

Research Article

The Decision-Making Process for Percutaneous Endoscopic Gastrostomy in People with Amyotrophic Lateral Sclerosis

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Abstract

Percutaneous endoscopic gastrostomy (PEG) insertion is recommended for people with amyotrophic lateral sclerosis (PALS) who are experiencing dysphagia resulting in diminished food and oral intake. Unintended weight loss and malnutrition are negative prognostic factors in PALS. Insertion of a PEG tube provides reliable access for nutrition, hydration, and medication, and can diminish the risk for aspiration pneumonia, choking, weight loss and fatigue. PEG use can significantly increase survival time for PALS; however, less than half of PALS who meet the criteria for PEG tube placement undergo the procedure. The factors influencing PALS in making this decision have not been extensively explored. This qualitative case study investigated the decision-making process in accepting a PEG as an alternative means of feeding. A purposive sample of 5 participants utilizing a PEG tube was recruited. Data was collected using in-depth semi structured interviews consisting of open-ended questions. Interviews were completed face to face through Zoom, a virtual platform. A thematic analysis was conducted to understand the unified subjective experiences of the participants. The analysis revealed four themes: (1) Survival; (2) Scary and Anxiety Provoking Process; (3) Wanted to Live Longer; and (4) Not Alone in My Decision.

Conclusions: The decision-making process for PALS is highly emotive and challenging. Lack of appropriate education and comprehensive discussions with health care providers were negative factors that influenced the decision making process. Social supports and the will to live were positive factors that facilitated autonomous decision-making and eased the angst in PALS during this very difficult process.

Keywords: Amyotrophic lateral sclerosis, Percutaneous endoscopic gastrostomy, Decision-Making, Feeding tube, Dysphagia

Introduction

Amyotrophic lateral sclerosis (ALS) is an incurable, progressive, fatal neurodegenerative disorder that destroys motor neurons in the nervous system. Motor neurons are key in the transmission of impulses from the spinal cord to skeletal muscles, as they enable individuals to have direct control of all muscle movements. As such, this neurodegenerative disease ultimately leads to progressive muscle weakness and loss of voluntary muscle control [1]. ALS has an incidence of 5.2 per 100,000 people in the United States [2]. The average life expectancy for patients with this disease is 2-5 years post diagnosis, with most deaths resulting from respiratory failure, often precipitated by pneumonia [3]. Several subtypes of ALS exist, with the most common resulting in limb onset (70%) and bulbar onset (25%) [4]. Both subtypes are characterized by upper motor neuron (UMN) symptoms, including hyperreflexia, spasticity, and bradykinesia, and lower motor neuron (LMN) symptoms, including fasciculations, muscle weakness, and atrophy. Despite the decreased mobility of people with ALS (PALS), the metabolic demands increase secondary to continuous muscle spasms and fasciculations [5]. The decreased nutritional intake due to difficulty swallowing results in negative caloric balance, further exacerbating muscle wasting, reducing body

mass index (BMI), and worsening functional status. Furthermore, weakness and atrophy of the tongue and muscles of mastication contribute to fatigue in chewing and increase the time required for feeding. Other serious complications such as aspiration pneumonia and acute episodes of choking, either of which can be life threatening, have also been observed. Similarly, progressive dysphagia diminishes patients' respiratory reserve, which will become a crucial factor in recommending and evaluating for further intervention [4].

Although the progression of symptoms and the areas of the body affected vary by subtype, approximately 85% of all PALS develop dysphagia [6], or difficulty swallowing, over the course of the disease. PALS with bulbar onset have a greater incidence of dysphagia early in the progression of the disease, whereas those with spinal onset develop dysphagia in the late stages [7]. Statistics reflect that dysphagia in those with bulbar onset increased from an initial incidence of 95% to 98% and those with spinal onset from 35% to 73% over a 2-year period [8]. Depending on the severity and onset of dysphagia, many PALS need additional support for receiving proper nourishment. Negative prognostic factors in PALS includes weight loss and malnutrition. Guidelines for intervention for dysphagia include placement of an enteral gastrostomy tube [1]. There are

