

Original Article

Speech-Language Therapy Considerations for Gastrostomy Indication in People with Neurodegenerative Diseases

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ABSTRACT

Caring for people with neurodegenerative diseases and dysphagia poses various clinical challenges. Percutaneous endoscopic gastrostomy (PEG) is a possible intervention in such cases, and speech-language therapists (SLTs) play a key role in recommending this form of support. This study aims to analyze the considerations of SLTs in Chile regarding PEG indication in people with neurodegenerative diseases and dysphagia. Methodology: This is a quantitative and exploratory study. A survey was conducted among 30 Chilean SLTs with at least five years of experience working with people with neurodegenerative diseases and dysphagia. Results: There is variability in the participants' considerations when recommending PEG. The severity of dysphagia, most commonly assessed using the FILS scale, emerges as the most influential factor in decision-making. Psychosocial aspects, such as the person's willingness and family support, also play a significant role. The interdisciplinary team typically includes neurologists, geriatricians, and intensivists. From an ethical perspective, there is a consensus that the final decision should involve the affected person and their family. Discussion-Conclusions: There is a need to develop standardized protocols for PEG indication. The importance of actively involving individuals and their families in the decision-making process is highlighted, as well as the need to ensure access to ethics committees in complex cases. The study has some limitations, such as its small sample size, which points to the need for further research.

Consideraciones fonoaudiológicas para la indicación de gastrostomía en personas con enfermedades neurodegenerativas

RESUMEN

La atención a personas con enfermedades neurodegenerativas y disfagia plantea retos clínicos, siendo la gastrostomía (GTT) un procedimiento posible en estas situaciones. Los/las fonoaudiólogos/gas desempeñan un rol fundamental en la indicación de este soporte. Este estudio tiene como objetivo analizar las consideraciones de estos profesionales en Chile respecto a la indicación de GTT en personas con enfermedades neurodegenerativas y disfagia. Metodología: cuantitativa y de tipo exploratorio, se encuestó a 30 fonoaudiólogos/as chilenos/as que tuvieran al menos 5 años de experiencia en el trabajo junto a personas con enfermedades neurodegenerativas y disfagia. Resultados: existe variabilidad en las consideraciones al recomendar la GTT. La severidad de la disfagia sobresale como la dimensión más influyente en la toma de decisiones, evaluada mayoritariamente con la escala FILS. Los aspectos psicosociales, como la voluntad de la persona y el apoyo familiar, desempeñan un papel relevante en la indicación. El equipo de trabajo incluye neurólogos/gas, geriatras e intensivistas. Desde una perspectiva ética, existe consenso en que la decisión final debe involucrar a la persona afectada y a su familia. Discusión-Conclusiones: existe necesidad de desarrollar protocolos estandarizados para la indicación de GTT. Se releva la importancia de involucrar activamente a las personas y sus familias en el proceso, junto con la necesidad de facilitar el acceso a comités de ética en casos conflictivos. Se reconocen las limitaciones de este estudio, como la limitada muestra, lo que sugiere la necesidad de futuras investigaciones.

Keywords:

Swallowing; Dysphagia; Gastrostomy; Bioethics; Autonomy

Palabras clave:

Deglución; Disfagia; Gastrostomía; Bioética; Autonomía

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INTRODUCTION

People with neurodegenerative diseases may experience difficulties with eating or swallowing as their condition progresses. These challenges must be addressed to prevent associated complications. To effectively intervene in these issues, healthcare professionals must consider multiple aspects of the swallowing process, including the severity of the dysphagia, the patient's food preferences and tastes, and their cognitive status, which may impact their ability to ingest food, among other factors (Royal College of Speech and Language Therapists [RCSLT], 2014).

Neurodegenerative conditions that can result in dysphagia include Alzheimer's disease, Parkinson's disease, Huntington's disease, Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS), and Frontotemporal Dementia, among others. Individuals affected by these conditions may also present with related impairments, such as difficulties with speech, breathing, and memory—such as forgetting whether they have eaten or how to prepare food. These impairments can negatively affect their nutritional status, potentially leading to malnutrition and dehydration (Burgos et al., 2018).

Managing dysphagia in this population is a critical priority for healthcare teams, as it can help prevent severe complications such as choking, aspiration of oral contents, aspiration pneumonia, dehydration, weight loss, and malnutrition (Hanson et al., 2012). In some cases, these complications may exacerbate the underlying disease and can even be life-threatening.

Dysphagia in people with neurodegenerative diseases is commonly associated with an impaired swallowing mechanism, an altered state of consciousness, or both (de Luis et al., 2015). However, a subset of patients exhibits resistance or apparent indifference toward food intake (Finucane et al., 1999). In light of these difficulties, medical and rehabilitation teams often recommend alternative feeding routes, such as percutaneous endoscopic gastrostomy (PEG) and/or palliative care approaches in this population (Mulkerrin et al., 2018).

