



Telemedicine Experiences of People Living with Amyotrophic Lateral Sclerosis at Home in South Korea

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Purpose: Telemedicine is advantageous in providing medical care to patients with mobility difficulties. This single-center study aimed to report on the provision of video televisits to people living with amyotrophic lateral sclerosis (pALS, ALS) who were registered with a home-based medical care (HBMC) team in a tertiary hospital in South Korea.

Materials and Methods: A retrospective cross-sectional study was conducted for pALS provided with video televisits by the HBMC team between July 2020 and February 2023. The patients' demographics, disease status, mobility level, and supportive care equipment were investigated. The main issues discussed at televisits were investigated.

Results: During the 32-month study period, video televisits were provided to 69 (81.2%) of the 85 pALS registered with the HBMC team. Their median (interquartile range) age was 66 (57–71) years, and 66.7% were aged 60 years or older. At the time of the televisits, 71.0% were non-ambulatory and 27.5% were at an assisted ambulatory level. Furthermore, 82.6% were receiving nutritional support with a nasogastric or gastrostomy tube, and 78.3% had received either non-invasive positive pressure ventilation (43.5%) or tracheostomy invasive ventilation (34.8%). Common issues addressed on televisits were disease-related symptoms (100%), management of supportive care equipment (92.8%), acute health issues (52.2%), and advance care planning (ACP) including goal of care discussion (14.5%).

Conclusion: Video telemedicine is feasible for pALS, including older adults with limited mobility due to muscle weakness or reliance on various supportive care equipment. Video televisits allow for a variety of discussions, ranging from acute health issues to ACP.

Key Words: Telemedicine, distance medicine, televisit, amyotrophic lateral sclerosis, home-based medical care

INTRODUCTION

Technological advancements have led to an increase in telemedicine,¹ defined as the delivery of medical service and exchange of healthcare information through audio or video rather

than face-to-face contact across distances.² Although it has been used in some areas since the early 1990–2000s, telemedicine has witnessed a global surge following the COVID-19 pandemic in 2020.³

Telemedicine has both pros and cons, but it can undeniably increase accessibility to healthcare services for patients with limited mobility for various reasons.^{4,5} In the aging era, the number of patients with mobility limitations is increasing.^{6,7} These include patients for whom the risk of frailty or muscle weakness increases as their disease progresses and those for whom movement is difficult due to their reliance on various medical devices, such as a home ventilator.^{8,9} These patients often cannot move around on their own and need help to visit the hospital. In the United States (U.S.), the number of homebound persons—defined as those who never or rarely left home

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on their own—reached 2 million in 2011.⁶ However, without a doubt, even individuals facing difficulties with mobility due to illnesses require medical services.

Progressive neurological diseases, such as amyotrophic lateral sclerosis (ALS), are characterized by increasing mobility restriction with disease progression.¹⁰ Various attempts have been made to leverage telemedicine and enhance healthcare access for people with such diseases who have difficulty visiting hospitals.¹¹ Telemedicine can increase access to multidisciplinary care, reduce travel time and costs, and improve patient satisfaction.¹² However, establishing a clinician-patient relationship and discussing high-impact topics, such as advance care planning (ACP), remain challenging.¹² Additionally, the widespread adoption of telemedicine could result in healthcare disparities due to cost and acceptance of digital technology.^{13,14} However, overall, many agree that telemedicine is feasible for people living with neurological diseases, such as ALS, and can effectively supplement traditional clinic-based medicine.¹⁵

However, most previous studies have been conducted in the U.S. or Western Europe, with scarce evidence on the application of telemedicine for people living with neurological diseases in Asia.^{12,13,16} While South Korea has a National Health Insurance (NHI) system that provides widespread access to medical care, the lack of legal allowance for telemedicine and the limited implementation of home-based medical care (HBMC), which entails medical staff visiting patients at home, result in relatively low accessibility for patients with reduced mobility.¹⁷⁻¹⁹ However, owing to the COVID-19 pandemic, the Korean government temporarily allowed telemedicine between 2020 and 2023,²⁰ making televisits possible for all patients, including pALS. This has enabled the exploration of the application of telemedicine to pALS in South Korea.