different enteral tube procedures utilized for tube placement, with the two most common procedures being the percutaneous endoscopic gastrostomy (PEG) and the Radiologically Inserted Gastrostomy (RIG). The RIG is less desirable than PEG because it has been associated with increased rates of dislodgement, tube blockages, and infections [9,10]. Further, a meta-analysis [11], studied the technical success rates, complication rates, and mortality rates between PEG and RIG resulting in the PEG having an increased success rate, with complications and mortality comparable after placement. Similarly, a prospective study [12], found mortality and complication rates comparable involving 50 patients with ALS who underwent a PEG or RIG procedure. Another meta-analysis evaluated postoperative complications, procedural success rate, and survival outcomes. In contrast, the PEG procedure was associated with less post-operative pain, but again had a lower success rate without any differences in survival [13]. An important advantage of the RIG procedure is that it does not require general anesthesia which lessens the possibility of respiratory complications, especially in patients with a reduced forced vital capacity (FVC) less than 50%, as measured by spirometry [12-14].

Furthermore, feeding tubes require specialized care and maintenance which oftentimes causes considerable burden on PALS and their caregivers leading to significant emotional impact and decreased quality of life. Although medically necessary, there is a limited amount of qualitative literature on the factors that influence the patients' decision-making process to undergo such a procedure. Current studies [15,16], have shown that PEG tube acceptance in patients with ALS varies across countries and that patients are often reluctant to undergo this procedure [17].

In a review, Bradly [18], evaluated changes (in terms of ALS management) established in the 1999 American Academy of Neurology ALS Practice Parameters publication and reported that only 46% of patients were recommended for a PEG tube and of those only 43% received one. This amounts to an overall 20% PEG insertion rate. The timely implementation of a PEG tube is important, as there is a limited window of opportunity to receive this type of treatment. Without a PEG tube, PALS nutritional intake is compromised and thus negatively impacts health.

Initial studies have failed to demonstrate the benefit of enteral feeding in survival duration in the ALS population. However, more recent research has shown a trend toward a positive effect, especially in studies following the most recent guidelines and larger sample sizes [7]. A retrospective study combined with a meta-analysis demonstrated that enteral feeding increased survival duration irrespective of ALS subtype and stabilized BMI. Furthermore, analysis determined that enteral tube placement in patients with an FVC greater than 50% had a better survival duration than those with a FVC less than 50%. This trend was magnified in patients with a FVC greater than 60% [19]. Lastly, the American Academy of Neurology (AAN) recommends a FVC of below 50% as a threshold where complication rates are increased [20]. However, other studies have proposed higher FVC, such as 60% to 70%, to improve outcomes [19,21,22].

Currently, there are no established criteria to determine the optimal timing of a tube placement. This may result in a delay in recommendations and patients missing a window of opportunity for the most beneficial outcomes and maximal risk reduction. To assist a patient in the decision-making process, it is important to understand the factors that influence and motivate an individual in choosing a course of action. Thus, the purpose of this study was to explore the decision-making process that contributed to the placement of a PEG feeding tube in people with ALS. The study also sought to highlight the influences and experiences, while obtaining such an invasive alternate feeding device.

Methods and Materials

Study Design

This research used qualitative case study methodology based on thematic analysis to conduct an in-depth exploration of the phenomena of the decision-making process among PALS who opted for PEG tube insertion. The question "how do PALS describe their decision-making process in obtaining a PEG "feeding tube"?" guided this study. Secondary questions included "how do people with ALS describe the experience of obtaining a PEG feeding tube?" and "what were the influences that impacted the decision to accept a feeding tube?"

The number of participants recruited for this study was based on previous qualitative studies. The literature suggests a small sample size, which enables a more in-depth perspective on the phenomena (decision-making process). Specifically, a purposive sample of 5 participants would offer a more in-depth perspective on the decision-making process of these individuals [23].

Approval from Hofstra University's Institutional Review Board (IRB) was obtained (HUIRB Approval Ref#: 20220727-OT-HPHS-CIA-1) prior to recruitment of participants.

Participants

A purposive sampling was used to recruit PALS who use PEG tube feedings. Recruitment occurred via ALS care teams in multidisciplinary clinics located in various areas of the northeast USA. Members of care teams were asked to inform PALS with PEGs of our study. Those PALS who were interested were contacted by the first author. Participation was voluntary and informed consent was obtained from all participants. Confidentiality and anonymity were assured as well as the right to withdraw from the study at any time.