Nevertheless, PEG indication in individuals with neurodegenerative diseases remains controversial. Evidence suggests that PEG may prolong life and facilitate the administration of nutrients and medications in certain patients, such as those with motor neuron disease (Labra et al., 2020). However, its use has been questioned in other conditions, particularly in advanced dementia. Contrary to previous assumptions, PEG has not been shown to significantly prolong life or improve the quality of life in this population. A study

conducted in the Netherlands reported adverse effects such as discomfort, dyspnea, restlessness, and pain (Pasman et al., 2005). Moreover, PEG placement in people with dementia raises significant ethical concerns due to their advanced cognitive impairment, especially in cases where the person is no longer capable of making decisions independently (Ayman et al., 2017).

It is noteworthy that decisions regarding alternative feeding methods, such as PEG, may be influenced by social factors, including personal beliefs, moral values, and the authority attributed to healthcare professionals. For instance, family members of individuals with dementia may consider gastrostomy a means of ensuring adequate nutrition, hydration, and medication delivery, thereby continuing care (Slachevsky et al., 2016). However, in many cases, PEG may negatively impact a person's quality of life, as it can require physical restraint to prevent tube removal and often results in the complete cessation of oral intake. Therefore, dysphagia management in the context of neurodegenerative disease poses significant ethical challenges for healthcare teams, patients, and families, raising critical questions about the actual usefulness and benefits of this intervention (Álvarez Hernández, 2009).

As previously discussed, the decision to place a PEG is influenced by social factors and expectations surrounding care. Nonetheless, recommendations by the healthcare team must be evidence-based and aligned with expert ethical guidelines (Vesey et al., 2008). In particular, healthcare professionals must strive to avoid bias and prejudice when offering guidance, recognizing the inherent value and right of individuals to make decisions regarding their own health (Leslie & Coyle, 2010). This includes respecting the moral autonomy of individuals with degenerative diseases, as well as that of their families, while also adhering to the ethical principles of beneficence, non-maleficence, and justice in clinical decision-making (Azulay Tapiero, 2001). Additionally, when evaluating the need for alternative feeding routes, the individual's quality of life and overall well-being should be prioritized. It is the responsibility of healthcare professionals to uphold the autonomy and wishes of the patient, even when they are no longer able to express them, by considering what the person would likely have wanted and assessing whether the proposed intervention would truly improve their current condition.

According to Shaker et al. (2013), the professional best equipped within the healthcare team to make recommendations regarding dysphagia management—including whether to continue with compensatory strategies (e.g., modifications to food consistency) or to pursue more invasive interventions such as PEG—is the speech and language therapist (SLT). In this regard, a study

conducted in Chile in 2015 examining the criteria used by physicians to recommend PEG in people with advanced dementia found that, although the decision formally rests with physicians, it is often influenced by the input of SLTs (Portales, 2015). This underscores the importance of discussing and exploring the specific considerations of Chilean speech and language therapists working with this population in relation to the use and recommendation of alternative feeding methods.

Accordingly, this study aimed to identify the specific factors considered by speech and language therapists when recommending PEG for people with swallowing disorders secondary to neurodegenerative diseases. The study focused on clinical criteria, psychosocial dimensions, and ethical factors associated with the indication for PEG in this population.

METHOD

This research employed a quantitative and exploratory design. The sample was non-probabilistic and selected based on convenience. The Ethics Committee of the Faculty of Medicine at the Universidad de Chile approved the study (Code No. 120-2020).

Data Collection Instrument

The researchers designed a survey to collect data and followed the steps below to ensure the validity and reliability of the instrument:

- 1) Literature Review: The initial structure of the survey was informed by the questionnaire developed by Mohandas et al. (2019), which investigates the rationale for PEG tube placement in individuals with advanced dementia. That instrument, previously administered to physicians in multiple countries, includes 15 items addressing various factors such as

post-PEG life expectancy, prevention of pressure ulcers, improvement of nutritional status, aspiration prevention, and four-week postoperative death rate, among others.

- 2) Adaptation to Speech and Language Therapy Context: To incorporate factors specific to speech and language therapy practice in the context of neurodegenerative diseases, additional items were added to the survey. These included variables such as the patient's age, presence of swallowing reflex, severity of dysphagia, and use of a dysphagia severity scale. Bioethical considerations were also integrated into the questionnaire, particularly those related to decision-making processes in caring for individuals with neurodegenerative conditions.
- 3) Expert Judgment: Three SLTs with extensive clinical experience (minimum of 8 years working with this population across various healthcare settings) reviewed the survey for content validity. They provided feedback on the relevance of the variables, the appropriateness of technical language, and other key aspects. Based on their feedback, several revisions were made to improve the instrument.
- 4) Pilot Testing: Following revisions, the updated version of the survey was evaluated by three additional SLTs with expertise in clinical practice, teaching, and research. The goal of this phase was to assess the clarity and suitability of the items. Minor suggestions were received and incorporated, resulting in the final version of the instrument.

