give examples of themes that participant B raised. Theme names are displayed above quotes and are formatted as bold and capitalized (**THEME**).

DECISION STEPS

When I was first diagnosed we decided we didn't want to know.

We did it day by day.

INFORMATION

No, I didn't quite understand what was happening.

DECISION STEPS

Well at the moment with not being able to eat I would think, you know, [get the tube] to keep the energy level up. I've still got the use of my arms and legs and I'm mobile. Getting proper feed [should build] my energy levels up. I should put weight on cause I have lost quite a lot of weight. So I should gain some quality of life back that I've lost.

SURGERY

I'm more worried, not that it won't be good, but I'm worried about the procedure... I suppose they're professionals and they'll get it down somehow.

INFLUENCE

No their opinions were very important but I think when it was first mentioned I realized it was the only way to go.

INDEPEDENCE

The nurse came back out again and said 'as you get nearer for the PEG, don't let anybody bully you into it.

3.2 FACTORS

The factors make up the code definition. For example, the definition of codes that had “burden” as the main theme included the factor of feeling that the feeding tube care requires extra work on patients themselves or family members/caregivers. Code definitions provided information on factors that influence patients’ decisions to receive or decline a feeding tube. In these data there were common factors that were mentioned a lot and unique factors that were only mentioned by one individual. Some of these most common and some unique factors are described in following sections.

3.2.1 Negative Experiences with Receiving Information

One factor that came up often across patients was not having enough information about the surgery procedure or post-surgery expectations.

Recovering from the op was longer than I thought and it was sore. I don't know why I just felt that it was this little op and it's tiny. I thought I would be up and about the next day.

Oh right, I didn't know that.

There was no mention of that, no, I think it took us all by surprise.

I want to know so much... nobody has any answers.

3.2.2 Professional Influences

Many patients discussed the influence of the medical team during the decision making process. Some participants were influenced by specific members of the medical team, while others spoke generally of the team's professional influence.

Their opinions were important as well, they understand.

I think because I had such a good relationship with [name] and the team.

Once ... the eating was becoming that difficult then it was time to consider a PEG then [name] just went ahead with it very quickly. I think the decision then was a good idea.

He [physician] knows the disease and what's likely to happen.

I think the doctors know everything

3.2.3 Positive First Impressions

Some factors were unique to just one or two participants. One example of a unique factor that was brought up by two participants was having a positive first impression of getting a feeding tube.

There was some relief because of the choking. It allowed you to take the pressure off yourself trying to force feed yourself, trying to maintain yourself, which was hard work.

It was a good idea

3.2.4 Being a Burden to Others

Only two participants made comments on the subject of burdening family or caregivers. Participant A elaborated quite a bit on the subject.

[I] needed to know the children's point of view, how manageable the PEG would be because I can't do it. My hands aren't very good so me (sic) daughter has to do it well a best friend has been doing it since March and me (sic) daughter has to do it if she is unavailable. So it was the practical side of it and how well we can look after it and what we needed to do.

My main concern was that I would still be allowed to be at home and it wouldn't affect the care at home.

3.3 COMPARISON TO SISTER STUDY

In the current study the sister study topic areas were used as a way to sub-classify the codes given to the patient's interview comments. Many codes in the current study were given further classification of positive or negative feelings about a certain topic. These results are displayed below (Table 5).

Table 5: Positive and Negative Comments by Topic Area

Topic Area	Positive Comments	Negative Comments	Neutral Comments	Total
Background (b)			94	94
Information (i)	27	24	64	115
Values (v)	6	6	66	78
Outside Pressures (o)			134	134
Support (s)	25	6	48	79
Reflection (r)		5	28	33
TOTAL	58	41	434	533

The overall occurrence of codes within the topic areas was also looked at. These are displayed below in terms of number of code occurrences within each target topic area vs. other topic areas (Table 6).