Five participants, 3 male and 2 female, were interviewed for this study. The mean age of the participants was 55.4 (range=36-75 years old). The mean time from diagnosis to PEG insertion was 5.6 years (range=2-11 years). All participants had a diagnosis of ALS, and all were using PEG tube for nutrition and hydration. All participants attend specialized multi-disciplinary clinics for ALS located in the northeast of the United States. None of the participants held any form of paid or volunteer employment, all resided with family, and all utilized a power wheelchair to meet their mobility needs (Table 1).

Table 1: Study participants demographics and related information.

Participant	Information
1	Diagnosed with ALS in 2014; PEG inserted in 2016; ventilator dependent, uses assistive technology devices for augmentative and alternative communication. Lives with spouse and dependent child.
2	Diagnosed with ALS in 2017; PEG inserted in 2021. Lives with spouse and adult children.
3	Diagnosed with ALS in 2008; PEG inserted in 2017; ventilator dependent. Lives with adult child.
4	Diagnosed with ALS in 2010; PEG inserted in 2021. Lives with spouse and adult children.
5	Diagnosed with ALS in 2019; a PEG inserted in 2022; uses assistive technology devices for augmentative and alternative communication. Lives with parents.

Data Collection

Participants were interviewed between August and September of 2023 by one of the researchers (GC) using a semi-structured interview format. Semi-structured interviews addressed the aims of this research and facilitated a deep understanding of the decision-making process, which was further appreciated by encouraging a bidirectional dialogue between researcher and participant. This is an inherent strength of interviews over questionnaires [24].

All interviews were conducted face-to-face using the online platform Zoom. Interviews were video and audio recorded. Participants reaffirmed consent verbally prior to the interviews. All interviews were scheduled at a time of the participant's choosing. Interview duration ranged from 55 to 89 minutes, as is typical for a semi-structured interview [25]. Interview time was longer for participants who used augmentative and alternative communication. A personal zoom account through the University was used to allow for great control of privacy and security. A unique private meeting ID and passcode was created for each interview. Unique identifiers were applied to each participant for referencing purposes and to protect confidentiality.

Data collection consisted of participants responding to demographic questions and semi-structured questions developed prior to the interviews which focused on the decision-making experience of having a PEG placement. The use of open-ended questions in a semi-structured interview format permitted the participants to expound upon their experience while allowing the interviewer to obtain relevant data across the participant sample. Data collected provided researchers with descriptive and personal findings from each participant.

Data Analysis

All interviews were audio recorded, transcribed, and anonymized. Demographic information was recorded and included age, sex, social support, living arrangements, date of ALS diagnosis and the date of the PEG procedure. Additional informational data recorded was the time, date, and location of each interview. Two researchers (GG and IS) independently analyzed and coded the five transcripts for description and themes. [26] This process assisted in isolating common responses between participants to assist in theme development. Using this method built textural and structural description of the participants' experiences [27]. Due to the qualitative design of this study, the information obtained is highly subjective. Participants had different reasons for agreeing to a PEG tube insertion and experiences surrounding the

process. Several steps were implemented to enhance trustworthiness and increase the rigor within the study design. Trustworthiness was established through formulating structured questions in advance to minimize bias and increase consistency between questions asked. This uniformity prevented the use of "lead in" questions, which also tends to bias responses from research participants [28]. Data collection was completed through a consistent interview technique involving open-ended non-leading questions. All interviews were voice recorded with typed verbatim transcriptions for researchers to verify for accuracy.

To confirm the accuracy of the researchers' interpretations, inductive thematic analysis was utilized to evaluate the data [29]. Researchers familiarized themselves with the data collected and initial construction of data was created, and hierarchies developed. This was then analyzed and aggregated to develop themes. Themes were further reviewed, defined, named, and refined by returning to the raw data for confirmation of an accurate representation of the participants' experiences. A written summary on each theme was completed with participants' responses linked to the themes that shared the essence of that theme. Results of their analysis were compared, and discrepancies discussed to enhance the credibility of the results and to minimize interpretation bias.

