Tokai J Exp Clin Med., Vol. 50, No. 3, pp. 112-118, 2025

Clinical Care Experience of Multidisciplinary Professionals in Amyotrophic Lateral Sclerosis: A Cross-Sectional Study

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(Received June 19, 2025; Accepted September 12, 2025)

Objective: To clarify the characteristics of medical care for amyotrophic lateral sclerosis (ALS) by examining the most memorable experiences of multidisciplinary medical professionals involved in patient care.
Methods: In a questionnaire, "the most impressive thing about the experience" was efficiently categorized using inductive thematic coding. Responses were categorized using keywords, and similar content was categorized using codes. The instances of each quantified item were calculated by expressing them as numbers and frequencies. Furthermore, representative quotations and context-specific nuances were analyzed to investigate the emotional and ethical dimensions of each category.
Results: Questionnaires were distributed to 269 medical professionals treating patients with ALS at three hospitals in the western region of Kanagawa Prefecture. Of these, 164 (60%) responded to the questionnaire, and 143 were included (valid response rate: 53%). Based on the questionnaire responses, the experiences of the medical professionals were classified into 27 categories. Medical professionals are continuously involved in fulfilling the wishes of patients as much as possible, realizing individuality and patient commitment, and intervening without giving up.
Conclusion: For multidisciplinary medical professionals involved in the care of patients with ALS in clinical practice, the most memorable experiences coincided with those associated with the challenges of ALS care.

Key words: Amyotrophic lateral sclerosis, multidisciplinary medical professionals, care practice experience

INTRODUCTION

Amyotrophic Lateral Sclerosis (ALS)

ALS is an intractable neurodegenerative disease that causes respiratory failure and death with the progression of bulbar palsy in the upper and lower limbs [1]. In Japan, the Medical Care Act for Patients with Intractable Diseases (Intractable Diseases Act) became effective in 2015 [2]. Intractable diseases are defined as "rare diseases for which the mechanism of onset is not clear, for which treatment methods have not been established, and the patients require long-term medical care." The number of patients will not be limited, and a wide range of target cities, surveys, and studies, and patient support will be promoted for diseases for which no other policy system has been established. Among them, designated intractable diseases are defined as "those with a high requirement for secure high-quality and appropriate medical care in view of the status of the patient," and ALS was designated as notification number 2 among 341 diseases in 2024 [3]. ALS is rare, and according to statistics from the Ministry of Health, in 2022, 9,765 individuals in Japan were certified recipients of ALS-specific medical expenses [4].

Treatment

Riluzole and edaravone have been developed as treatments and slightly improve the survival rate of patients with ALS [5]. Additionally, a successful regulatory application have been submitted to the Pharmaceuticals and Medical Devices Agency for Tofersen, a therapeutic agent for patients with ALS (superoxide dismutase 1 [SOD1]-ALS) [6], in which the SOD1 protein forms an abnormal structure [7]. However, developing effective treatments for all patients with ALS is not yet possible.

Symptoms

Patients with ALS have dysphagia and dysarthria due to dysfunction of the upper and lower motor neurons and progressive paralysis of the voluntary skeletal muscles. When respiratory function decreases owing to paralysis of the respiratory muscles, patients are required to make decisions that affect their survival. ALS is most common at the age of 60–79 years, with a median survival time of 2–4 years; however, there are also juvenile onsets, and many patients have a long prognosis after disease onset. Additionally, some patients with ALS have frontotemporal lobe dementia. Symptoms associated with ALS progression include muscle weakness in the trunk and limbs, motor symptoms associated with bulbar palsy, respiratory failure associated with paralysis of the respiratory muscles, and non-motor symptoms, such as cognitive decline, emotional regulation, physical pain, depression, fatigue, sleep disturbances, muscle spasms, and salivation [8]. Paralysis of the voluntary skeletal musles progresses; however, physical sensations, vision, hear-

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ing, and internal functions are preserved [9]. Patients with ALS live a normal daily life until disease onset. As the disease progresses, they experience recurrence loss of function. As health worsens, patients with ALS can choose whether to be mechanically ventilated with a tracheostomy. Nursing care is required for all aspects of daily life, and with further progression, a totally locked-in syndrome is established in which sensation and hearing remain, and the person is unable to express their intentions.

