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# Exploring Gastrostomy Care-Related Information Needs in Patients With Amyotrophic Lateral Sclerosis and Their Families

## ABSTRACT

The aim of this study was to explore gastrostomy care-related information needs in amyotrophic lateral sclerosis (ALS) patients and their families. This was a quantitative content analysis. Data were collected from a major online patient community in Korea by analyzing posted free texts. A total of 173 posted free texts from January 2010 to July 2020 from the “question and answer” bulletin board were analyzed. Questions were mostly asked by the adult children of patients, and the most frequent question period was “after hospital discharge.” The commonly mentioned topics related to gastrostomy and G-tube complications. Patients with ALS and their families have a high requirement for gastrostomy care and enteral feeding information. These findings indicate that there is a need to support decision-making for gastrostomy in hospitals and to provide information about G-tube care and enteral nutrition after leaving the hospital. This information and coaching/support for patients with amyotrophic lateral sclerosis and their families currently appears to be obtained mainly through online patient communities. Both hospital and home care nurses could play a greater role in providing this information.

Amyotrophic lateral sclerosis (ALS), also known as motor neuron disease (MND), is a representative neurodegenerative disease, which results from the death of motor neurons in the brain and spinal cord and is accompanied by systemic symptoms such as upper and lower extremity muscle loss, swallowing and speech disorders, and respiratory distress. The exact cause of ALS has not been identified, and no treatment has yet been established for a full recovery. According to a domestic

epidemiological study based on data from the Korean National Health Insurance Service (June et al, 2019), the annual incidence of ALS in South Korea is 1.2 per 100,000 population, and the prevalence is reported to be 3.43 per 100,000 population.

According to the site of onset, ALS is classified as either spinal or bulbar onset. For spinal, symptoms begin in the upper and lower extremities and bulbar begins with a speech or swallowing disorder (Brown & Al-Chalabi, 2017). However, over time, both spinal-onset and bulbar-onset ALS lead to upper and lower extremity muscle loss and swallowing disorders (van Es et al., 2017). In particular, swallowing disorder is a common symptom in patients with ALS and is a major cause of disruption for the safe intake of adequate fluids and food. ALS patients with swallowing disorders experience various negative health consequences such as increased time and effort for eating, weight loss, and dehydration (Stavroulakis et al., 2014). Weight loss and malnutrition are important factors that negatively affect disease prognosis and are also known to affect survival time. Therefore, for patients with ALS who experience a severe swallowing disorder, gastrostomy

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is recommended in order to provide adequate nutrition and prevent aspiration pneumonia.

The various methods of gastrostomy include surgical, radiological, and percutaneous endoscopic gastrostomy (PEG); however, PEG is the most common and generally performed method (ProGas Study Group, 2015). Gastrostomy and cervical nutrition therapy have been reported to prolong survival and improve the quality of life in patients with ALS. At the same time 5–40% of complications are known to be caused by gastrostomy and enteral tube feeding.

Many patients with ALS live at home, and most are cared for by family members. It is important to understand the methods and complications of enteral feeding through the gastrostomy tube (G-tube) including the continuous management of both patients and family members. However, ALS patients and their families experience a lack of information on gastrostomy and enteral tube feeding. In the UK and the United States, multidisciplinary and postdischarge care programs are provided for patients in need of enteral nutrition. In South Korea, the patient and family are responsible for gastrostomy management and enteral tube feeding after discharge. In general, information on G-tube care and enteral nutrition inevitably relies entirely on nurses to educate patients and family members before discharge; alternatively, this information is obtained from non-medical sources such as the family members and caregivers of other patients. However, the education of the patient and family before discharge that is provided by clinical nurses is chronically hindered by a lack of nursing manpower and time, burden of work, and lack of administrative support (Yoo & Suh, 2000). Inadequate enteral nutrition management and lack of a care plan after discharge can lead to increased hospitalization and negative health consequences due to complications associated with enteral nutrition. Sezer, Ozdemir Koken, and Senol Celik (2020) found that family caregivers who care for ALS patients experience a lack of G-tube-related education and training, which should be provided by the hospital and that such education and training should include demonstration and practice. In the same way, caregivers expect nurses to give comprehensive care-related training after PEG tube insertion and to communicate effectively with them. In a study by Seo and Lee (2019) conducted with professional home nurses, enteral nutrition was identified as an item with a high frequency of education. However, there is still very limited research of patients with ALS and their family members regarding the demand for information about gastrostomy and enteral nutrition.