Results

Results of the thematic analysis illuminated the many challenges that impact the decision-making process of undergoing an invasive procedure as a PEG insertion. Analysis produced 4 themes and included the following: (1) survival; (2) scary and anxiety provoking process; (3) wanting to live longer; and (4) not alone in my decision.

Theme 1: Survival

As the disease progressed, participants described the ability to swallow becoming more difficult with various type of food consistencies. Participants reported starting with solid foods, then moving to solids cut into very small pieces and eventually progressing to puree. Besides the physiology intricacies of swallowing, the psychological fear of choking became apparent (Table 2).

Theme 2: Scary and Anxiety Provoking Process

Participants experienced a range of emotions from being scared to having anxiety in the decision-making process to obtain a PEG. These feeling stemmed from the lack of education and misinformation from the medical team who conveyed the urgency for a PEG, although not necessarily needed at the time. Participants expressed that medical teams were overly assertive and too comfortable in recommending

such an invasive procedure that would have a lasting impact in their lives. The fear of the procedure was only heightened when participants were told they would not be able to feed orally post PEG placement. These factors and inconsistencies contributed to the theme of scary and anxiety provoking process, which is reflected in the following statements (Table 3).

Theme 3: Wanted to Live Longer

Although the participants ranged in age, the need to live longer was an overarching theme for different reasons. The decision to have a PEG insertion weighed heavily as participants wanted to spend time with their children and see them through the stages of their

lives. Besides their own children, the thought of not meeting future grandchildren seemed apparent. Other participants wanted to be able to live longer to spend time with family (Table 4).

Theme 4: Not Alone in My Decision

The decision-making process to have a PEG placement can be influenced by an individual’s immediate or extended family to a health care provider, having the knowledge of the outcomes of prior patients. In this study, participants cited that both family and healthcare team members were instrumental in the decision-making process. These influences in decision-making were reflected in participants’ statements (Table 5).

Table 2: Participant responses related to survival.

Participant	Exemplar Responses
1	"I was having trouble swallowing solid foods; ALS, and that the expected progression, the next step would be that I wouldn't be able to feed myself; Went from cut up food very small then to puree then to straining the food. You know we'd rather do it earlier then wait till it's too late ... I choked a couple of times, scared the hell out of me...It was an awful submission to come to."
2	"I knew it had to be done, do it now before it is too late"
4	"I was having trouble swallowing solid foods so I thought that with ALS that was the expected progression, the next step I wouldn't be able to feed myself."
5	"I was losing weight and my ability for chewing and swallowing...and muscles in my mouth got weaker... I was having trouble swallowing solids- food...concerned I wouldn't be able to feed myself to stay alive"

Table 3: Participant responses related to scary and anxiety provoking process.

Participant	Exemplar Responses
1	"It was awful!! It was scary. I saw the doctor and he wanted to PEG me right away even though my vital capacity was near 70.....not the type of bedside manner I could handleAwful submission to come to."
2	"They wanted to do it preemptively....I did not want to stop eating. I was concerned that I could no longer eat my favorite food. I mean...you know...my gosh!"
3	"The doctor decided, I went to the hospital because of pneumonia and ending up with a tracheostomy and a PEG inserted...It was very terrifying... I was misinformed by the doctors as I was still able to eat by mouth. At that time, no one believe in those guys (doctors)... I didn't need this as I never had a swallowing issue...I don't recall them (doctors) sorry about the issue. Not well informed." "I was misinformed by the MDs, as they told me I need it (PEG) as I would not be able to eat.... I still eat by mouth. Either I get the tracheotomy and the feeding tube, or they (doctors) unhook me. It was terrible... It was terrible."
4	"I had a bad experience... the anesthesiologist, she scared the heck out of me; she had no experience. We were told that it was going to be a very simple procedure, it's a common procedure, it happens all the time, it's not a big deal. And we had a very different experience. When the anesthesiologist wasn't experienced with ALS patients, apparently, and said in a nutshell that I was going to have to be intubated in order to do this procedure, and there was a very strong possibility that I would have a tracheostomy for the rest of his life, after that procedure. There was discussion when we went to the ALS Clinic, that you should get a feeding tube before you need it, but at that time I was eating food just fine; Overall it was scary...I fear procedures."
5	"The ALS clinic very persistent (in PEG placement). "I was told that there was a possibility that if I didn't come out of anesthesia I would be put on a vent and they weren't sure if it could be reversed"

Table 4: Participant responses related to wanting to live longer.