Current issues in the care of patients with ALS

Currently, care for patients with ALS involves multidisciplinary medical professionals, including physicians, nurses, rehabilitation therapists, and medical social workers. They work together from the initial to definitive diagnosis and at the end of life. In each field, medical professionals provide a variety of care to alleviate the physical and mental pain of patients, who repeatedly experience loss on a daily basis because of the irreversible progression of ALS symptoms, enabling them to have a safe and comfortable daily life based on their individual needs. Additionally, collaborative decision-making support is provided to patients with ALS and their families so that they can live without regret. The care of patients with ALS stands out for its treatment modality according to the needs of the patient, and medical professionals strive to meet these needs as much as possible. To the best of our knowledge, no study has specifically examined the experiences of healthcare professionals caring for patients with ALS. Therefore, this study aimed to clarify the experiences of medical professionals from multiple fields caring for patients with ALS. This will assist in clarifying the characteristics of the treatment of patients with ALS.

MATERIALS AND METHODS

Aims

The free-form content of the experiences that left impressions on multidisciplinary medical professionals involved in the care of patients with ALS was analyzed. The aim was to clarify the specific practical experiences of multidisciplinary medical practitioners and the characteristics of ALS treatment.

Survey period

This study was conducted between August 2 and November 1, 2021.

Respondents

The participants were multidisciplinary medical practitioners specializing in ALS management, who delivered clinical services at three hospitals in the western region of Kanagawa Prefecture, located in western Japan.

Contents of the Study

Information regarding the provision of clinical care for patients with ALS was obtained from multidisciplinary medical professionals. After obtaining approval from the directors of the respective institutions, explanatory booklets and questionnaires were distributed to the medical staff of the institutions, and anonymous responses were requested. The questionnaire consisted of questions related to demographic information (age, sex, and occupation), years of experience, specialty, and implementation of clinical care practices. Additionally, the respondents were requested to provide open-ended descriptions of “what they consider important in the practice of clinical care for patients with ALS,” “what was the most memorable experience they had with patients with ALS,” and “how they felt at that time” (Sample 1). The investigators scheduled the date and time of questionnaire collection and placed designated boxes for questionnaire submission at each facility. The questionnaire guaranteed anonymity, and agreement of respondents to participate in the study was confirmed by their responses.

Analytical methods

Among the questionnaire responses, “what impressed me the most in my experience” was efficiently classified using inductive thematic coding. For investigators to classify the coding objectively rather than subjectively, reliability was ensured through constant consultation with international experts and contributions of investigators in ALS medicine as super advisors. The data included the original text, words, and expressions written by the respondents, and there was no intentional manipulation by the investigators when categorizing the items. First, the responses were categorized by keywords and similar content, and then by codes using medical terminology. Excel (Microsoft, USA) was used to create a pivot table. The number of instances of each quantified item was expressed as a number and its frequency. Next, the items were sorted and listed in order of frequency, and a ratio was calculated. As a result, the experiences that made a particularly strong impression on multidisciplinary medical professionals regarding the practical experience of ALS care were elucidated. Finally,representative quotations and context-specific nuances were analyzed to investigate the emotional and ethical dimensions of each category. The factual data obtained from the responses were objective, but they were more accurate in understanding the intentions of the respondents and conducting a qualitative analysis.

