

# Exploration of the Factors Impacting Sustained Clinical Care by Multidisciplinary Professionals for Amyotrophic Lateral Sclerosis

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**Objective:** This study examined the experiences of multidisciplinary medical professionals in providing daily clinical care for patients with amyotrophic lateral sclerosis (ALS), with a focus placed on their persistence in sustaining clinical care for this patient group.

**Methods:** A questionnaire survey was administered to multidisciplinary medical professionals involved in ALS care at three hospitals in western Kanagawa Prefecture, Japan. The questionnaire results were used to examine the relationships between years of medical experience, years of ALS care experience, self-evaluation, and motivation to continue providing clinical care to patients with ALS.

**Results:** Of the 269 questionnaires distributed and 164 collected by the multidisciplinary medical professionals, 143 (53%) were deemed valid. Analysis revealed an association between “years of medical experience” with both “self-assessment of clinical care for ALS patients practice experience” and “commitment to continue clinical care for ALS patients,” as well as between “years of ALS medical experience” and “self-assessment of clinical care for ALS patients.”

**Conclusion:** Medical professionals with more than ten years of medical experience expressed their commitment to continue providing medical care in a comprehensive self-assessment of both the positive and negative aspects of their practice. Negative evaluations can be used to identify and improve ALS medical practices.

**Key words:** Amyotrophic lateral sclerosis, multidisciplinary medical professionals, medical experience year, sustaining of clinical care for ALS patients

## INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is an incurable neurodegenerative disorder, officially recognized by the Japanese government as rare and intractable. Despite extensive research efforts, no effective treatment for ALS has yet been established. ALS is characterized by dysphagia, dysarthria, progressive paralysis of the voluntary skeletal muscles affecting respiratory function, and functional impairment associated with bulbar palsy. In a prior study, Feldman *et al.* updated the statistics on ALS [1], showing that the typical age of onset is between 60–79 years, while the median survival time is 2–4 years. However, considerable heterogeneity exists among patients with ALS, particularly among those with juvenile-onset or prolonged survival after onset. Riluzole and edaravone are two available drug treatments which can improve survival. In the final stages of life, patients must decide whether or not to undergo a tracheostomy using mechanical ventilation (TMV). Compared with Western countries, the rate of wearing TMV is notably higher in Asia and Japan, with an increase in the number of elderly people aged 65 years and older since 1999. Some patients with ALS also experience concomitant frontotemporal dementia [2].

According to the ALS treatment guidelines of the

Japanese Society of Neurology, palliative care goals for ALS patients include the assessment and management of pain, dyspnea, and anxiety. The guidelines also recommend pain management, end-stage dyspnea treatment, and end-of-life anxiety treatment. Future considerations include implementation of the Advance Directive and addressing issues related to individual values and views on life and death [3]. The irreversible progression of symptoms from the onset of ALS to the end of life affects both ALS patients and their families, while posing significant challenges for medical professionals who work with ALS patients.

In this study, we investigate the features of clinical care for ALS patients practiced in various situations by multidisciplinary medical professionals involved in the management of patients in clinical practice. Medical professionals involved with patients with ALS come from various fields and maintain their involvement from the initial consultation and definitive diagnosis to the end of life. Additionally, some patients require subsequent grief care. Medical professionals thus provide clinical care to alleviate both the physical and psychological distress experienced by patients as they experience repeated losses due to the irreversible progression of ALS symptoms. The objective of medical professionals is to empower patients to live safe and comfortable lives, according to their individuality

while honoring their wishes. They also help patients with ALS and their families to cope with ALS and make decisions without regret. However, this process is fraught with difficulties associated with the physical and psychological care of ALS patients and their families. One survey conducted in 2022 reported that 70% of healthcare professionals considered quitting their jobs [4], while the turnover rate of hospital nurses has been shown to increase in recent years [5]. In addition to nurses, other medical professionals also aspire to protect human life and health and contribute to society as professionals engaged in healthcare. The desire for recognition increases with experience within the organizational culture to which they belong. However, the escalating turnover rate of medical professionals poses serious concerns when considering future social situations. This challenge is of significant relevance in amyotrophic lateral of ALS medicine, where a high level of expertise and skill is essential.

## SUBJECTS AND METHODS

### Aims

This study aimed to elucidate the current state of ALS care by conducting a statistical analysis of the perspectives of multidisciplinary medical professionals actively involved in the provision of clinical care to patients with ALS. This study focused on understanding the factors that motivate professionals to continue providing ALS clinical care based on their experiences. By identifying the factors influencing medical professionals' career retention, we aim to provide constructive recommendations for the future maintenance of ALS clinical care.

### Survey period

The survey was conducted from August 2 to November 1, 2021.