The finalized questionnaire consisted of 46 closed-ended items. Table 1 presents the variables and dimensions included in the survey, which participants were asked to assess based on their criteria for recommending the placement of a PEG tube.

Table 1. Variables influencing the recommendation of a Gastrostomy.

Variables	Dimensions
Health status	Age Type of neurodegenerative disease Stage of the neurodegenerative disease Altered level of consciousness Severity of dysphagia Impaired management of salivary and/or bronchial secretions Presence of aspiration Recurrent aspiration pneumonia Impaired Swallowing reflex Impaired cough reflex Fatigue during oral intake Compromised nutritional status Compromised hydration status Difficulty with medication intake by mouth Impaired head control Impaired trunk control Improved quality of life Increased life expectancy Personal decision Support Network Access to Speech Therapy following PEG implementation Socioeconomic level
Psychosocial Factors	
Team dynamics for decision-making regarding PEG indication	Please specify the members of the multi/interdisciplinary team with whom you decide to implement PEG placement (e.g., neurologist, intensivist, dietitian, physiotherapist, among others). How often is PEG placement carried out despite your recommendation as a speech and language therapist not to proceed with it? How often do you participate in a meeting with the professional team and the patient's family before recommending or placing a PEG tube?
Bioethical Aspects	In your opinion, who should make the final decision regarding PEG tube placement? How often are the patient's prior wishes and beliefs regarding the use of PEG taken into consideration in your practice? Do you have access to support from an ethics committee or team when there is a conflict regarding expectations and decisions about PEG placement in people with dementia?

Participants

A total of 36 speech-language therapists agreed to participate in the study, of whom only 30 met the inclusion criteria.

Inclusion criteria: Having more than five years of clinical experience in the intervention of people with dysphagia due to neurodegenerative diseases.

Table 2 provides relevant information about the sample's characteristics, detailing the profile of the SLTs involved in the research.

Table 2. Summary of participant characteristics.

Characteristics	%
Gender	
Woman	76.7
Man	23.3
Work Sector	
Public	66.7
Private	33.3
Length of Professional Experience	
5 Years	3.3
6-10 Years	43.3
11-20 Years	50
> 20 Years	3.3
Mean	11.2
Years of Experience Working with People with Neurodegenerative Diseases	
0-5 Years	13.3
6-10 Years	56.7
11-20 Years	26.7
> 20 Years	3.3
Mean	9.5
Professional Training Level	
Courses	16.7
Diplomas	50
Master	16.7
Employment Location (Region of Chile)	
Metropolitana	53.3
Bio Bío	20
Los Lagos	13.3
Araucanía	3.3
Ñuble	3.3
Valparaíso	3.3
Magallanes	3.3

Procedures

The survey was administered via a Google Forms questionnaire to participants who consented, facilitating dissemination and access among the target population. Speech-language therapists were contacted by email, which included a link to the survey and

an informed consent form. Participation in the survey was voluntary. The period for receiving responses and inviting new participants spanned six months from the date the initial survey was sent, as established in the study timeline.

Data Analysis

Data were analyzed using the statistical software R (R Core Team, 2024; Wickham, 2016). Frequency tables were created for each response (which can be observed in the corresponding figures), except for the item addressing gastrostomy use. This item required respondents to rank 16 dimensions without assigning explicit scores. To identify the most important dimensions, the top nine ranked options from each participant were extracted. Subsequently, scores were assigned as follows: 3 points to the top three options, 2 points to the fourth through sixth options, 1 point to the seventh through ninth options, and 0 points to all options ranked tenth or lower. Thus, this item does not have a one-to-one correspondence with individual responses but rather reflects a composite score representing the overall importance of each dimension based on the ranking provided by each participant.

RESULTS

Aspects Related to the Individual's Health Status

1) *Characteristics of the Population Served*

Regarding the general data collected from the respondents, the most frequent neurodegenerative disease among their patients was dementia, followed by Parkinson's disease (see Figure 1). It is important to note that participants could report more than one pathology.

2) *Variables Influencing the Recommendation of Gastrostomy in Relation to Health Status*

Concerning the decision to recommend gastrostomy, participants were asked to rank 16 dimensions related to the individual's health status (see Figure 2). The severity of dysphagia emerged as the most influential factor in decision-making.