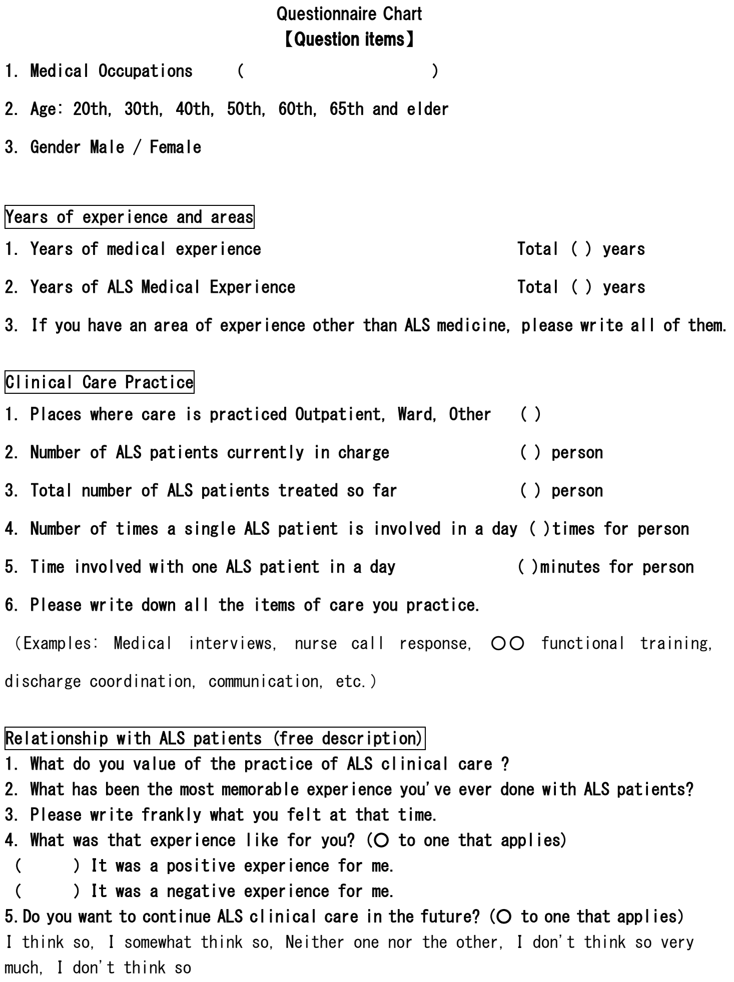
Ethical considerations for the participants

This study was approved by the Tokai University School of Medicine Clinical Research Review Committee (approval no. 19R-290). In addition to the questionnaire, the participants were provided with a booklet outlining the background and objectives of the study. The participants provided anonymous and voluntary consent after completing the questionnaire. Their responses were coded to ensure confidentiality and prevent individual identification.

RESULTS

Study participants

Patients who underwent ALS treatment at three hospitals in the western region of Kanagawa Prefecture received multidisciplinary medical care. Questionnaires were distributed to 269 respondents, of which 164 were completed (response rate: 60%). Of the 164 completed questionnaires, 143 (valid response rate: 53%) were included in the analysis.



Questionnaire Chart
【Question items】

1. Medical Occupations ( )
2. Age: 20th, 30th, 40th, 50th, 60th, 65th and elder
3. Gender Male / Female

Years of experience and areas

1. Years of medical experience Total ( ) years
2. Years of ALS Medical Experience Total ( ) years
3. If you have an area of experience other than ALS medicine, please write all of them.

Clinical Care Practice

1. Places where care is practiced Outpatient, Ward, Other ( )
2. Number of ALS patients currently in charge ( ) person
3. Total number of ALS patients treated so far ( ) person
4. Number of times a single ALS patient is involved in a day ( )times for person
5. Time involved with one ALS patient in a day ( )minutes for person
6. Please write down all the items of care you practice.

(Examples: Medical interviews, nurse call response, ○○ functional training, discharge coordination, communication, etc.)

Relationship with ALS patients (free description)

1. What do you value of the practice of ALS clinical care ?
2. What has been the most memorable experience you've ever done with ALS patients?
3. Please write frankly what you felt at that time.
4. What was that experience like for you? (○ to one that applies)
( ) It was a positive experience for me.
( ) It was a negative experience for me.
5. Do you want to continue ALS clinical care in the future? (○ to one that applies)
I think so, I somewhat think so, Neither one nor the other, I don't think so very much, I don't think so

Sample 1 Questionnaire Chart【Question items】English version

Occupational distribution

The valid respondents included 13 (9%) physicians, 35 (24%) nurses, 38 (27%) physical therapists (PTs), 17 (12%) occupational therapists (OTs), and nine (6%) speech therapists (STs) in the rehabilitation domain. Additionally, five (3%) clinical engineers, 11 (8%) medical social workers, four (3%) pharmacists, five (3%) care workers, three (2%) registered dietitians, one licensed practical nurse, one medical assistant, and one care worker (1% each) were included. There were 64 PTs, OTs, and STs in the rehabilitation domain, accounting for 45% of the total respondents. A summary of these data is presented in Fig. 1.