Table 6: Code Occurrences in Target Topic Area vs. Other Topic Areas (definitions in Appendix B)

Code	Occurrences within Target Topic Area	Occurrences in Other Topic Area	Total Occurrences
APPEAR_NEG_v	1	2	3
ASK_INFO_i	3	2	5
BURDEN_OTH_v	3	1	4
BURDEN_SELF_v	0	2	2
DECIS_STEPS_s	6	9	15
DECIS_TIME_s	1	10	11
DISEASE_DECLINE_v	3	9	12
EMO_FEAR_b	3	6	9
EMO_OTH_b	6	1	7
HEALTH_NEG_v	2	0	2
HEALTH_POS_v	7	0	7
IMP_FIRST_v	6	4	10
IMP_FUT_v	4	0	4
IMP_RETRO_r	5	2	7
INDEP_o	14	10	24
INFL_ITEM_PART_i	2	2	4
INFL_OTH_GEN_o	6	3	9
INFL_OTH_PART_o	6	2	8
INFL_PROF_GEN_o	9	7	16
INFL_PROF_PART_o	5	29	34
INFO_SEARCH_i	0	2	2
INFO_SPEECH_i	0	2	2
INFO_SURG_NEG_i	10	10	20
INFO_SURG_POS_i	11	7	18
INFO_SWAL_NEG_i	2	1	3
INFO_SWAL_POS_i	8	0	8
INFO_SWAL_STRAT_i	6	2	8
INFO_TIME_NEG_s	1	1	2
INFO_TIME_POS_s	5	2	7
LOG_v	0	2	2
RELIG_NONE_v	6	0	6
RESTR_ACT_b	2	4	6
RESTR_DIET_b	8	0	8
SUPP_NEG_MED_s	0	1	1
SUPP_NEG_OTH_s	0	3	3
SUPP_POS_MED_s	3	8	11
SUPP_POS_OTH_s	6	2	8
SURG_NEG_r	6	4	10
SWAL_GEN_b	10	1	11
SWAL_PHYS_b	10	1	11

3.4 ADDRESSING DYSARTHIC SPEECH

In the current study two participants answered all of the questions completely themselves. Four participants' responses were affected by their dysarthric speech. The reporter used an iterative approach to clarify what word or phrases the participant wanted to use in order for clearer transcription. One patient could not answer all questions and was given yes/no questions for the majority of the questioning. Table 7 shows these data.

Table 7: Questions Asked (Original Survey Questions) and Patient Response Type

*See below for legend

Question	FQ	IR	YN	FM
<i>Tell me about your swallowing difficulties:</i>	2	3	1	
How long have you had problems?	2	3		1
Was it a gradual or sudden onset?	4	1		1
Can you eat anything at all?	4	2		
How did you feel when the problems began?	2	3		1
How would you describe the effects on your life?	2	3	1	

Question	FQ	IR	YN	FM
<i>Who has been involved in the treatment of your swallowing difficulties?</i>	2	2	1	1
Did you see your GP/SaLT/ Specialist Doctor?	3			3
Were you given information about the problems?	2	3		
Who gave you the information?	2	1	2	1
Do you feel you understood the nature of your difficulties?	3	3		
Do you think you had enough information/ would you have liked more?	3	2		
Did you feel able to ask questions?	4	1		

Question	FQ	IR	YN	FM
<i>Who first mentioned the idea of a feeding tube to you?</i>	2	2	1	1
Do you remember who first told you about tube feeding?	2	4		
Did you understand the term?	3	2		1
Had you heard the term before?	3	3		
Do you feel it was explained well?	2	2		1
Did you understand what it would involve?	2	2		1
How did you feel when it was mentioned to you?	2	4		

Table 7 (Continued): Questions Asked (Original Survey Questions) and Patient Response Type

Question	FQ	IR	YN	FM
<i>What did you consider when you made your decision to go ahead or decline the PEG placement?</i>	2	4		
Did you have strong feelings about alternative feeding?	2	3		1
How did you feel when it was mentioned to you?	2	2		1
Were your religious beliefs/social values important?	4	2		
Your overall health?	2	2		1
Your thoughts and hopes for the future?	2	2	1	