The present study aimed to investigate the characteristics of pALS based on video televisits and their content at a tertiary hospital in South Korea. Telemedicine experiences in actual clinical environment can inform the design of telemedicine systems required for patients living with serious illness and limited mobility.

MATERIALS AND METHODS

This study employed a cross-sectional observational approach using retrospective medical records review data.

Study settings

Since 1988, South Korea has implemented the NHI, covering both inpatient and outpatient service.¹⁷ NHI offers high coverage for serious illnesses such as cancer and rare neurodegenerative diseases, enabling patients to benefit from medical services with reduced out-of-pocket costs.²¹ However, telemedicine has been strictly regulated.¹⁸ In some regions, such as small islands, coordination between doctors is permitted

as an exception, but telemedicine between patients and doctors is prohibited.¹⁸ Additionally, HBMC is in the introductory stage and is therefore not yet widespread.¹⁹ A home nursing service, involving visits by nurses, was launched in 2001, and a home-based primary care project for the disabled and home-bound was initiated in 2017 and 2018 as pilot projects. However, they are not widely available and access is limited.¹⁹ Although medical expenses are covered by the NHI, there is no provision for transportation costs and personnel helping to move patients to the hospital. As a result, those with mobility difficulties have limited access to medical services.

During the global COVID-19 epidemic in 2020, hospitals were identified as high-risk areas for infection transmission in South Korea. To prevent large gatherings and the spread of infection through contact, non-face-to-face visits (televisits) were fully permitted for a limited time, from February 2020 until May 2023, when the serious threat alert ended in South Korea.²²

This study was conducted at a tertiary hospital located in Seoul, the capital city of South Korea, with 1700 beds and 2.45 million annual outpatient treatments as of 2022. Since 2020, in addition to the traditional outpatient clinic, the hospital has operated a HBMC clinic that provides supportive care through home visit services to patients with serious illnesses or mobility difficulties living in Seoul. With an area of 605 km² and a population of 10 million, it typically takes 1–1.5 hours one way by car to visit patients living in Seoul.

Study population

Between July 2020 and February 2023, pALS who used televisits and were registered at the study hospital's HBMC clinic were included as the study population. Patients who used video televisits at least once were included, while those who used only audio televisit services were excluded.

Variables and measures

Patient demographics (age, sex, type of health insurance, residential region) and care partner demographics (relationship and sex) were investigated. Residential region was classified into major cities and provinces. Gyeonggi-do and Incheon, which are the closest provinces to Seoul, are typically 1–1.5 hours away one-way by car, while other provinces are further away. A care partner was defined as a person who participated in the video televisit along with pALS. The investigation also considered the year in which pALS were registered at the HBMC clinic and whether they received home visit services.

The first televisit event was labelled the index televisit. The Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALSF-RS-R) score assessed at the nearest time preceding the index televisit and patients' mobility level (ambulatory, assisted ambulatory, and non-ambulatory) at the index televisit were investigated. The use of nutritional and respiratory support equipment at the index and last televisits was investigated. Nutritional support included nasogastric and gastro-

tomy tubes, while respiratory support included ventilator use, non-invasive positive pressure ventilation, and tracheostomy with invasive ventilation. The duration from the first outpatient visit for ALS to the neurology department to the first televisit was investigated, and the total duration of televisits from the first to the last televisit was also investigated.

The contents discussed during televisits were investigated by reviewing the medical records. Considering that the number and frequency of televisits, as well as disease status, differed for each patient, the contents of individual televisits were not investigated. Instead, whether discussions on specific topics, such as ACP, took place for each patient was investigated. Based on previous studies, the main issues discussed during televisits were classified into six categories: disease-related symptoms, acute health issues, management of supportive equipment, ACP, others, and regular checkups by the HBMC team for pALS living in Seoul.¹⁵ Commonly known disease-related symptoms of ALS included dysphagia, dyspnea, and muscle weakness. Acute health issues were newly occurring symptoms (within a week), including upper respiratory infection (URI) symptoms, such as cough and rhinorrhea, and urinary symptoms, such as hematuria and frequency. Management of supportive equipment included instruction or education for nutritional and respiratory support equipment. ACP included discussions such as whether to perform tracheostomy or provide intensive care unit (ICU) care in case of acute exacerbation in the future. Regular checkups by the HBMC team included coordination regarding the home visit scheduling for pALS living in Seoul and re-assessment for home visit. Anything else discussed during televisits was classified as others. We also investigated the number of times each patient used televisits.