Attribute distribution of participants

The median age of the respondents was in the third decade of life, ranging from the second to the sixth decade. The median duration of medical practice was 13 years, and the median exposure to ALS was five years. Notably, in each profession, physicians rotate between various specialties for two years after obtaining a license and majoring in a specialized field. Additionally, there were individual differences in the number of nurses and rehabilitation staff owing to changes in ward structure and the patients they managed.

Coding results and percentages

The response “most impressive experience so far” among the free entries obtained from the questionnaire was examined. First, all free entries were transcribed into Excel (Microsoft, USA), and a pivot table was created for inductive thematic coding.

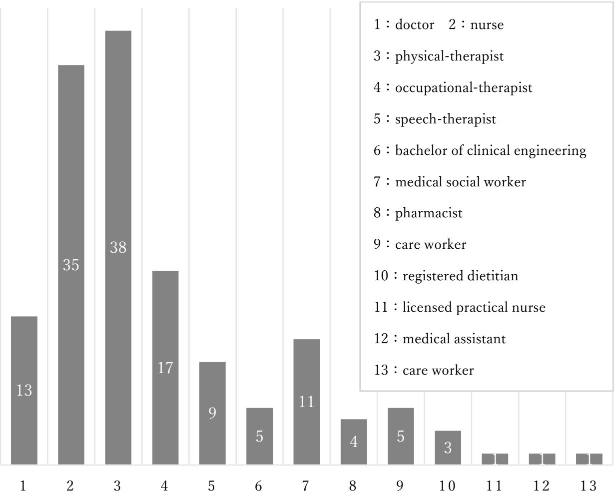


Fig. 1 Distribution of the study participants (n = 143)

Next, keywords were extracted from the experiences and situations of the respondents from the free descriptions. The keywords were categorized into 29 items. As a result of classification according to descrip-

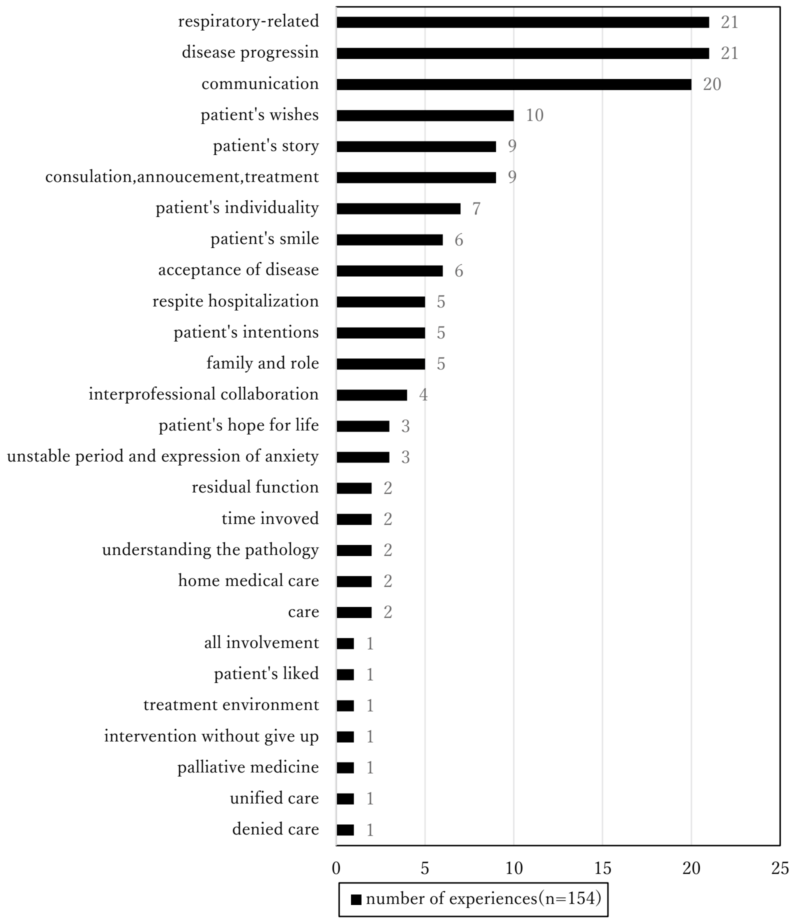


Fig. 2 Most memorable experiences of medical professionals in the care of patients with amyotrophic lateral sclerosis (n = 154): The contents of the free descriptions obtained from the responses were classified into 29 categories, and the rates of occurrence are indicated. Specifically, the number of each item is shown.