Question	FQ	IR	YN	FM
<i>Tell me what your family/friends thought about the idea.</i>	2	3	1	
Did you ask their opinions?	4	2		
Were their opinions important to you?	3	3		
Did they influence the decision you made?	2	3		1
What about your doctor?	2	4		
Did you feel the doctors or medical team had a strong opinion about the feeding tube?	2	4		
Did they suggest that you should go ahead or not?	3	2		
Did their opinions feel important to you?	4	2		
Did this have an impact on your thoughts /decisions?	4	2		

Question	FQ	IR	YN	FM
<i>Was it a difficult decision to make?</i>	5			
Did you take a long time to consider?	3	2		
Were you given time to consider your decision?	4	1		
Did you ask for help in making your decision?	4	1		
Whose opinion did you value most?	3	2		
Did you feel well supported in making the decision?	3	2		

Question	FQ	IR	YN	FM
<i>Do you remember much about the procedure?</i>	2			
Was there much pain/discomfort?	1	1		
Did that last long?	1	1		
Were you prepared for that?	1			1

Question	FQ	IR	YN	FM
<i>Are you happy with the decision that you made?</i>	2	1		
Was it the right choice for you?	2	1		
Did it turn out the way you expected?	1	2		
Would you make the same choices again?	1	2		

What would others advise in the same situation?	3	3		
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[legend: number of participant responses to full question (FQ), number of responses in which the researcher used iterative dialogue (ID), number of participant responses with a yes/no answer to a questions that was not yes/no in its original form (Y/N), and number of responses given by an accompanying family member (FM)].

4.0 DISCUSSION

This is the first study looking at factors that patients with ALS reported they considered when deciding whether or not to have a feeding tube. These preliminary results suggest that there are many factors that may influence this decision and that each patient making this decision will have factors unique to him or her. Many participants in the study had a large number of comments in the themes of independence, influences, information, or support.

4.1 MAJOR THEMES, CODES, AND FACTORS

Results from coding indicate that the topic areas in which participants had the most comments were “information” and “outside pressures.” The most commonly used codes were:

- INDEP (24): Independence
- INFL_PROF_PART (34): particular/specific professional influence
- INFL_PROF_GEN (16): general professional influence
- INFO_SURG_POS (18): having good or enough information about the surgery
- INFO_SURG_NEG (20): not having good or enough information about the surgery
- DECIS_STEPS (15): steps involved in decision-making

The frequency of these codes suggests that factors such as influence and opinions from the medical team, good information about the surgery and expectations, and maintenance of independence in the decision-making process were important to the majority of patients in this study. The number of participants in this study was small. There was a wide range of factors raised across individuals and several themes came up repeatedly. This unique and small data set can be used as preliminary information on what clinicians should consider discussing with patients with ALS as they decide whether or not to have a feeding tube.

Several codes were only used twice, including:

- BURDEN_SELF: feeling additional self-burden after getting a feeding tube
- HEALTH_NEG: negative effects of a feeding tube on overall health
- INFO_SEARCH: seeking information from outside sources
- INFO_SPEECH: seeking information about speech changes
- INFO_TIME_NEG: not having the necessary information in enough time to make the decision

Although these factors did not commonly occur, this could be due to the small scale of the study. These factors might occur more often in a larger-scale study, meaning that these points may be important ones to discuss with patients. Discussing these points with patients could be beneficial for two reasons: 1. Patients may be thinking about certain factors but are not comfortable bringing up the subject on their own. 2. Patients may not have thought about these factors but, once they do discuss them, realize that they do have an influence on their decision.