Statistical analysis

Demographic information of the patients and their care partners was presented descriptively. Categorical variables were presented as numbers and percentages. Continuous variables were reported as median and interquartile range (IQR). Patients' ALSFRS-R score, mobility level, and use of supportive care equipment were also presented descriptively. The proportion of pALS among the total study population who discussed the televisit contents was presented as numbers and percentages. The number of televisits per person and the average number of televisits per year were recorded. If the average could not be calculated due to only one televisit being completed, it was marked as not applicable. The number of pALS who had their first televisit was presented in a time series format by month.

Ethical statement

The study was approved by the Institutional Review Board of the study hospital (IRB No. H-2305-070-1432), and the requirement for informed consent was waived.

RESULTS

Study population

During the 32-month period, 216 patients with neurological diseases were enrolled at the HBMC clinic, of which 85 were pALS. Among them, 70 patients used televisits; one patient was unable to engage in a video televisit due to functional limitations of the equipment. Ultimately, 69 pALS who used video televisits more than once were included as the study population.

Patient and care partner demographics

Among the patients, 53.6% were female and the median (IQR) age was 66 (57–71) years. Regarding residence, 60.9% lived in Seoul, and 29.0% lived in the adjacent Gyeonggi-do and Incheon. People living in other areas who required more than an hour of transit time constituted 10.0% of the sample. Home visits were provided to the 37 pALS (53.6%) living in Seoul. Among the care partners who participated in televisits with the patients, spouses comprised the majority (53.6%), followed by children (30.4%). A small percentage of pALS 5.8% did televisits alone (Table 1).

Disease-related characteristics and use of supportive care equipment

The median (IQR) score of ALSFRS-R was 26 (17–33). Of the study sample, 36.2% had ALSFRS-R scores of less than 30, and 18.8% had scores of less than 20. Only one of them was ambulatory (1.4%); 27.5% required assistance with ambulation and 71.0% were non-ambulatory.

Among the study population, 82.6% of pALS used supportive equipment for nutritional support (73.9% had a gastrostomy tube and 8.7% has a nasogastric tube); 78.3% used home ventilator and 34.8% required tracheostomy care. During the televisit period, one pALS began nasogastric tube feeding, two started gastrostomy feeding, and seven underwent tracheostomies (Table 2).

The median (IQR) duration from the first outpatient visit to the department of neurology for ALS to the first televisit was 1.8 (1.0–4.4) years. The median (IQR) duration from the first to the last televisit was 0.6 (0.2–1.1) years.

Contents of video televisits

Disease-related symptoms were discussed by pALS during every televisit (100%). In 92.8% of televisits, management of supportive care equipment, such as a home ventilator or gastrostomy, was discussed. Half of the pALS (52.2%) received treatment for newly developed acute health issues, such as URI and urinary symptoms. In 14.5% of the cases, ACP for tracheostomy or ICU care was provided (Table 3).

Number of video televisits per person

During the study period, 29.0% of pALS used televisits more than 10 times, and 5.8% used televisit more than 20 times. The

average number of televisits per year ranged from 7–12 for 39.1%, 3–6 for 15.9%, and 13–18 for 14.5% (Table 4). The average number of pALS per month was 2.17 in 2020–2021 and 2.14 in 2022–2023 (Supplemental Fig. 1, only online).

Table 1. Demographics of People Living with Amyotrophic Lateral Sclerosis and Their Care Partners (n=69)