Regarding the severity scale used (see Figure 3), the Food Intake Level Scale (FILS) was predominantly utilized.

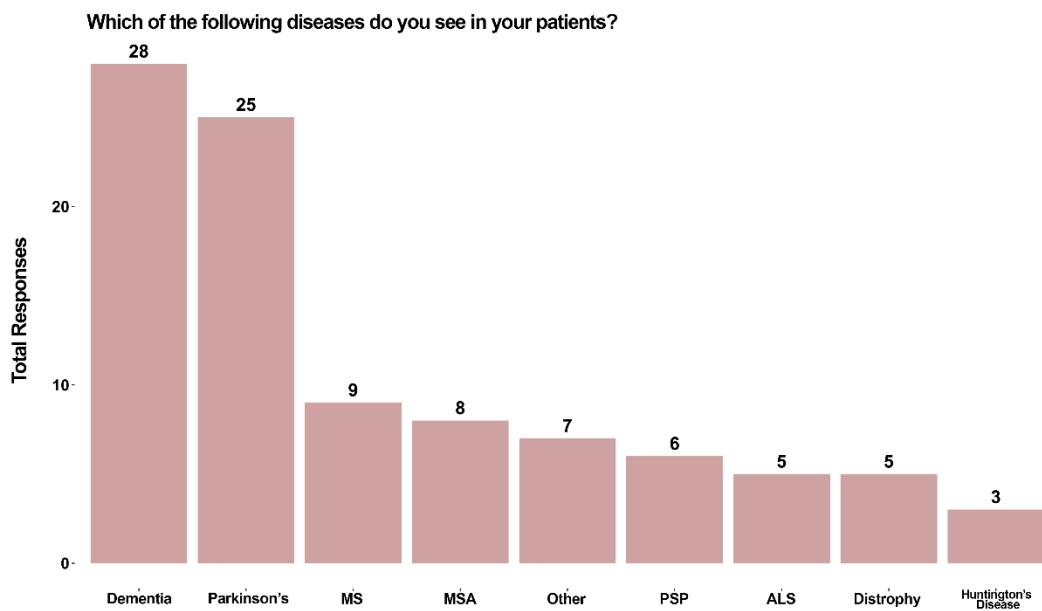


Figure 1. Most common diseases of people treated by the participants.

*MS: Multiple Sclerosis, *MSA: Multi System Atrophy, *PSP: Progressive Supranuclear Palsy, *ALS: Amyotrophic Lateral Sclerosis, *Other: Diseases such as Corticobasal Degeneration, Friedrich's Ataxia, Olivopontocerebellar Atrophy, CADASIL, and Encephalopathies.