Participant	Exemplar Responses
1	"I did it (PEG insertion) for my daughter, I wanted to be here longer for her. The practical reasons were lost on me. I just needed more time with my daughter."
2	"It was all steppingstones, I walked with the walker, then a scooter. I couldn't drive my car anymore. So it's like each step...O.k., this is real, I'm not getting better.
3	"They (doctors)could do anything they want; I want to live...all I want was to live a few more years. That's what I'm thinking about. The day I can't eat or swallow is the day that I'll lose all hope."
4	"I want to be here to see my kids grow up, see my grandchildren...so it's my driving force."
5	"losing weight, not being able to chew or swallow, not having enough nutrition, I want to go on"

Table 5: Participant responses related to not alone in my decision.

Participant	Exemplar Responses
1	"I was bombarded by them, my family. My mom, spouse, siblings, mother-in-law who wanted me to live longer...There were just a lot of them... you should do it sooner, don't wait too long... The person that helped me agree to it was my nurse practitioner working for my neurologist.. She had a nice bedside manner and explained the process."
2	"My spouse and I... We talked about it; it was scary... My spouse, together we made the decision... We knew it had to be done. I started to cry...just another step further into the disease... We knew it was time...do it earlier than wait till it's too late...My RN played a huge role in my decision. She knows everything, she's really smart"
4	"My spouse and I made the decision... didn't want to get it until I needed it...when I had difficulty that would be the time to get it."
5	" Family, brothers, sister- in- laws, parents, aunts, uncles, cousins, all encouraged and supported that this would be the best thing before my lungs got worse"

Discussion and Conclusion

Participants of this study went through a myriad of feelings and emotions including fear and anxiety when faced with the decision to have a PEG tube inserted. The decision-making process was described as very difficult and layered, filled with an array of varying opinions, facts, and influences from family members, friends, and health care professionals. Participants described the support from family and friends and the need to survive and live on as greatly contributing to the decision-making process. Two participants identified the nurse or nurse practitioner at multidisciplinary clinics as being instrumental in the decision-making process because they took the time to explain and educate on what the procedure and what living with a PEG might be like.

Some participants expressed frustration and resentment over feeling pushed by into the decision even though they were not quite ready. These feelings were exacerbated by receiving differing or no information from healthcare professionals about the PEG procedure, the need for the PEG, and what to expect after the procedure. Additionally, participants described some healthcare professionals as being cavalier in their discussions with them, which left them feeling disrespected and not heard. The experience in decision making of our participants was found to be congruent with research reviewed. Shaghayegh (2016) found that inconsistent or poor patient involvement between the medical team and patients led to patients' loss of autonomy and responsibility for their own care [30]. Similarly, Covvey et al. 2019, identified themes for barriers to shared decision making were uncertainty in the treatment decision, concern regarding adverse effects, and poor physician communication [31].

Research reflects that patients are often fearful to engage health professionals in discussions regarding medical issues beyond their understanding, placing patients in a negotiating position from fear and confusion, rather than knowledge and shared discussion, Berry (2017) refers to as "hostage bargaining syndrome" (HBS) [32]. This idea of HBS, where an imbalance of knowledge exist, will only further breakdown shared decision-making and lead to a sense of frustration, anger, or helplessness on part of the patient. The outcome of this study reflects some participants who were offered little options or medical justification for the PEG insertion, rather "since you're here in the clinic already, you will need a PEG eventually". This mindset left participants with increased anxiety and a loss of autonomy over their own care. Although participants were able to cope with these challenges, it was not without exerting a toll on their emotional well-being. The data also suggests collaborative decision-making can provide benefits in terms of a reduction of conflict between families and healthcare members to improve the overall decision-making process. Effective communication is a medical necessity for the delivery of quality professional care to PALS and their families, as vital decisions cannot be made lightly.