Variable	Value
Patient	
Sex	
Male	32 (46.4)
Female	37 (53.6)
Age (yr)	
20–29	1 (1.4)
30–39	2 (2.9)
40–49	3 (4.3)
50–59	17 (24.6)
60–69	24 (34.8)
70–79	16 (23.2)
≥80	6 (8.7)
Median (IQR)	66 (57–71)
Insurance	
NHI	67 (97.1)
Medical aid	2 (2.9)
Residential region	
Seoul	42 (60.9)
Gyeonggi-do	16 (23.2)
Incheon	4 (5.8)
Chungcheong-do	3 (4.3)
Jeolla-do	1 (1.4)
Gyeongsang-do	3 (4.3)
Year	
2020	18 (26.1)
2021	22 (31.9)
2022	25 (36.2)
2023	4 (5.8)
HBMC clinic home visit	37 (53.6)
Care partner	
Relation	
Spouse	37 (53.6)
Children	21 (30.4)
Parent	5 (7.2)
None (alone)	4 (5.8)
Others	2 (2.9)
Sex	
Male	21 (30.4)
Female	48 (69.6)

IQR, interquartile range; NHI, National Health Insurance; HBMC, home-based medical care.

Data are presented as n (%).

DISCUSSION

When telemedicine was allowed, 80% of pALS who had registered at the HBMC clinic for supportive care used video tele-visits; 40% lived outside Seoul and usually required more than

Table 2. Disease-Related Characteristics and the Use of Supportive Care Equipment during the First Video Televisit and the Last Televisit (n=69)

Variable	Value
First televisit	
ALSFERS-R	
0–9	3 (4.3)
10–19	10 (14.5)
20–29	12 (17.4)
30–39	14 (20.3)
40–48	1 (1.4)
Unknown	29 (42.0)
Median (IQR)	26 (17–33)
Mobility level	
Ambulatory	1 (1.4)
Assisted ambulatory	19 (27.5)
Non-ambulatory	49 (71.0)
Nutritional support	
Nasogastric tube	6 (8.7)
Gastrostomy tube	51 (73.9)
Respiratory support	
Ventilator support	54 (78.3)
NIPPV	30 (43.5)
TIV	24 (34.8)
Last televisit	
Nutritional support	
Nasogastric tube	7 (10.1)
Gastrostomy tube	53 (76.8)
Respiratory support	
Ventilator support	61 (88.4)
NIPPV	30 (43.5)
TIV	31 (44.9)
Televisit initiation time from the first visit to the department of neurology	
Less than 1 year	21 (30.4)
1–2 years	14 (20.3)
2–3 years	13 (18.8)
Over 3 years	21 (30.4)
Median (IQR), years	1.8 (1.0–4.4)
Televisit duration from the first to the last televisit	
Less than 6 months	32 (46.4)
6 months–1 year	19 (27.5)
Over 1 year	18 (26.1)
Median (IQR), years	0.6 (0.2–1.1)

ALSFERS-R, Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised; IQR, interquartile range; NIPPV, non-invasive positive pressure ventilation; TIV, tracheostomy with invasive ventilation.

Data are presented as n (%).

Table 3. Contents of Video Televisits (n=69)

Classification	n (%)	Major issues
Disease-related symptom	69 (100)	Dyspnea, dysphagia, muscle weakness
Management of supportive equipment	64 (92.8)	Gastrostomy, NIPPV, suction
Acute health issues	36 (52.2)	URI symptoms, urinary symptoms
Advance care planning	10 (14.5)	Pre-determining tracheostomy and ICU care preferences
Others	5 (7.2)	Test results explanation, issue of certification for insurance
HBMC team regular checkup	37 (53.6)	Home visit scheduling and re-assessment

NIPPV, non-invasive positive pressure ventilation; URI, upper respiratory infection; ICU, intensive care unit; HBMC, home-based medical care.

Table 4. Number of Video Televisits Per Person

Total number (n=69)		Average number per year (n=69)	
Range	n (%)	Range	n (%)
1–3	16 (23.2)	N/A	5 (7.2)
4–6	22 (31.9)	3–6	11 (15.9)
7–9	11 (15.9)	7–12	27 (39.1)
10–19	16 (23.2)	13–18	10 (14.5)
20–29	2 (2.9)	19–24	7 (10.1)
30–89	2 (2.9)	≥25	9 (13.0)

N/A, residents outside the visited area.

an hour of transit time by car to visit the hospital. More than 70% of pALS using televisit were non-ambulatory, more than 80% were using nutritional support equipment, and 80% used home ventilator for respiratory support. In addition to management of disease-related symptoms and education for supportive equipment use, ACP was also provided during the televisits. For pALS with mobility challenges, video televisits are a feasible option and can complement outpatient clinic visits or home visits.