### Respondents

The participants were multidisciplinary medical practitioners specializing in ALS management who delivered clinical services at three hospitals (abbreviated as A, B, and C) in the western region of Kanagawa Prefecture.

### Contents of the survey

This study sought to gather insights regarding the provision of clinical care for patients with ALS from multidisciplinary medical professionals at three facilities in the western region of Kanagawa Prefecture, Japan. After obtaining approval from the facility directors, the researchers distributed explanatory booklets and questionnaires to the medical staff and requested their anonymous responses. The questionnaire comprised questions related to demographic information (age, sex, and occupation), years of experience and specialty, and implementation of clinical care. Additionally, the respondents were asked to provide open-ended descriptions of "what they consider important in the practice of clinical care for ALS patients," "what was the most memorable experience they had with ALS patients," and "how they felt at that time." Furthermore, they were asked to classify experiences as "positive" if it is an experience that they feel is good, and "negative" if they feel that it was not a good

experience. Finally, they were questioned regarding their motivation to continue providing clinical care for patients with ALS, by selecting from the following response options: "I agree, I somewhat agree, I neither agree nor disagree, I somewhat disagree, or I disagree." The researchers scheduled the date and time for collecting the questionnaires, and placed a designated box for questionnaire submission at each facility. The questionnaire guaranteed anonymity, and respondents' agreement to participate in the study was inferred from their responses.

### Analytical methods

The questionnaire results were quantified by the participants' self-evaluation of their ALS clinical care practice experience, which was rated as "1: positive" or "2: negative". Regarding their motivation to continue providing clinical care for ALS patients, the participants chose one of the following responses: "1: I agree, 2: I somewhat agree, 3: I am neutral, 4: I somewhat disagree, 5: I disagree." The Fisher's exact test was used to assess categorical data, while statistical significance was set at  $p < 0.05$ . Statistical calculations were performed using a personal computer with the Windows version of EZR [6]. Overall, we examined the correlations between: "years of medical experience" and "self-evaluation of ALS clinical care practice experience", and that between "years of medical experience" and "motivation to continue ALS clinical care" using the Kruskal-Wallis test. Likewise, the Kruskal-Wallis test was used to assess the correlation between "years of ALS medical experience" and "self-evaluation of ALS clinical care practice experience," that between "years of ALS medical experience" and "motivation to continue ALS clinical care." Furthermore, the correlation between "self-evaluation of ALS clinical care practice experience" and "motivation to continue ALS clinical care" was analyzed using the Fisher's exact test.

### Ethical considerations for survey respondents

This study was approved by the Tokai University School of Medicine Clinical Research Review Committee (approval no. 19R-290). Along with the questionnaire, participants were provided 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 to prevent the identification of individuals.

## RESULTS

### Research participants

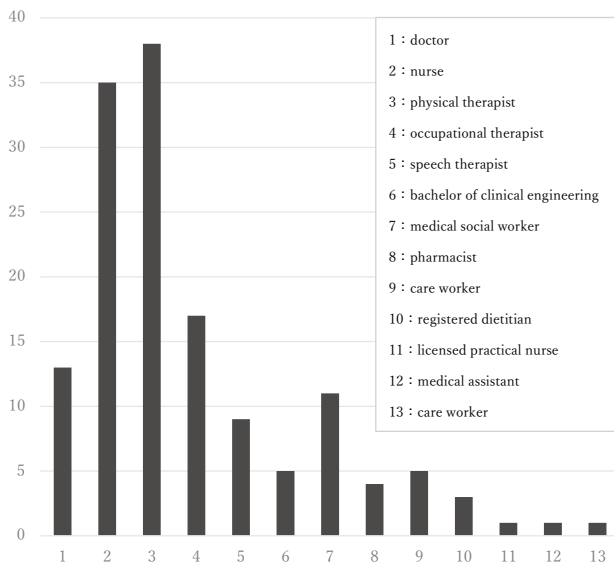
Patients who participated in ALS treatment in three hospitals (A, B, and C) in the western region of Kanagawa Prefecture, performing multidisciplinary medical care, and met the eligibility criteria were enrolled. Questionnaires were distributed to 269 respondents of whom 164 (response rate: 60%) completed the questionnaires. Of these, 143 (valid response rate: 53%) were included in the analysis. Responses that lacked information on clinical care practices, care practice locations, number of current and past ALS patients treated, and the number and duration of ALS patient visits per day were deemed invalid and excluded from the study.

**Occupational distribution**

The valid respondents comprised 13 physicians (9%), 35 nurses (24%), 38 physical therapists (PT) (27%), 17 occupational therapists (OT) (12%), and 9 speech therapists (ST) (6%) in the rehabilitation domain. Moreover, five clinical engineers (3%), 11 medical social workers (MSWs) (8%), four pharmacists (3%), five care workers (3%), and three registered dietitians (2%), in addition to one licensed practical nurse, one medical assistant, and one care worker (1% each) were also included. The total number of PT, OT, and ST in the rehabilitation domain was 64, accounting for 45% of the total respondents (n = 143). Considering the voluntary nature of all questionnaire responses, a high proportion of medical professionals in the rehabilitation domain were interested in participating. Nurses comprised the highest proportion of the respondents, followed by physicians, MSWs, and care workers. A summary of these results is shown in Fig. 1.