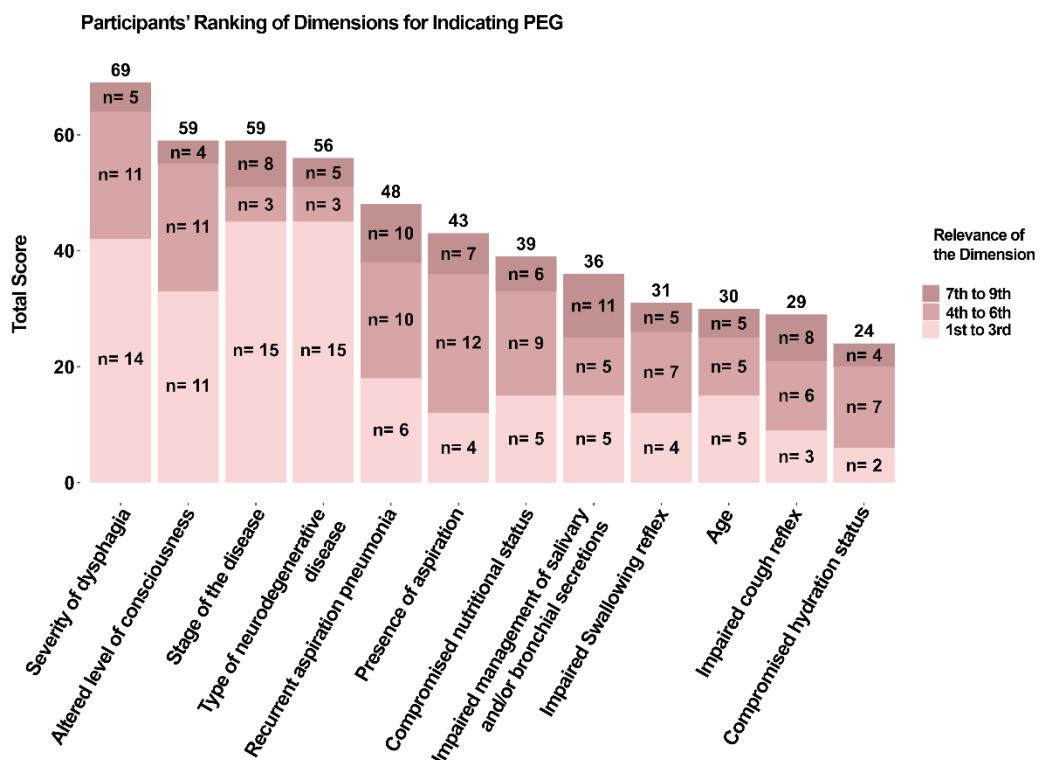


Figure 2. Ranking of Health Dimensions for the Indication of PEG. Each bar represents the total score observed for each dimension based on the ranking assigned by each participant.

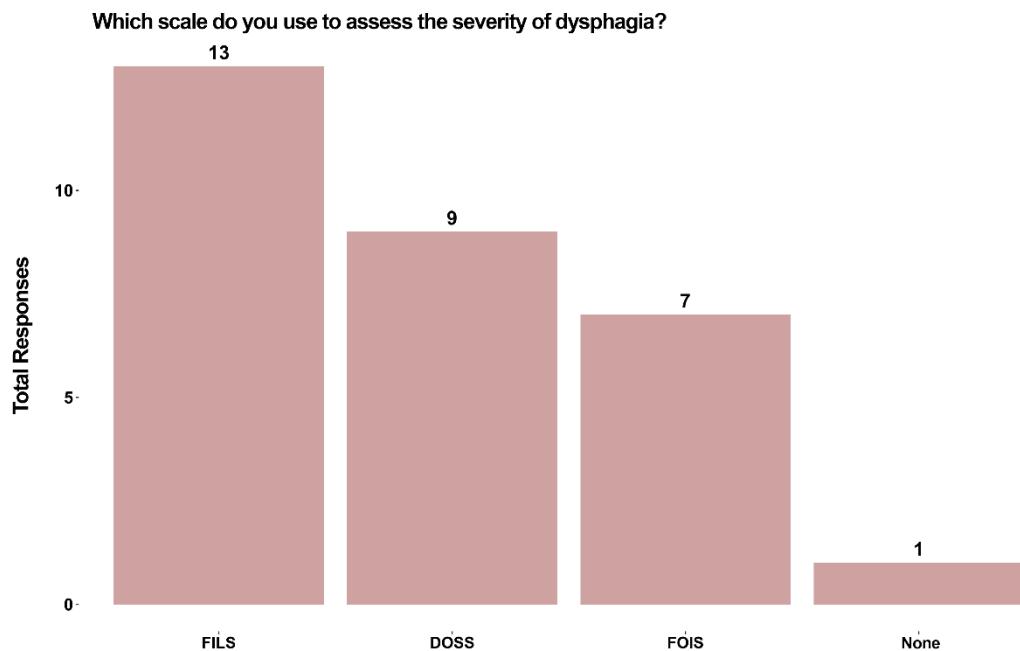


Figure 3. Dysphagia severity scales employed by the participants

*FILS: Food Intake Level Scale, *DOSS: Dysphagia Outcome and Severity Scale, *FOIS: Functional Oral Intake Scale.

Regarding the severity level considered for recommending PEG based on the scale, all participants indicated that they would

consider gastrostomy recommendation in cases of moderate to severe dysphagia.