tion, there were 154 descriptions. The items included: “1: Respiratory-related matters, 2: Consultation and diagnosis situations, 3: Announcements, 4: Treatment, 5: Patient’s family and role, 6: Patient’s wishes, 7: Patient’s intentions, 8: Unstable periods and expressions of anxiety, 9: Patient’s hope for life, 10: Acceptance of disease, 11: Disease progression, 12: Communication with patients, 13: Patient’s story, 14: Events of respite hospitalization, 15: Care, 16: Inter-discipline collaboration, 17: Denied care, 18: Unified care by medical professionals, 19: Palliative medicine, 20: Individuality and commitment of patients, 21: Home medical care, 22: Necessity of understanding the pathology, 23: Intervention without giving up, 24: Residual functions, 25: Patient’s smile, 26: Time involved, 27: Treatment environment, 28: What the patient liked, and 29: All Involved”.

Next, a pivot table was created to code and easily classify the keywords as items. Similar items were sorted using a pivot table, and the number and percentage of each item were calculated. “2: Scene of consultation and diagnosis, 3: Notification, and 4: Treatment” were calculated together as similar items. When sorted according to the number of descriptions, the following were obtained: “1: Respiratory-related”, “” ”11: Disease progression”, 21 (13.6%); “12: Communication with patients”, 20 (12.9%); “6: Patient’s wishes”, 10 (6.4%): “2: Consultation and diagnosis, 3: Announcements, 4: Treatment”,” “13: Patient’s story”, 9 (5.8%); “20: Patient’s individuality and commitment”, 7 (4.5%); “10: Acceptance of disease”; “25: Patient’s smile”, 6 (3.8%); “5: Patient’s family and role”; “7: Patient’s intentions”; “14: Incident of respite hospitalization”, 5 (3.2%); “16: Interprofessional collaboration”, 4 (2.5%); “8: Unstable period and expression of anxiety”; “9: Patient’s hope for life”, 3 (1.9%); “15: Care”; “21: Home medical care”; “22: Necessity of understanding the pathology”; 24: Residual functions”; 26: Time involved, 2 (1.2%); 17: Denied care; 18: Unified care by medical professionals; 19: Palliative medicine; 23: Intervention without giving up; 27: About the treatment environment; 28: What the patient liked; and 29: All involvement, 1 (0.6%). The results are presented in Fig. 2 and 3.

Contents of the items

Respirators and progression of the disease

Twenty-one (13.6%) of the 154 descriptive entries were experiences with “**respirators**.” The descriptions comprised 12 experiences with patients who did not wear a respirator, and 10 experiences with patients who wore a respirator. When categorizing specific content, there were 22 responses, including those that described both experiences. Medical personnel had experienced many situations, with one responding, “*the scene where a person died because he maintained his belief that he could not wear a respirator*,” and the responses showed serious