Technological advances are driving the growth of online patient communities (Zhu, Shen, & Xu, 2020). An online patient community is a form of self-help group, which provides a forum for patients, their

families, and others. It is a group formed mainly by patients diagnosed with the same disease and their families. The members consist of not only patients and their families, but also other unspecified people related to them. It is defined as an online community where activities such as sharing emotional and social support, exchanging information, and providing assistance take place (Bartlett & Coulson, 2011; Oh & Kim, 2017).

Online patient communities allow communication among patients independent of time, space, and social-economic position and provide effective support for information sharing between patients (Zhu, Shen, & Xu, 2020). Patients with ALS and family members also share emotional and social support through online communities. They impart knowledge of the illness and caregiving experiences that have not been provided by healthcare professionals (Oh & Kim, 2017). In addition, most patients with ALS and family members use the internet and online patient communities as an auxiliary means of obtaining information on treatment and care (Chu & Oh, 2020). The aim of this study was to analyze the postings in the online ALS community focused on understanding the demand for information by patients and their families about gastrostomy and enteral nutrition. It will provide basic data for developing educational programs in the future.

## Methods

### Data Analysis and Ethical Considerations

Quantitative content analysis was used in this study. Data were collected from the Lou Gehrig's Disease Network (<http://cafe.daum.net/alsfree>), which is one of the largest online communities used by patients with ALS and their families in South Korea. With nearly 6,567 members, this website serves as a forum for patients and families to share a variety of information. Anyone can write a posting on the free bulletin board after signing up and being approved by the administrator of the ALS network. After a thorough explanation of the purpose of the study, the administrator of the online community provided consent to conduct this study. The collected postings included the date, title, and content of each posting, excluding the ID of the author in the community. This study was approved by the Institutional Review Board of the researchers' university (IRBNo. HYUIRB-202107-002).

The following were inferred from the questions' contents and coded: relationship of the questioner with the ALS patient, gender of the patient with ALS, and question period. The main questions of the messages were coded and categorized according to the classification scheme developed in previous studies (Hucl & Spicak, 2016; Stavroulakis et al., 2016; Suluhan, Yildiz, Surer, Fidanci Eren, & Balamtekin, 2020).

## Results

### Number of Postings

Of the 626 postings from January 2010 to July 2020, which included “gastrostomy tube,” “gastrostomy,” “G-tube,” “enteral nutrition,” “tube feeding,” and “enteral tube feeding” in the title or contents, but excluded redundant questions and advertisements, a total of 173 postings including questions related to gastrostomy and enteral nutrition were collected for the final analysis.

### Sociodemographic Information of Questioners

Among the contents included in the postings, the sociodemographic variables that could be collected and analyzed included the gender of the patient, the relationship between the author and the ALS patient, and the current gastrostomy stage of the ALS patient (Table 1). The gender of the ALS patient was unknown in 49.1% ( $n = 85$ ) of the postings. Postings were mostly written by a son or daughter, which accounted for 46.2% ( $n = 80$ ) of the postings. Most postings were written after leaving the hospital, 67.1% ( $n = 116$ ).

### Gastrostomy and G-Tube-Related Information Needs

As a result of analyzing the postings, the demand for information was classified into four categories: gastrostomy and G-tube complications, gastrostomy care

and tube changes, G-tube feeding, and information for decision-making for gastrostomy; this was then classified into 31 subcategories (Table 2).

The demand for information on gastrostomy and G-tube complications was the highest category at 30.1% ( $n = 51$ ), followed by gastrostomy care and tube changes at 23.7% ( $n = 41$ ), G-tube feeding at 23.1% ( $n = 40$ ), and the information for decision-making for gastrostomy at 23.1% ( $n = 40$ ). The demand for information related to gastrostomy and G-tube complications varied across 12 subcategories including stomal pain and skin irritation. No one subcategory accounted for a higher demand than the others.

The demand for information related to gastrostomy care and tube changes varied across six subcategories. G-tube changes was the subcategory with the highest demand at 7.5% ( $n = 13$ ). The demand for information related to G-tube feeding also varied across six subcategories. The subcategories with the most demand were commercial enteral formula at 7.5% ( $n = 13$ ) and enteral feeding regimens at 6.9% ( $n = 12$ ). The demand for information related to decision-making for gastrostomy varied across seven subcategories. The subcategory with the most demand was gastrostomy procedures at 8.1% ( $n = 14$ ).

## Discussion

This study aimed to explore the demand for information about gastrostomy and enteral nutrition by analyzing the postings in an online patient community. Patients with ALS and their family members share their experiences and information in the online community, which can be a valuable resource for researchers as well as healthcare professionals. As a type of user-produced content, the results of analyzing the postings could provide an important clue to discovering unmet needs of patients and family members, which have not been previously identified and can provide basic data for conducting patient-centered care.