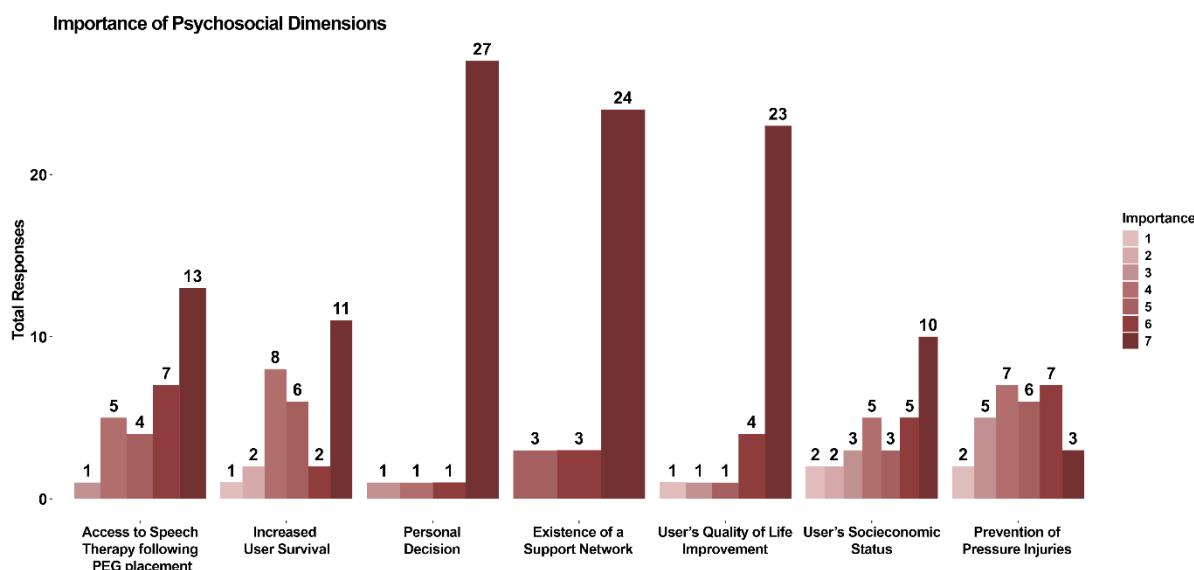


Figure 4. Ranking of psychosocial factors influencing PEG recommendation by the surveyed speech-language therapists.

The bars represent the number of responses for each dimension, according to the importance assigned by respondents, rated on a 7-point Likert scale.

3) Variables Influencing the Recommendation of Gastrostomy in Relation to Psychosocial Factors

Regarding the ranking of the six psychosocial dimensions (see Figure 4), respondents considered the patient's decision as the most important factor, ranking it first in relevance. The availability of a support network was ranked second.

4) Aspects Related to Team Dynamics in Decision-Making for PEG Recommendation

Concerning medical specialties with whom the decision to implement a PEG is typically made, the participants reported most frequently collaborating with neurologists/neuro-gastroenterologists, followed by geriatricians and intensivists (see Figure 5). Respondents were allowed to select more than one specialist to reflect their clinical reality accurately.

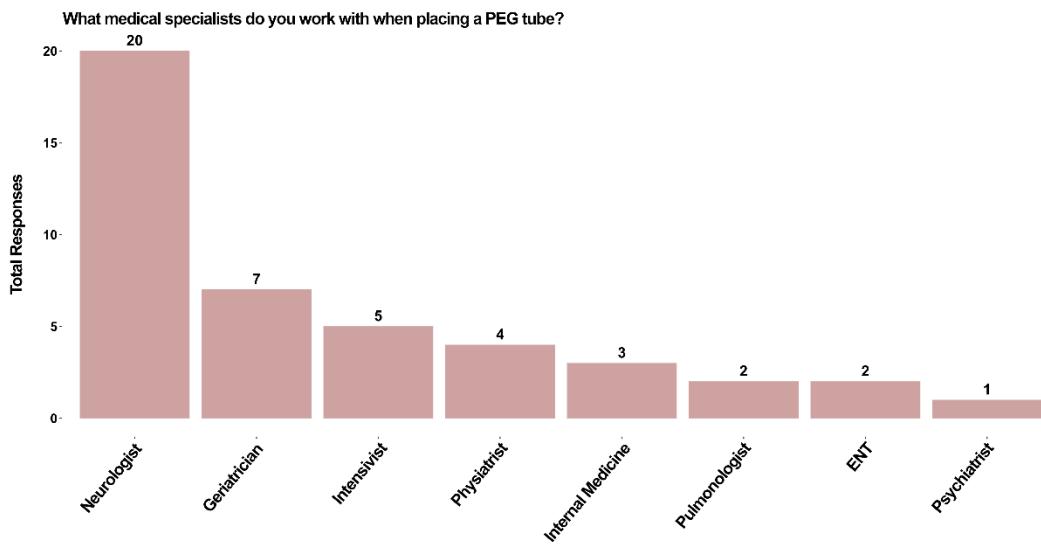


Figure 5. Medical specialists most frequently involved in PEG implementation decisions, as reported by participants.

Figure 6 presents the health professionals involved in the decision-making process. Dietitians predominate in the responses.

5) Aspects Related to Bioethical Considerations in Decision-Making for PEG Recommendation

Regarding whether participants consider the patient's prior beliefs and wishes before suggesting the implementation of a PEG tube, 18 participants responded "Always" or "Usually." Conversely, 11 participants indicated that they "Rarely" or "Never" take these aspects into account.

When asked who should make the final decision regarding PEG placement, 20 respondents indicated that it should be the patient and/or their family, while the remaining 10 mentioned members of the healthcare team (see Figure 7).

Concerning support of an ethics committee in cases of conflict or need for counseling regarding PEG, 15 participants reported that they "Never" have had such support. In contrast, only three reported that they "Always" have access to this resource.