The strength of this study is that it is the first in South Korea to investigate the characteristics of video televisits conducted in real clinical settings targeting patients with a serious illness. Before the COVID-19 pandemic, televisits were prohibited by law, making related studies impossible. However, since their temporary allowance in South Korea in 2020, several studies on televisits have been published. Studies using administrative data, such as the NHI database, investigated general characteristics of patients who used telemedicine, while hospital-based studies examined the satisfaction of patients and medical staff with telemedicine.^{20,23,24} However, evidence on how patients with serious illnesses used televisits was scarce. This study is meaningful in that it investigated the televisit experiences of pALS in actual clinical settings.

In this study, 80% of pALS registered at the HBMC clinic utilized telemedicine, with only 1% of the users (1 out of 70) opting for an audio televisit instead of a video televisit due to device function limitations. Most of the televisit users (99%) utilized mobile phones equipped with video conferencing capabilities. More than half of the pALS who used video televisits were over 65 years of age. This was a similar result to the study based on administrative data, which revealed that 40% of televisit users were older adults aged 65 and above.²⁰ A telemedi-

cine study conducted in Canada on patients with Parkinson's disease reported that the average age was 65.8 years and older adults also used telehealth services extensively.²⁵ Despite concerns about older adults' use of technology, the results revealed that since older adults are more likely to have diseases, many have learned to use telehealth in actual situations.²⁶ In our study, more than 90% of pALS conducted televisits with the assistance of another person. While it is challenging to determine the age range of the care partner, this suggests that televisits can be effectively utilized with the support of a care partner when it is difficult to conduct them alone.

Telemedicine is a useful tool that can increase healthcare accessibility in populations with low physical accessibility to medical services. In the U.S., telemedicine has proven valuable for providing injured rural patients with high-quality trauma care that would otherwise be difficult.²⁷ A German study reported the need for telemedicine in pediatric palliative home care, and a U.S. study also reported that tele-palliative care is helpful for patients with cancer.^{28,29} Considering its high utility in people who have difficulty visiting medical institutions due to geographical or physical limitations, the American Academy of Neurology established a telemedicine workgroup and endorsed the use of telemedicine in neurology.¹¹ ALS is a representative disease in which muscle weakness increases as the disease progresses and mobility decreases due to the need for various supportive equipment to maintain life.³⁰ Many countries are attempting to apply telemedicine to pALS.^{31–33} A U.S.-based ALS clinic analyzed 97 patients who had video televisits over a 3-year period starting in 2014, revealing that the median distance from hospital to patients' homes was 211 miles (340 km) and half of the population were ambulatory.¹⁵ In comparison, this study population had lower mobility levels and a relatively shorter travel distance to the clinic. This may be attributed to the study being conducted at the HBMC clinic for supportive care, which primarily included pALS whose disease had already progressed and had limited mobility. In this study, 80% used home ventilators for respiratory support, and more than 30% had undergone tracheostomy. These patients require assistance from others and often must use an ambulance to visit the hospital. South Korea has high accessibility to medical care, especially for patients with serious illnesses, such as pALS, since the cost burden is very low.¹⁷ However, in reality, people with advanced ALS may struggle to access

medical care owing to difficulties in traveling to the hospital.¹⁷ For these patients, telemedicine is a feasible way to receive medical services. In South Korea, televisits are legally prohibited and are available only in some island regions as a pilot project. However, they were temporarily allowed during the COVID-19 pandemic, making the present study possible. The fact that there was no significant difference in the average monthly number of new pALS between 2020 and 2021 (when visiting the hospital was difficult due to the COVID-19 pandemic) and between 2022 and 2023 suggests that the study population required televisits owing to mobility difficulty, irrespective of the pandemic. In this study, over a median duration (IQR) of 0.6 (0.2–1.1) years of using telemedicine, televisits were used an average of 8.9 times per person (standard deviation, 11.7), and in-person visits to the department of neurology averaged 3.3 times per person (standard deviation, 3.7). Televisits were more than twice as frequent as in-person visits. Televisits provide patients with limited mobility easier access to healthcare services, complementing traditional in-person visits when necessary.