In our study, the adult children of patients accounted for the most of the authors of postings on the free bulletin board (46.2%). In order to access the online patient community, patients and family caregivers need to have Internet literacy. It seems that adult children, rather than patients with ALS themselves or their older spouses, have easy access to the online patient community because they are more familiar with the Internet (Estacio, Whittle, & Protheroe, 2019). The most frequent period for posting questions was after leaving the hospital. Since the responsibility for gastrostomy care and enteral nutrition shifts from healthcare professionals to family members after gastrostomy, patients and family caregivers tend to experience

**TABLE 1. Sociodemographic Information of Questioners ( $N = 173$ )**

Variables	$n$ (%)
Relationship to PALS	
Unknown	75 (43.4)
Adult child	80 (46.2)
Spouse	7 (4.0)
Patient	2 (1.2)
Relatives	2 (1.2)
Gender of PALS	
Unknown	85 (49.1)
Male	33 (19.1)
Female	55 (31.8)
Question posting period	
Before gastrostomy	39 (22.5)
Hospital admission	18 (10.4)
After hospital discharge	116 (67.1)
<i>Note.</i> PALS = patient with amyotrophic lateral sclerosis.	

**TABLE 2.** Gastrostomy and G-Tube Feeding-Related Information Needs in Korean Amyotrophic Lateral Sclerosis Online Community ( $N = 173$ )

Categories		Subcategories	<i>n</i> (%)
1	Gastrostomy and G-tube complications ( $n = 52$ , 30.1%)	<i>Peristomal pain</i>	9 (5.2)
		Stoma site and surrounding skin irritation	8 (4.6)
		G-tube dislodgement	6 (3.5)
		Discharge from the G-tube site	5 (2.9)
		G-tube leakage	4 (2.3)
		Blockage or clogging in the tube	3 (1.7)
		Peristomal infection	3 (1.7)
		Abdomen distension	3 (1.7)
		Bleeding	3 (1.7)
		Diarrhea	3 (1.7)
		Nausea and vomiting	3 (1.7)
		Constipation	2 (1.2)
2	Gastrostomy care and tube changes ( $n = 41$ , 23.7%)	<i>G-tube changes</i>	13 (7.5)
		Dressing for gastrostomy sites	8 (4.6)
		Bathing	7 (4.0)
		Maintaining G-tube patency	5 (2.9)
		Replacement feeding adapter	4 (2.3)
		Home preparation for people with G-tube	4 (2.3)
3	G-tube feeding ( $n = 40$ , 23.1%)	<i>Commercial enteral formula</i>	13 (7.5)
		Enteral feeding regimens	12 (6.9)
		Oral intakes after gastrostomy	7 (4.0)
		Oral care	4 (2.3)
		Giving medicines through G-tube	2 (1.2)
		Purchasing enteral feeding supplies	2 (1.2)
4	Information for decision-making for gastrostomy ( $n = 40$ , 23.1%)	<i>Gastrostomy procedures</i>	14 (8.1)
		Optimal timing for placing a gastrostomy	7 (4.0)
		Expected outcomes of gastrostomy	5 (2.9)
		Patient's denial of gastrostomy	5 (2.9)
		Hospital recommendation for gastrostomy	4 (2.3)
		Nasogastric tube using an alternative for gastrostomy	3 (1.7)
		Cost of gastrostomy	2 (1.2)

more problems after leaving the hospital (Stavroulakis et al., 2016).

We found that there were a variety of demands for information in all areas. The category of information most in demand was gastrostomy and G-tube complications. The demand for information was mostly on peristomal pain and stoma site skin irritation. In

previous studies related to gastrostomy in patients with neurodegenerative diseases, skin irritations such as stoma site pain and granuloma formation were reported as a common and minor problem (Gye & Mortensen, 2018; Sarkar, Cole, Scolding, & Rice, 2017). In addition, various complications associated with G-tubes, such as G-tube loss, leakage, and blockage, have been



reported regarding G-tube care. The questions posted revealed the need to provide information on general symptoms that may appear after gastrostomy, how to manage a G-tube, and how to cope with a problem. Online consultation services for information on G-tube and enteral nutrition or consultation on the symptoms or visiting nursing services like the services of Hospital-at-Home proposed by Dollard and Dunn (2004) can increase the satisfaction of family caregivers and reduce patient anxiety.