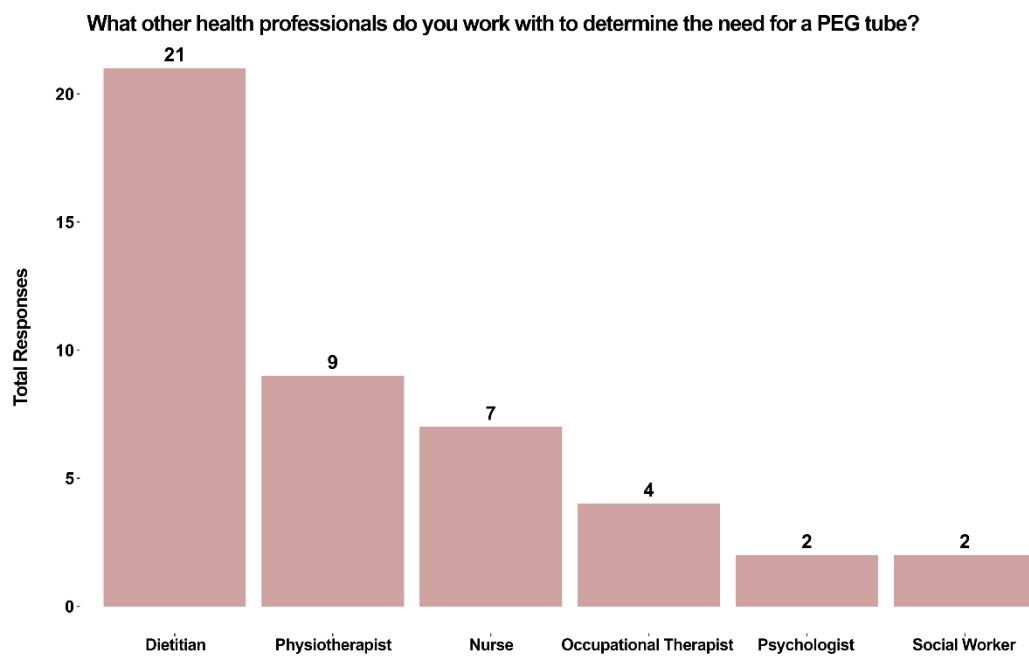


Figure 6. Other healthcare professionals involved in the decision-making process regarding PEG indication.

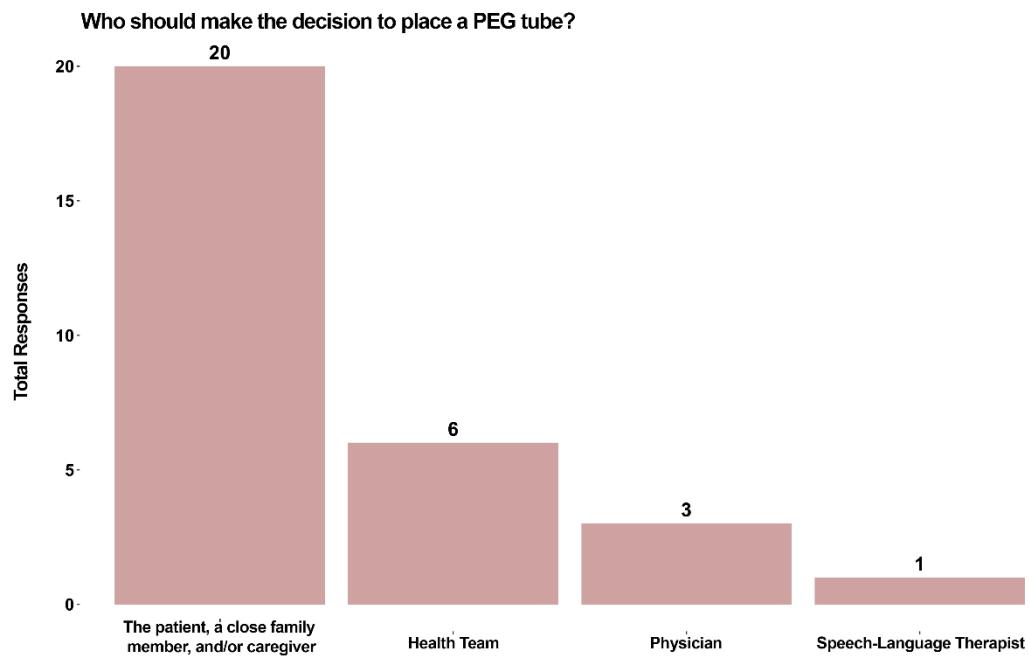


Figure 7. Other healthcare professionals involved in the decision-making process regarding the indication for PEG.