**Attribute distribution of participants**

Table 1 presents the demographic characteristics of the participants. The median age of the respondents was within the third decade of life. The median duration of medical practice was 13 years, whereas the median exposure to ALS was 5 years. The participants' ages ranged from the second to the sixth decades, with the third decade being the most prevalent. A two-year discrepancy was observed between the duration of medical practice and ALS exposure, particularly among physicians who rotated between various departments before selecting their specialty after licensure.



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

Moreover, nurses and rehabilitation staff commonly undergo inter-departmental transfers, contributing to individual variations in the duration of medical practice and exposure to ALS.

**Response rate**

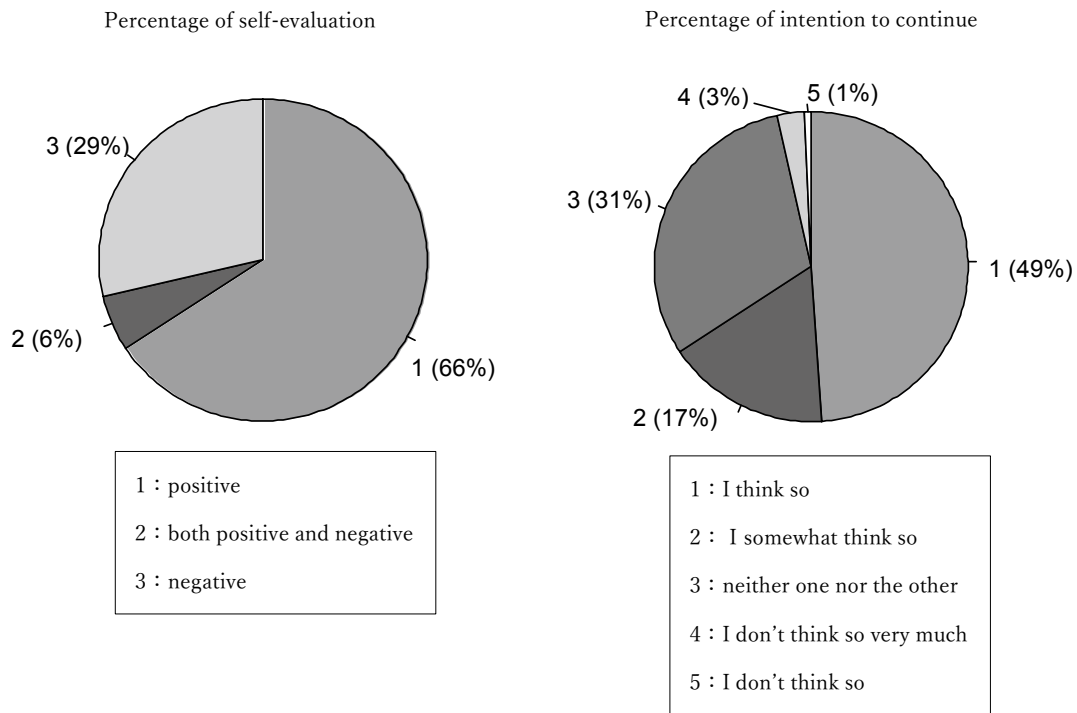
Of the 143 respondents, 66% reported a positive self-assessment of their ALS clinical care practice experience, 5% had a mixed evaluation, and 29% had a negative evaluation. Approximately 49% of responders responded either “strongly agree,” or “somewhat agree”; 16.8% “neither agreed not disagree”; 30.8% “somewhat disagree”; 2.8%, and 0.7% of the respondents who strongly disagreed, respectively, expressed their intention to continue ALS clinical care (Fig. 2).