After the codebook was completed each code was given a suffix letter assigning it to the predetermined topic area to which it was proposed to belong: background (b), information (i), values (v), outside pressures (o), support (s), and reflection (r). Many of the codes had the

majority of occurrences within the proposed topic area. Two codes (SUPP_MED_POS_s and _INFL_PROF_PART_o) occurred in other topic areas, and eight codes (DECIS_STEPS_s, DECIS_TIME_s, DISEASE_DECLINE_v, EMO_FEAR_b, INDEP_o, INFL_PROF_GEN_o, INFO_SURG_NEG_i, INFO_SURG_POS_i) had roughly equal occurrences in the proposed topic area and other topic areas. This large number of occurrences outside of the expected topic area could suggest that these factors would be spontaneously elicited without the predetermined topic areas used to determine the questions asked in this study. Clinicians should engage in broad dialogue with these patients, keeping in mind that what patients think about is not always the same as what clinicians think patients think about.

This study uses the methodology of coding which is used for qualitative data analysis. Coding can be used for any type of text-based data, including focus groups, field notes, or interviews. This is the first time this coding and analysis has been applied to a study about people with ALS deciding on a feeding tube. Using this methodology to analyze interview transcripts, the primary investigator was able to pull out individual importance as well as factors seen across the entire small sample.

Some codes used in this study were very specific while others were fairly broad. A specific example is the code EMO_FEAR_A which corresponds to comments specifically describing fear as opposed to other emotional words used such as “*puzzled*”. A broader example is the code SURG_NEG_F which corresponds to any negative comments about the surgery process. The code names were determined by the primary investigator or by the second coder and primary investigator together during the definition-changing process. The participant comments led the code creation, but there may be investigator bias as to which codes were more specific vs. which were broad. For example, in this study the primary investigator chose to leave

the theme “appearance” as a broad code that encompassed all quotes related to participants’ views toward their physical appearance as a result of the feeding tube. The primary investigator chose to expand on the theme “information” by making nine codes that have more specific definitions about certain aspects of information.

4.2 SISTER STUDY COMPARISON

There were both similarities and differences between the “sister study” (Vesey, Leslie, & Exley, 2008) and the current study. The interview questions used were the same, but the studies included different patient populations. The sister study looked at perspectives of patients with progressive dysphagia due to a variety of diagnoses including multiple sclerosis, pharyngeal scarring, cerebellar ataxia, and unknown diagnosis (Vesey, Leslie, & Exley, 2008). These patients had all made the emergency decision to get a feeding tube. The participants in the sister study were included only if they were well enough and able to independently complete the entire interview. The current study was completed with patients with ALS who had made the decision to either get or not get a feeding tube. Participants in the current study were included regardless of their ability to independently complete the interview. Some questions were changed to a yes/no format, and some patient answers required an iterative process in order for the researcher to enable the patient to have a “voice” when it came to transcription.

The interview process was similar in the two studies, but the analysis of the data differed. The sister study analysis was completed by a constant comparative method, meaning that data collection and analysis occurred at the same time. In the current study, the interviews were

conducted by a third-party clinical researcher, referred to as the reporter, and the analysis occurred after all interviews were complete.

In the sister study all participants reported that they had no option other than to accept the feeding tube, which resulted in medical opinion and physical deterioration being the most powerful reported influences (Vesey, Leslie, & Exley, 2008). Many of these patients viewed the decision as a medical one – of survival or death. Though medical opinion is also a commonly reported factor in the current study it appeared as a positive theme. Patients in the current study describe very supportive medical involvement that allowed for independence in the decision-making process.

4.3 LIMITATIONS OF CURRENT RESEARCH

The sample used in this study was small and included patients who were all fairly similar on personal factors including time since diagnosis and ALS type. It can be an advantage to have a population that is similar in these personal factors as possible environmental factors could be expected to be comparable across patients. The sample in the current study is representative of the ALS population in that most people with ALS will have a similar disease pattern. There is a certain window of time during which this decision will need to be made. Patients with ALS will be facing the same limited options of care. A study including a larger and more diverse participant sample could provide additional data on how different groups of people are affected by various factors.