DISCUSSION

This study aimed to determine the specific aspects considered by speech-language therapists (SLT) in Chile when recommending percutaneous endoscopic gastrostomy (PEG) in people with swallowing disorders secondary to neurodegenerative diseases. This evaluation considered clinical criteria, psychosocial factors, and ethical considerations relevant to this decision in the target population. This topic is increasingly relevant in Chile due to the growing elderly population and, consequently, the higher likelihood of developing neurodegenerative diseases such as dementia (Ministerio de Salud [MINSAL], 2017).

Overall, the results indicate variability in the criteria considered when recommending the use of PEG. This variability is evident in the ranking of dimensions, where responses differ among factors such as dysphagia severity, type of neurodegenerative disease, disease stage, and level of consciousness impairment. This finding agrees with previous results from a survey conducted in Chile among medical professionals (Portales, 2015). The response variability may be attributed to multiple factors, including the context in which respondents practice, the type of clinical service (e.g., neurology, internal medicine, geriatrics), internal decision-making dynamics, the predominant care model (biomedical, palliative care, etc.), and the composition of the professional team, among other elements.

Regarding the health variables prioritized in PEG decision-making, dysphagia severity was one of the most frequently considered factors. However, although dysphagia severity obtained the highest overall score, the type and stage of the neurodegenerative disease appeared more frequently among the top three ranked options. This result aligns with evidence indicating that treatment perspectives vary among individuals with different neurodegenerative diseases. For example, in motor-related conditions such as amyotrophic lateral sclerosis (ALS), PEG implementation is often conducted in the early stages (Shijo et al., 2023). Conversely, outcomes may differ for individuals with dementia (Pasman et al., 2005).

The most frequently used scale to determine the severity of dysphagia is the Food Intake Level Scale (FILS). This scale is a subjective functional tool that measures a person's ability to safely and effectively consume food and liquids, as well as rehabilitation outcomes (Nagai et al., 2022). However, FILS lacks specific validity for individuals with neurodegenerative diseases. In contrast, the Functional Oral Intake Scale (FOIS) allows for a more objective assessment without requiring active patient

collaboration (Kunieda et al., 2013), making it a potentially more suitable tool for this population.

It was also observed that the interdisciplinary teams with whom SLTs collaborate and who participate in the decision to implement a PEG are diverse, primarily consisting of neurologists, followed by geriatricians and intensivists. This detail is particularly relevant, as the composition and organization of healthcare teams can influence the decision-making process.

Participants attribute significant importance to ethical considerations when deciding to place a PEG tube in people with neurodegenerative diseases. However, only half of the participants reported having had support from an ethics committee in managing conflicting cases or receiving guidance in their decision-making process. The literature underscores that it is crucial for both the patient and their family to receive support in this matter, whether from the healthcare team or an ethics committee (Dharmarajan et al., 2021). This is critical given that ethical considerations in the care of individuals with neurodegenerative diseases encompass issues related to quality of life and patient autonomy. Therefore, promoting greater support from specialized bioethics teams is recommended to assist in these decisions (Mondragón Barrios, 2013).

Regarding the final decision on implementing a PEG tube, most respondents indicated that this responsibility lies with the patient and/or their family, emphasizing the importance of educating them so that the decision is informed and based on a thorough understanding of the benefits and other relevant considerations. This highlights the need to discuss and explore different decision-making models, as well as provide training in this area, to increase preparedness and mitigate potential ethical tensions (Prat Martínez, 2021).

The results of this study should be interpreted with caution due to certain limitations. The primary limitation is the small sample size and limited representativeness, which may not adequately reflect the realities of all SLTs working with people with neurodegenerative diseases. Additionally, the lack of control over external variables, such as resource availability or institutional policies, may have influenced the decisions and practices reported by participants.

Despite these limitations, the findings provide relevant insights into the specific criteria considered by SLTs in Chile when recommending gastrostomy for this population. These findings can significantly contribute to improving the quality of care and promoting an approach that adequately incorporates bioethical considerations in the clinical management of dysphagia in

patients with neurodegenerative diseases. It is essential to continue researching and fostering interdisciplinary work to comprehensively address the needs of this population, ultimately aiming to improve their quality of life.

CONCLUSIONS

The results indicate that, among health-related factors, speech-language therapists consider dysphagia severity and the stage of the disease as key elements in recommending gastrostomy. Regarding psychosocial aspects, the patient's opinion is deemed fundamental, followed by the presence of an adequate support network. As for bioethical aspects, the active participation of the patient and their family in decision-making about gastrostomy indication is highlighted. However, participants also noted limited access to specialized institutional resources, such as ethics committees. Finally, in terms of work dynamics, participants reported considerable variability in the composition of teams involved in decision-making, which mainly depends on the clinical service in which SLTs have their practice.

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