Regarding the contents of televisits in the U.S. study, medication management (89%) and goal of care (74%) were the main topics of discussion, followed by the management of supportive equipment (50%); acute care issues were rarely discussed.¹⁵ Unlike the U.S. study, most of the pALS included in this study used supportive care equipment and started supportive care equipment during the televisit periods, resulting in extensive discussions about it. Moreover, fewer discussions about ACP may be attributed to the fact that one-third of pALS had already undergone a tracheostomy. Nevertheless, the fact that ACP was discussed in 15% of cases aligns with previous findings, which revealed that ACP for serious illnesses is feasible through televisits.^{34,35} The finding that more than half of the study population discussed acute health issues revealed that pALS experience various health problems in their daily lives that require medical care in addition to symptoms directly related to ALS. In this study, in one case, the physician ordered a hospital visit after a televisit to rule out a fracture after a fall at home. Televisits are inherently incomplete since patients are not treated in person, but their needs can be addressed in conjunction with home or clinic visits. Since this study analyzed televisits of pALS registered with a HBMC team, there may have been fewer cases in which patients were instructed to visit the hospital due to periodic home visits by medical staff. These results can be used as a reference when developing telemedicine protocols specific to pALS in the future.

During the COVID-19 pandemic, telemedicine was offered to pALS in many countries; overall, pALS who participated in televisits expressed satisfaction with the service.^{16,36} Although many patients still prefer face-to-face visits, televisits can be a useful alternative for those who find them difficult.³⁶ Based on these experiences, two systematic review papers published in 2016 and 2020 reported that telehealth in ALS care is well re-

ceived by pALS and their caregivers, and that the use of technology to improve access to specialist care should be actively considered.^{33,37} In South Korea, where the distance from Seoul to Busan, the farthest city, is 430 km (267 miles), restrictions on access to specialty care due to geographical distance are less severe compared to larger countries, such as the U.S. and Canada. However, since ALS involves mobility restrictions and the use of supportive equipment, telemedicine offers a practical solution to enhance access to care. Telemedicine is feasible for pALS in South Korea, and further research is needed to investigate how to provide it appropriately.

This study had some limitations. First, since our study was conducted at one tertiary hospital, it is difficult to generalize its findings. Additionally, as a retrospective observation study based on medical record review, it is unclear why some patients did not use televisits. Considering that a telemedicine study on Parkinson's disease reported healthcare disparities among women and minorities, populations with challenges in accessing telehealth services should be considered for the universal provision of telemedicine.¹³ Second, as a retrospective observational study based on medical record review data, it did not investigate the patients' and physicians' satisfaction with telemedicine. Previous studies reported that both patients and their caregivers expressed overall satisfaction, but satisfaction in the Korean health context needs to be investigated.^{16,36} Third, in South Korea, telemedicine was suddenly allowed during the COVID-19 pandemic and provided to patients with various conditions. Research on the appropriate timing for initiating telemedicine according to patient characteristics can be conducted when telemedicine becomes a universal service. Fourth, the present study did not examine the use of other healthcare services, such as in-person clinic visits, and evaluate the health outcomes. This study focused on the feasibility of televisits for pALS, and further in-depth studies are needed to explore their effects. Fifth, time from the first neurology visit to telemedicine initiation was used to assess the timing of telemedicine initiation. However, this may not reflect the actual time from ALS diagnosis. Lastly, although nearly 50% of the patients discontinued telemedicine within 6 months, we could not investigate the reason for the discontinuation since this was a retrospective study. Understanding why patients discontinued telemedicine and whether there are differences in the frequency of in-person visits between those who continued using telemedicine and those who stopped are important topics for future research.

In conclusion, when telemedicine was allowed in South Korea, pALS with mobility limitations, such as home ventilator and gastrostomy tube users, benefited from televisits. Although most had limited mobility, telemedicine enabled them to receive direct treatment from a physician for various concerns, including not only disease-related symptoms but also acute health issues and ACP. Video telemedicine is feasible for pALS with limited mobility due to muscle weakness or their

reliance on various supportive care equipment, in addition to traditional outpatient-based care and home visits. This study highlights the need to develop telemedicine strategies to provide medical services for people who have difficulty accessing healthcare due to mobility issues.

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AUTHOR CONTRIBUTIONS

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