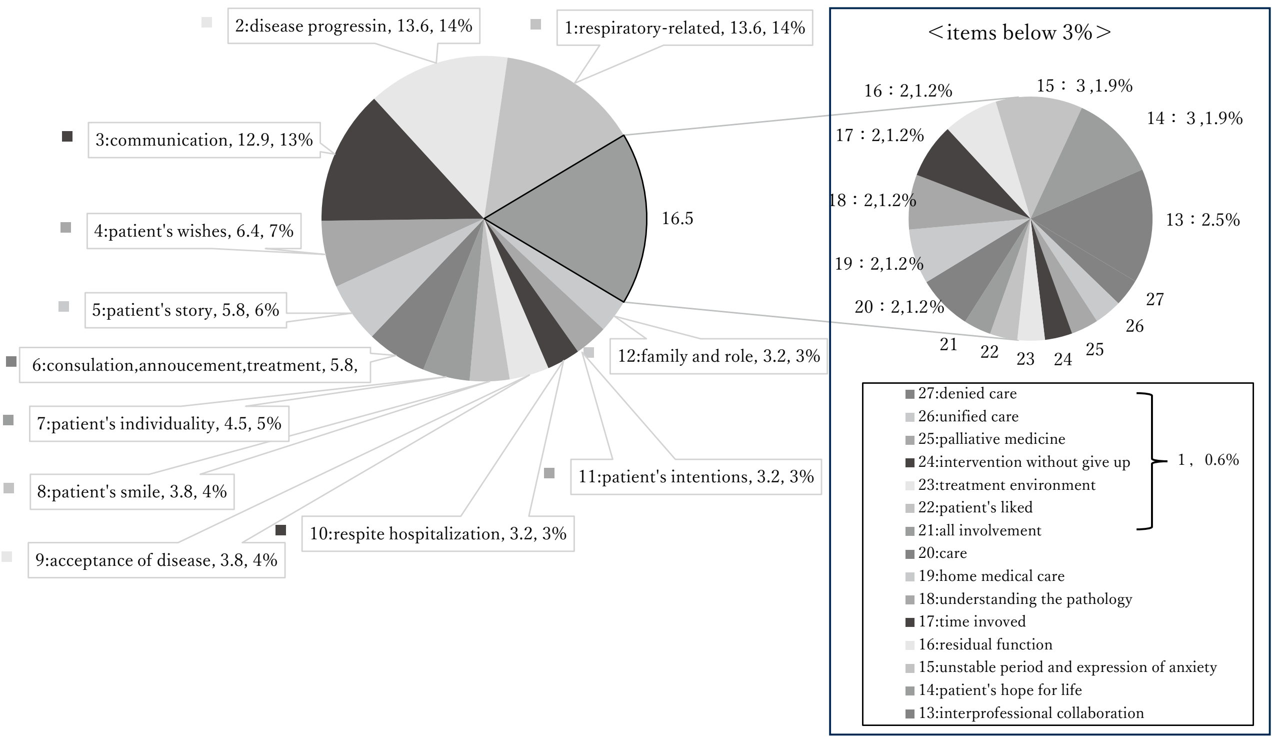


Fig. 3 Percentages of items of the most memorable experiences of medical professionals in the care for amyotrophic lateral sclerosis (n = 154): The contents of the free descriptions obtained from the responses were classified into 29 categories, and the rates of occurrence are indicated. Particularly, the percentages for each item are shown.

decision-making support related to the life and death of patients and their families. First, the experiences of the patients who did not wear a respirator included those who did not wear a respirator until death while recuperating in a state of respiratory distress, those who did not want to die, those who were desperate to live, and those who refused to wear a respirator and chose to die. Specifically, "*Patients who did not use a respirator and refused tracheostomy because I don't want to cause nursing care or financial trouble to my family. A case where he could have lived longer, but he disagreed with his family until the end and followed his wishes*". A medical professional has encountered this situation. The patient considered his family and insisted on not wearing a respirator. The medical practitioner provided daily care while realizing the will of the patient and the family who wanted him to live. However, medical professionals have had confusing experiences in understanding these patients. Additionally, medical personnel had experienced, as one respondent remarked, "*they were happy to receive care while wearing a respirator,*" and there was a clear opinion that it was good to choose to wear a respirator. For patients who wore respirators, there was a process of building relationships, such as difficulty in wearing a mask, and professionals were happy to provide the best possible care through multidisciplinary cooperation. What they had in common was a difference in their feelings towards their families regarding their decision to wear respirators. What was common in both scenarios was the desire of the patient not to cause trouble to their family and the desire of the family for the patient to continue living with a respirator. In other instances, a family member requested a respirator because of decreased consciousness; however, the patient did not want to use a respirator. Patients also experienced discrepancies in their intentions after wearing a respirator. The description reads, "Patients who decide to stay on a ventilator for a long time and patients who decide not to wear a ventilator. Both seem to have been made up in isolation. Medical professionals at the scene appreciated that patients themselves were isolated from making decisions about wearing respirators.

"Disease progression" was included in 21 (13.6%) of the 154 descriptive items. Medical professionals had experienced, as a characteristic response, "*the number of things that can be done on a daily basis decreases due to the severity of the disease,*" "*The speed of progression of the disease and the acceptance of the disease by the person and his family could not keep up, and he was unable to reach a satisfactory end of life.*" Particularly in this instance, while confused by the speed of intractable diseases, the participant emphasized the response based on the experience of medical professionals who practice care. Many participants were surprised by the rapid progression of their symptoms. Patients also experienced difficulties communicating with medical professionals because of dysarthria. Regarding the impairment of various functions due to the progression of ALS, medical professionals were affected by the rapid progression of the disease while interacting with patients in the course of their care, responding, "*We spent the process of progressing the patient's symptoms and gradually losing basic abilities in life, such as speaking and eating.*" During this process, the patients continued to live their lives despite frustration and resignation.