The primary investigator did not conduct the interviews or transcribe the interviews. The transcription of the interviews was sometimes unclear. It could have been beneficial to have the

primary investigator conduct the interviews, or to have the interviews videotaped. This would allow the primary investigator to pick up on patient intonation, observe any type of nonverbal communication, or catch some dialogue that was not included in the transcripts. The disadvantage of an investigator using these nonverbal or voice intonation is that the investigator would be inferring what the patient may be thinking, which may not be correct.

The patients included in this study were able to participate regardless of their ability to independently complete the interview. Four of the six participants required iterative dialogue to be used or questions in yes/no format to complete the interview. One of these four patients could not complete all interview questions even with the modifications. The study could have limited participant inclusion to have only those who were able to adequately express themselves through natural speech or by using an assistive communication device. An advantage of using participants who were able to verbally communicate is that there are multiple patient perspectives in the study. There is no participant bias due to including only those who are healthy enough to complete the interview independently. These patients could be in a different frame of mind than those who are further into the disease process or who have not been able to benefit from their feeding tube, which would result in a more positive attitude on the whole.

There is a potential interviewer bias with yes/no questions, as the interviewer had to make a quick decision on how to formulate the new question type. One example of possible bias is from the question “How did you feel when the problem began?” In one case from this study in which the patient was unable to give answers to open responses, the interviewer asked “Do you remember feeling confused or worried or anything like that at all?” followed by a question “Is there a word you could use to describe how you felt?” In this case the patient’s family member came up with the word “puzzled” and the patient agreed on that. It is unclear whether this

response was biased by the interviewer question. One way to combat this potential interview bias would be to have an augmentative or alternative communication device. This would allow the patient to answer questions in an alternative (non-verbal) format. Another option would be to send a survey or questionnaire to be filled out at home. An at-home survey would restrict the information, as there is no room for dynamic exploration. It must be recognized that once we ask people to reflect on their experiences in any way, this process changes the experience.

This study used predetermined topic areas to structure the interview. There were no questions included about other possible important factors such as cost (of tube feeding, care, surgery, or insurance). Of note, this is not an oversight by the previous researchers or the reporter. In the United Kingdom, there would be no cost factor for patients who needed feeding tubes. This means that fear of cost is not an issue with the healthcare system in the UK, though these fears may be present in patients from the USA. It is also possible that, if the question set were changed, some issues that were brought up in this current study would not have been brought up at all. Some questions were originally in yes/no form. It is possible that an entirely open-ended question set could change what information was offered or bring up new information. The reporter did ask the participant if s/he had any other comments at the end of the interview. Typically there was no new information brought up at this point; the patient either said s/he had no more comments or s/he restated something said earlier.

4.4 CLINICAL IMPLICATIONS AND FUTURE RESEARCH

Results of this study can be used for intervention purposes in a clinical setting. Clinicians working with this patient population in the future will be able to better provide the patient with information that can help him through the process of making his decision. The codebook provided in appendix B will not be handed out to clinicians, but a checklist could be developed from these data. This data would provide clinicians with a starting point or a guideline for discussion. An *informed* clinician will be able to better educate a patient on the different factors that may influence him. This in turn will support patients to be more *informed* in terms of consenting to clinical intervention. Clinicians can use the issues and concerns that are highlighted by the codes and their definitions to provide better counseling and, ultimately, help patients to make a decision that is best for him or her. This codebook and clinician knowledge will allow the patient to work with his medical team to make this important decision based on his individual needs and informed preferences. The dialogue between the client and clinician on these broad topics will help identify when the client needs more information or clarification of information.

A common theme that occurred across patients was that they did not have enough information about the procedure or about the expectations of having a feeding tube. This shows that sometimes clinicians think they give adequate information, but that is not how the patient perceives it. Clinicians need to ensure that they are providing their patients with an adequate amount of information, including asking the patients if they have done so. About half of the United States follows the legal standard that is based on a patient perspective. If a malpractice lawsuit is brought against a clinician, it will be the clinician's responsibility to prove that enough

information was given to the patient. This will be decided from the patient's perspective, not what the clinician thought was appropriate.