The study further shows that the decision-making process is multifaceted, from participants' healthcare team, spouses, children, to extended family and friends. Participants highlighted that family played an integral role supporting them in the process. Although family may have not understood the process, through their eyes, it was an extension of life. Besides family, participants discussed their healthcare teams in both a positive and negative context. Some PALS found the

nurses and nurse practitioners in the multidisciplinary ALS clinics that they attend, to be helpful. Some PALS perceived that some members of their health care team showed little compassion or that they treated the situation as "another day on the job". All participants wished that they had received better education on PEG tubes from their health care teams. Patients with ALS face a difficult and multifaceted decision when it comes to accepting or refusing the placement of a permanent feeding tube. Interviewing these participants who decided to obtain a PEG tube allowed us to obtain first-hand information on the factors that went into their decision-making process. Beside researchers, healthcare teams may be better equipped in meeting patients' needs in preplacement stages to reduce overall stress and anxiety. Ultimately, the study shed light on the reasons that participants choose to receive a feeding tube despite the procedure's implications. Given that patient participation results in improved health outcomes, increased quality of life, and provision of more client-centered interventions, patients need to be involved in the shared decision making process [33-35]. Based on the information widely available through current technology, patients need to be regarded as equal partners in the discussion of their own health care process, to better make more informed decisions.

Finally, we note that the results of this study cannot be generalized to the rest of the ALS population. Findings are not intended to speak for the experiences of other PALS who made the decision to receive a feeding tube. However, the study collected meaningful, individualized data, allowing participants the opportunity to share their personal experiences and tell their stories. This will contribute to the knowledge base regarding PEG feeding and have the potential to help other PALS, caregivers, and healthcare professionals. There are several limitations to this study. There are a small number of participants, all attending multidisciplinary ALS clinics, and all living in the same region of the United States. As such, these factors may limit the generalizability to PALS living in other geographical locations.

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References

1. Masrori P, Van Damme P (2020) Amyotrophic lateral sclerosis: a clinical review. *European Journal of Neurology*. [crossref]
2. Mehta P, Kaye W, Raymond J, Wu Ruoming, et al. (2020) Prevalence of amyotrophic lateral sclerosis—United States, 2014. *Morbidity and Mortality Weekly Report* [crossref]
3. Brown RH, Al-Chalabi A (2017) Amyotrophic lateral sclerosis. *New England Journal of Medicine*. [crossref]
4. Zarei S, Carr K, Reiley L, Diaz K, et al. (2015) A comprehensive review of amyotrophic lateral sclerosis. *Surgical Neurology International*. [crossref]
5. Muscaritoli M, Kushta I, Molfino A, Inghilleri M, et al. (2012) Nutritional and metabolic support in patients with amyotrophic lateral sclerosis. *Nutrition* [crossref]
6. Epps D, Kwan JY, Russell JW, Thomas T, et al. (2020) Evaluation and management of dysphagia in amyotrophic lateral sclerosis: a survey of speech-language pathologists' clinical practice. *Journal of Clinical Neuromuscular Disease*. [crossref]
7. Castanheira AÉ, Swash M, De Carvalho M (2021) Percutaneous gastrostomy in amyotrophic lateral sclerosis: a review. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*.