Communication

"Communication" was included in 20 (12.9%) of the 154 descriptions provided. One respondent remarked, "*they did not understand the content of the complaint*", or that "*they were able to communicate*, and the response was clear regarding the communication difficulties necessary for mutual understanding. There were 12 instances of communication and nine cases of inability to communicate; 21 instances were described because both descriptions were present. In addition to "*there were times when I did not understand the content of the complaint and there were patients who shed tears,*" there was a description of the difficulty of implementing an initiative to introduce alternative communication for patients who refused to communicate, such as "*it was difficult, so it remains as a very memorable memory.*" Additionally, there was an instance when a happy experience was not described as "*I was looking for a way to express my intentions on the dial during training, but gradually became able to have a conversation.*" Several requirements must be met regarding the experience of effective communication, including difficulties with nonverbal communication methods, the requirement for careful intervention, and the establishment of effective communication methods. A lack of communication led to refusal, difficulty with intervention, and discouragement. However, there were instances when patients worked hard to cooperate, even though there was no communication with them.

Ten items or less

References to **"patient preferences"** accounted for 10 (6.4%) of the 154 descriptions. Patients with ALS continue to have individual hopes, even though the disease is intractable, and medical professionals have the experience of doing everything feasible to fulfill their wishes. Many descriptions concerned experiences that fulfilled their wishes and included multidisciplinary collaboration.

Nine of the 154 descriptions (5.8%) included **"consultation, diagnosis, and notification."** Participants were concerned about the time required for diagnosis, the difficulty in dealing with the lack of a diagnosis, and the patient's experience of acceptance and psychological support.

Nine of the 154 descriptions (5.8%) included **"patient stories."** Medical practitioners described having a conversation with the patient, even though the patient had difficulty communicating due to dysarthria. There were instances of listening to patients speak about how they felt about their illness, future, death, their experience of loss, and how they wanted to be understood. There was also an instance in which the patient laughed, spoke about death after the announcement, and expressed their emotions.

"Individuality and commitment" were included in seven (4.5%) of the 154 descriptions. Medical professionals have observed that each patient with ALS has a different method of dealing with the disease and its symptoms, and that it takes a long time to pay attention to details in terms of body position adjustment and care. One patient also described his experiences with other patients who took care of their surroundings.

Six respondents (3.8%) included **"acceptance."** A patient received support from his family after being informed of, and subsequently accepting his ALS diagnosis. **"Patient's smile"** was also included in six (3.8%) descriptions, indicating that the patient smiled while receiving care. The term **"Family role"** was included in five (3.2%) items, and descriptions were provided of discrepancies in the thoughts of patients and their families, including changes in roles due to hospitalization. **"Patient's intention"** described decision-making, and in **"Respite hospitalization,"** patients stated that being hospitalized reminded them of home-based care, that they were able to take oral medications when hospitalized, and that they had a sense of trust in medical professionals. In four (2.5%) descriptions of **"Multidisciplinary collaborations,"** the participants had experience discussing patient care with other medical professionals. In the three **"Unstable periods"** (1.9%), patients described difficulties in coping with unstable periods. In three (1.9%) responses, patients were asked about the meaning of life, and they expressed feelings about a way of life that they wanted to cherish, even if their physical function changed. Two (1.2%) patients stated that they wanted to spend their last days **"in care."** In **"Understanding the pathology of patients living alone at home."** There were experiences that led to a requirement for medical professionals and patients to understand the pathology. There were descriptions of experiences in which the patients felt that they had little **"time to be involved"** and experiences of practicing care that made use of **"residual functions."** There was also an experience of being **"refused care"** by one patient (0.6%), an experience of realizing the requirement for **"unified care,"** an experience of practicing **"palliative medicine,"** and **"intervention without giving up,"** believing in the possibility of utilizing the remaining functions.

DISCUSSION

The questionnaire yielded valid responses from 143 individuals, including 13 physicians. In the medical field, the roles are governed by the laws of each profession. Although the content of the free descriptions in this study regarding the qualifications and occupations of several participants varied, it was evident that they were willing to provide care in the medical field as medical professionals. As the professions and roles were different, it was expected that there would be differences in how they were involved in care. However, contents of the descriptions were similar, and it was possible to classify them by item.