Future research is needed to fully assess the many factors that may influence a patient's decision to get a feeding tube. These factors are important information to have as a clinician because they provide clues as to how to best help these patients. Future research could focus on expanding the question set or adding prompts in order to explore other subjects that may bring up additional factors important to the patients' decisions.

In addition to expanding the question set, the sample size could also be expanded. The current study was done with six patients and provides good preliminary information. A larger sample size might allow for more unique factors to surface, and could provide data on factors that are most common throughout patients.

Participant personal factors, including gender, age, ALS type, or time since diagnosis, are important to consider when looking at factors influencing patient decisions on whether or not to get a feeding tube. It could also be beneficial to have additional information on participant race, religion, or culture, in order to learn about any cultural or religious difference in this highly personal decision-making process. It is important to keep in mind that all patients are unique, and that each individual will have factors that are most important to him/her.

4.5 CONCLUSION

Factors influencing a patient's decision on whether or not to get a feeding tube are highly individual. Patient-generated themes and individual factors were derived from the interview transcripts. Major themes found across patients include information, influences, support, and

independence. Some factors commonly found across participants in this study included: patient report of not getting enough information about the feeding tube and procedure, weighing risks and benefits in relation to when to have the feeding tube placed, influences from medical professionals, influences from family and friends, and feeling of independence in the decision-making process.

Clinicians need to understand factors patients consider when making the decision to get or to decline a feeding tube. This small scale study was the first of its kind but provides preliminary information that can be used in clinical discussions. Clinicians working with this patient population are able to use the data from this study as a starting point when having this discussion with their patients.

APPENDIX A

QUESTION SET

Section A: Background

1. Tell me about your swallowing difficulties:

How long have you had problems?

Was it a gradual or sudden onset?

Can you eat anything at all?

How did you feel when the problems began?

How would you describe the effects on your life?

Section B: Information

2. Who has been involved in the treatment of your swallowing difficulties?

Did you see your GP/SaLT/ Specialist Doctor?

Were you given information about the problems?

Who gave you the information?

Do you feel you understood the nature of your difficulties?

Do you think you had enough information/would you have liked more?

Did you feel able to ask questions?

3. Who first mentioned the idea of a feeding tube to you?

Do you remember who first told you about tube feeding?

Did you understand the term?

Had you heard the term before?
Do you feel it was explained well?
Did you understand what it would involve?
How did you feel when it was mentioned to you?

Section C: Values

4. What did you consider when you made your decision to go ahead or decline the PEG placement?

Did you have strong feelings about alternative feeding?
How did you feel when it was mentioned to you?
Were your religious beliefs/social values important?
Your overall health?
Your thoughts and hopes for the future?

Section D: Outside Pressures

5. Tell me what your family/friends thought about the idea.

Did you ask their opinions?
Were their opinions important to you?
Did they influence the decision you made?
What about your doctor?
Did you feel the doctors or medical team had a strong opinion about the feeding tube?
Did they suggest that you should go ahead or not?
Did their opinions feel important to you?
Did this have an impact on your thoughts /decisions?

Section E: Support

6. Was it a difficult decision to make?

Did you take a long time to consider?
Were you given time to consider your decision?
Did you ask for help in making your decision?
Whose opinion did you value most?

Did you feel well supported in making the decision?

Section F: Reflection

7. Do you remember much about the procedure?

Was there much pain/discomfort?

Did that last long?

Were you prepared for that?

8. Are you happy with the decision that you made?

Was it the right choice for you?

Did it turn out the way you expected?

Would you make the same choices again?

What would others advise in the same situation?