8. Onesti E, Schettino I, Gori M C, Frasca V, et al. (2017) Dysphagia in amyotrophic lateral sclerosis: impact on patient behavior, diet adaptation, and riluzole management. *Frontiers in Neurology*.
9. Khan M A, Thompson N P, McGowan L (2021) P37 complication rates in first 30 days post peg and riginserion: single tertiary centre experience. *Gut*.
10. Pols J, Limburg, S (2016) A matter of taste? quality of life in day-to-day living with ALS and a feeding tube. *Culture, Medicine, and Psychiatry*. [crossref]
11. Yuan T-wen, He Y, Wang S-bo, Kong P, et al. (2020) Technical success rate and safety of radiologically inserted gastrostomy versus percutaneous endoscopic gastrostomy in motor neuron disease patients undergoing: a systematic review and meta-analysis. *Journal of the Neurological Sciences*. [crossref]
12. Desport JC, Mabrouk T, Bouillet P, Perna A, et al. (2012) Complications and survival following radiologically and endoscopically-guided gastrostomy in patients with amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis*. [crossref]
13. Yang B, Shi X. 2017. Percutaneous endoscopic gastrostomy versus fluoroscopic gastrostomy in amyotrophic lateral sclerosis (ALS) sufferers with nutritional impairment: a meta-analysis of current studies. *Oncotarget*. [crossref]
14. Thomas K, Schragger J, Neel R, Brook L. (2020). Percutaneous endoscopic gastrostomy tube placement in amyotrophic lateral sclerosis: a case series with a multidisciplinary, team-based approach. *Annals of Gastroenterology*. [crossref]
15. Greenaway LP, Martin NH, Lawrence V, Janssen A, et al. (2015) Accepting or declining non-invasive ventilation or gastrostomy in amyotrophic lateral sclerosis: patients' perspectives. *Journal of Neurology*. [crossref]
16. Martin N H, Lawrence V, Murray J, Janssen A, et al. (2016) Decision making about gastrostomy and noninvasive ventilation in amyotrophic lateral sclerosis. *Qualitative Health Research*. [crossref]
17. Katzberg HD, Benatar M (2011) Enteral tube feeding for amyotrophic lateral sclerosis/motor neuron disease. *Cochrane Database of Systematic Reviews*. [crossref]
18. Bradley W G, Anderson F, Gowda N, Miller R. G, et al. (2004). Changes in the management of ALS since the publication of the AAN ALS practice parameter 1999. *Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders*. [crossref]
19. Bond L, Ganguly P, Khamankar N, Mallet N, et al. (2019) A comprehensive examination of percutaneous endoscopic gastrostomy and its association with amyotrophic lateral sclerosis patient outcomes. *Brain Sciences*. [crossref]
20. Miller RG, Jackson CE, Kasarskis EJ, England JD, et al. (2009) Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. [crossref]
21. Chiò A, Finocchiaro E, Meineri P, Bottacchi E, et al. (1999) Safety and factors related to survival after percutaneous endoscopic gastrostomy in ALS. *Neurology*. [crossref]
22. Pena M J, Ravasco P, Machado M, Pinto A, et al. (2012) What is the relevance of percutaneous endoscopic gastrostomy on the survival of patients with amyotrophic lateral sclerosis? *Amyotrophic Lateral Sclerosis*.
23. Schoch K (2020) *Case Study Research. Research Design and Methods: An Applied Guide for the Scholar-Practitioner*. Thousand Oaks, CA: Sage Publishing 245-258. [crossref]
24. Mashuri S, Sarib M, Alhabsyi F, Syam H, et al. (2022). Semi-structured interview: a methodological reflection on the development of a qualitative research instrument in educational studies. *Journal of Research & Method in Education*.
25. Jamshed S (2014) Qualitative research method-interviewing and observation. *Journal of Basic and Clinical Pharmacy*.
26. Creswell J, Poth C (2018) Qualitative Inquiry and Research Design: Choosing among Five Approaches. Thousand Oaks, CA: Sage Publishing 96-102.
27. Creswell JW (1998) Qualitative Inquiry and Research Design: Choosing among Five Traditions. Thousand Oaks, CA: Sage Publishing 186-187.
28. Moustakas C (1994) Phenomenological Research Methods. Thousand Oaks, CA: Sage Publishing 1994: 90-104.
29. Nowell LS, Norris JM, White DE, Moules NJ (2020) Thematic analysis. *International Journal of Qualitative Methods*.
30. Shaghayegh V, Hamzehgardeshi L, Hessam S, Hamzehgardeshi Z. (2014). Patient involvement in health care decision making: a review Iranian Red Crescent Medical Journal.
31. Covvey JR, Kamal, KM, Gorse EE, Mehta Z, et al. (2019) Barriers and facilitators to shared decision-making in oncology; a systematic review of the literature. *Supportive Care in Cancer*.
32. Barry LL, Danaher TS, Beckham D, Awdish LA. et al. (2017) When patients and their families feel like hostages to health care. *Mayo Clinic Proceedings*.
33. Hibbard JH (2003) Engaging health care consumers to improve the quality of care. *Medical Care*.
34. Gluyas H (2015) Patient-centered care: improving healthcare outcomes. *Nursing Standard*.
35. Zizzo N, Bell E, Lafontaine AL, Racine E (2017) Examining chronic care patient preferences for involvement in health-care decision making: the case of Parkinson's disease patients in a patient-centered clinic. *Health Expectations*. [crossref]

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