The results revealed the percentages and content of memorable experiences among the medical professionals. The experiences presented herein are consistent with the challenges associated with the characteristic symptoms of ALS. One of the biggest challenges in the advanced stages of treatment for patients with intractable neurological diseases is decision-making support, which is directly linked to life support [9]. Patients with ALS require assistance in making decisions on the use of a ventilator because of decreased respiratory function caused by paralysis of the muscles necessary for spontaneous breathing. Although the rate of mechanical ventilation in patients with ALS in Japan is relatively high (30%) compared to that in other countries (10%), medical professionals have witnessed the lives of patients who use a ventilator and those who do not. It became clear that there was a gap between the intention of the patients not to wear a respirator because they did not want to cause trouble to their family and the family who wanted them to live with a respirator.

Medical professionals are interested in the speed of progression of ALS. In addition, delays in consultation and diagnosis reduced the quality of life of patients and were associated with patients and their families struggling to cope with the diagnosis. Onodera *et al.* investigated the site of onset, period until diagnosis at the first visit, and time until examination. They reported that the overall period from onset to diagnosis was 13.0 ± 9.8 months. They emphasized the importance of early diagnosis of ALS and the need to reduce the time to diagnosis. Delays in consultation and diagnosis reduce the quality of life of patients and are associated with the inability of patients and their families to maintain acceptance [11]. Due to the rapid progression of the disease from diagnosis to death, patients and their families were unable to accept the diagnosis, and patients continued to live with frustration and resignation. Patients with ALS should be diagnosed and treated at the early stages of the disease. Therefore, knowledge and awareness of ALS and other rare and intractable diseases are required. Medical professionals also had experience of being able to and unable to communicate with patients with dysarthria. However, they continued to have unchanging relationships, even when it was difficult to express their intentions [13].

The questionnaire responses in this study included items that self-evaluated experiences and indicated an intention to continue caring for patients with ALS in the future. As reported by Serizawa [14], even medical professionals who self-evaluated their care practice experience negatively expressed their intention to continue providing medical care. This took more time than for medical professionals in other fields to want to continue to be involved in the care of patients with ALS and they wanted to reflect on their own care practices and provide better care. While witnessing the experiences of patients with ALS, some medical professionals respected them, believed in their inherent potential, and tried to live together to support a better way of life. For multidisciplinary medical professionals involved in the clinical care of patients with ALS have the most memorable experiences associated with the unique challenges of ALS. In the face of numerous challenges, medical professionals continue to strive to fulfill the wishes of patients, as much as possible, recognize patient individuality and commitment, and intervene without giving up, even when care is denied.

Limitations and challenges of the study

This cross-sectional analysis was conducted among multidisciplinary medical professionals involved in ALS care at three hospitals in the western region of Kanagawa Prefecture. Each center accepts patients with ALS and provides specialized medical care. However, as there are no wards that specifically care for patients with ALS, the frequency of interactions with patients with ALS, a rare disease, is lower than that in hospitals and wards that specialize in caring for patients with intractable diseases. Furthermore, self-selection bias may have existed because participation was voluntary, potentially favoring individuals with more vivid or intense experiences. In future, it is necessary to conduct surveys including the attitudes of medical staff at specialized institutions. Given the influence of the sociocultural context on healthcare provision in each region, it is imperative to broaden the scope and conduct surveys to validate and expand the findings of this study. To elucidate the commonalities and discrepancies among medical professionals, substantial data categorized according to professional roles should be collected and examined for possible correlations. To expand the scale and conduct similar surveys in the future, the accuracy of inductive thematic coding must be further improved. Furthermore, as patients are the ultimate recipients of healthcare, the significance of this study will be enhanced by including a survey of patients and incorporating qualitative study methods, such as interview content, in addition to quantitative analysis to construct a “mixed study.”

ACKNOWLEDGMENTS

I express my sincere gratitude to the directors of the three hospitals, chiefs of each department, and multidisciplinary medical experts who collaborated in this study. I also thank Dr. Hiroyuki Kobayashi and Dr. Shinji Hadano of the Tokai University School of Medicine for their mentorship and Dr. Eiichiro Nagata for his assistance.

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