APPENDIX B

CODEBOOK

APPEAR_NEG_v – person feels that the physical feeding tube affects his/her appearance in a negative way

ASK_INFO_i – feeling able to ask questions; communication between medical staff is open; patient feels he/she will not be judged by medical staff

BURDEN_OTH_v – person feels that their needs are extra work to be provided by family members or caregivers

BURDEN_SELF_v – person feels that their needs are extra work to take on himself/herself

DECIS_STEPS_s – steps the individual has taken specific to feeding tube placement (deciding to get the feeding tube or not)

DECIS_TIME_s – weighing the risks and benefits in the decision of when to have the procedure

DISEASE_DECLINE_v – perception of a definitive mark of decline of physiological aspects in the disease and disease process

EMO_FEAR_b – person using the emotional word “fear” in relation to the physical aspects of swallowing difficulties or having a feeding tube and using it for nourishment

EMO_OTHER_b – person using other emotional words, different from fear, in relation to the physical aspects of swallowing difficulties or having a feeding tube and using it for nourishment

HEALTH_NEG_v – health risks of getting a feeding tube

HEALTH_POS_v – health benefits of getting a feeding tube

IMP_FIRST_v – first impressions or thoughts after hearing about the option of getting a feeding tube or immediately after receiving the feeding tube

IMP_FUT_v – impressions of how the tube will affect the patient in the future

IMP_RETRO_r – would the person get or not get the feeding tube, knowing what he/she does now

INDEP_o – independence in decision making process; not feeling pressured by medical professionals or family members/caretakers into a decision

INFL_ITEM_PART_o – a particular item or document that was most useful/helpful in the decision making process.

INFL_OTH_GEN_o – general influence from family/friend

INFL_OTH_PART_o – particular family/friend of influence mentioned by name or title (e.g. sister, daughter)

INFL_PROF_GEN_o – general influence from professional team

INFL_PROF_PART_o – particular professional person of influence mentioned by name or title (e.g. my nurse, Dr. Smith)

INFO_SEARCH_i – influence from outside sources such as internet searches, research papers, other professional or personal sources, etc that were independently sought after by the individual.

INFO_SPEECH_i – individually seeking and acquiring information from medical team about speech deficits

INFO_SURG_NEG_i – (in terms of the feeding tube, the procedure, or expected outcomes) the patient was not given enough information from medical team, the information was conflicting between professional, or the information given to the person was not helpful

INFO_SURG_POS_i – (in terms of the feeding tube, the procedure, or expected outcomes) the patient was given enough information from medical team and the information given was helpful

INFO_SWAL_NEG_i – (in terms of swallowing or swallowing difficulties related to ALS) the patient was not given enough information from the medical team or given information that was not helpful

INFO_SWAL_POS_i – (in terms of swallowing or swallowing difficulties related to ALS) the patient was given enough information from the medical team

INFO_SWAL_STRAT_i – neutral comments discussing information given to the client about the effects of ALS on swallowing, strategies to use, foods to avoid, etc

INFO_TIME_NEG_s – after seeking information, it was not given to patient in a timely fashion, patient need to make a decision without enough time to process the information.

INFO_TIME_POS_s – after seeking information, it was given to patient was done in a timely fashion that was not given too early as to overwhelm or too late to where all options are not available.

LOG_v – logistics of how the tube feeding/cleaning/care will work

RELIG_NONE_v – not having any religious influences in the decision-making process

RESTR_ACT_b – restrictions in activity secondary to deficits of disease

RESTR_DIET_b – restrictions in diet secondary to the deficits of disease

SUPP_NEG_MED_s – comments in opposition to patient's view from medical team throughout decision making process

SUPP_NEG_OTH_s – comments in opposition to patient's view from family/friends throughout decision making process

SUPP_POS_MED_s – positive support from medical team that agrees with patient decision

SUPP_POS_OTH_s – positive support from family/friends that agrees with patient decision

SURG_NEG_r – negative thoughts/feelings related to surgical process or recovery from surgery

SWAL_GEN_b –factual, neutral information the patient provides about his swallowing difficulties

SWAL_PHYS_b – description of specific physical impacts of the swallowing difficulties

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