Regarding G-tube care and tube changes, there were many questions about tube changes and dressings for gastrostomy sites. ALS patients and family caregivers receive education and information on G-tube care and enteral nutrition from healthcare professionals prior to leaving the hospital after gastrostomy. However, they feel that they have not been provided with enough information and hope to gather the information through the online community.

In addition to providing thorough education on the G-tube dressing and timing of G-tube replacement, ALS patients and families will benefit from home care services after leaving hospital. A study conducted in the UK by Stavroulakis et al. (2016) reported that patients with ALS and family caregivers were educated on G-tube care and enteral nutrition at home before and after leaving the hospital, but they still did not feel sufficiently prepared for at-home care. The use of a demonstration method of actually performing gastrostomy care and enteral nutrition as part of the educational program for patients with ALS and family providers would be more effective. The education should also include key information on life changes after gastrostomy, bathing after gastrostomy, and home preparation after leaving the hospital.

In the category of G-tube feeding, there were many questions regarding commercial enteral formulas and enteral feeding regimens. Commercial enteral formulas require less time and effort to prepare for enteral feeding than homemade blenderized meals and are nutritionally stable. Although many patients and family caregivers choose commercial enteral formulas, they experience difficulties in selecting the most suitable commercial enteral formula for the patient (Klek et al., 2011). Some patients with ALS and family caregivers asked whether it was possible to consume food through the oral cavity and oral care methods after gastrostomy. This suggested that patients and family caregivers did not have sufficient understanding of the purpose of gastrostomy. The purpose of gastrostomy is to correct malnutrition in patients due to swallowing disorders and to prevent pneumonia caused by choking and aspiration. Even after gastrostomy, it is possible for patients to consume food within the range that does not cause choking and aspiration. Regarding oral

care after gastrostomy, if patients are able to brush their teeth, they should brush their teeth or perform oral care using foam sticks (Griffiths & Lewis, 2002). However, many patients and family caregivers seemed to lack information on this subject (Tay, Howe, & Borromeo, 2014).

In the category of information for decision-making for gastrostomy, users of the online patient community asked many questions about gastrostomy procedures, optimal timing for gastrostomy, and expected outcomes of gastrostomy. In general, the optimal timing for gastrostomy is determined based on the symptoms, nutritional status, and respiratory function of each patient with ALS (EFNS Task Force, 2012). The optimal timing is often missed, and gastrostomy tends to be performed late due to the refusal of gastrostomy by many patients with ALS and family caregivers (Stavroulakis et al., 2014). This presents another knowledge gap that needs to be addressed.

Family caregivers also asked for opinions on how to manage patient refusal of gastrostomy. Muoki's (2020) study suggested that when considering gastrostomy, patients were concerned about limitations of social life, uncertainty, fear and anxiety, body image, sexual intimacy, and complications resulting from gastrostomy. In a situation where they are not provided with accurate and sufficient information on gastrostomy, most patients and family caregivers rely on the decision of healthcare professionals. Nurses are well-positioned to provide accurate and sufficient information about gastrostomy and enteral nutrition as well as supportive care in order to encourage decision-making, which respects the characteristics, values, and preferences of the patient (Bassola & Lusignani, 2017).

Patients with ALS and family caregivers have a high demand for information in various areas. This ranges from information about decision-making for gastrostomy to management after gastrostomy. It is not enough to simply provide education and information. Patients with ALS and family caregivers need a patient-centered, individualized, and integrated intervention such as a nurse navigation program to maintain the continuity of nursing care from decision support for gastrostomy to home care service after gastrostomy (Simmers, 2019).

ALS patients and family caregivers are using the online patient community to ask questions. They post difficulties that they had not been able to ask or discuss with their healthcare professionals. However, the information provided in the online patient community is based on personal experiences rather than based on scientific evidence. It is imperative to provide accurate information through the participation of healthcare professionals. This helps ensure scientific verification of the information available in the patient online community.

## Limitations

Since the data were analyzed by extracting only the postings related to gastrostomy and enteral nutrition in an online community, there are limitations in generalizing the results. A future study which accurately depicts the demographic and clinical characteristics of patients and family caregivers would be valuable. A qualitative study examining the comments in the postings in the online patient community would also be helpful.

## Conclusion

This study identified the gastrostomy care-related information needs of patients with ALS and their families in Korea. There was a high demand by both patients and family caregivers for information about G-tube feeding and enteral nutrition. This included information for decision-making about gastrostomy, G-tube care, and enteral nutrition information. The results of this study suggests the need to support the decision-making for gastrostomy in hospitals and also provide information about G-tube care and enteral nutrition after leaving the hospital. Both hospital and home care nurses could play a greater role in providing this information, which may decrease reliance on online communities for obtaining such information. ☯

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