**Approval**

For the “self-evaluation of ALS clinical care practice experience”, in addition to “positive” and “negative” answers, several multidisciplinary medical professionals responded with “both positive and negative” answers. Therefore, the evaluation items were “1: positive, 2: both positive and negative, 3: negative”. Of the 143 respondents, the majority of multidisciplinary medical professionals who reported their experiences as “positive” or “both positive and negative” expressed their intention to continue in ALS clinical care. Among medical professionals who rated their experiences as negative, only one indicated that they did not plan to continue. A significant association was observed between “self-evaluation of ALS clinical care practice experience” and “intention to continue ALS clinical care” according to the results of Fisher’s exact test (p = 0.0008) (Table 2). Further, the effect of “years of medical experience” on “self-evaluation of ALS clinical care practice experience” (1: positive, 2: both positive and negative, 3: negative) was examined using the Kruskal-Wallis test, revealing a significant difference between the groups (p = 0.0086). Furthermore, when the p-value adjustment method was applied using Holm’s procedure, a significant difference was observed in the median “years of medical experience” between medical professionals who rated their experience as “positive” or “negative” and those who had “both positive and negative” self-evaluations (p = 0.017). The effect of “years of medical experience” on “intention to continue ALS clinical care practice experience” (1: I think so, 2: I somewhat think so, 3: neither one nor the other, 4: I don’t think so very much, and 5: I don’t think so) was also examined using the Kruskal-Wallis test. No significant differences were observed between the groups (p = 0.245). The effect of “years of ALS medical experience” on “self-evaluation of ALS clinical care practice experience” was further analyzed

**Table 1** Characteristics of the research participants (survey respondents) (n = 143)

	average	Universal standard deviation	0%	25%	50%	75%	100%
Age			20s	20s	30s	40s	60s
Years of medical experience (years)	14.3	9.7	1	6.5	13	20	41
Years of ALS medical experience (years)	7.9	8.5	0.16	2	5	10	41



**Fig. 2** The percentage of self-evaluation of ALS clinical care practice experience, and percentage of medical professionals who expressed intent to continue ALS clinical care, as assessed from the effective responses of all multidisciplinary medical professionals (n = 143).

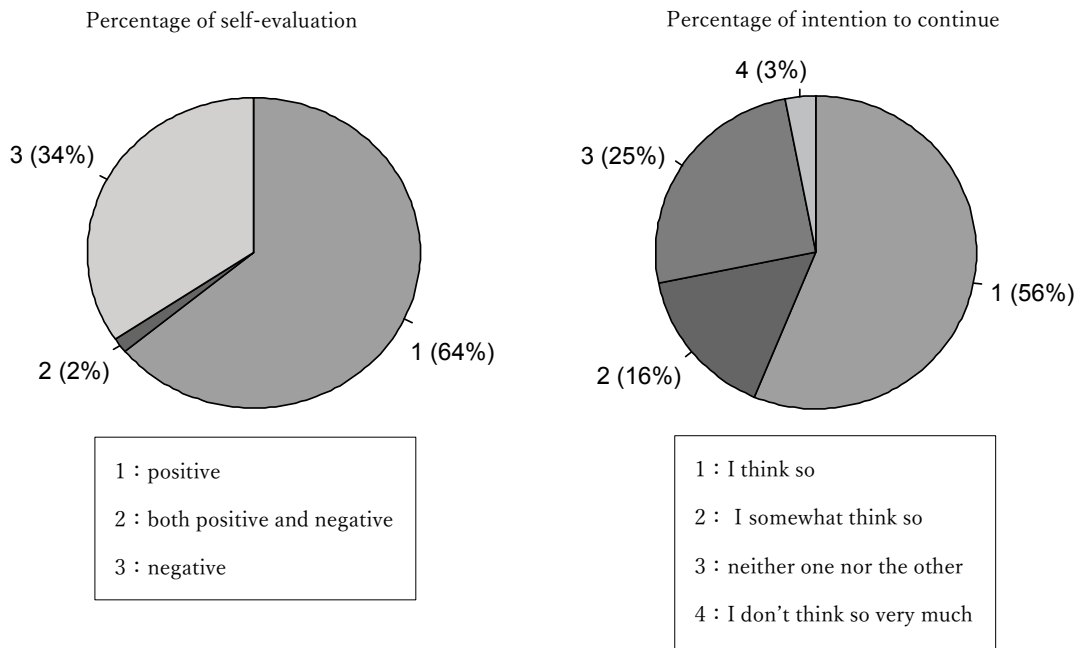
**Table 2** Correlation between “self-evaluation of ALS clinical care practice experience” and “sustaining to continue ALS medical care” (n = 143)

Self-evaluation of ALS clinical care practice experience	sustaining to continue ALS clinical care				
	I think so	I somewhat think so	Neither one nor the other	I don't think so very much	I don't think so
Positive	56 80%	13 54.2%	25 56.8%	0 0%	0 0%
Both positive and negative	4 5.7%	2 8.3%	2 4.5%	0 0%	0 0%
Negative	10 14.3%	9 37.5%	17 38.6%	4 100%	1 100%

using the Kruskal-Wallis test, revealing a significant difference between the groups ( $p = 0.031$ ). The effect of “years of ALS medical experience” on “intention to continue ALS clinical care” was also analyzed using the Kruskal-Wallis test; however, no significant differences were observed between the groups ( $p = 0.48$ ). The associations and distributions are visually represented using histograms. When the “years of medical experience” and “self-evaluation of ALS clinical care practice experience” were compared the results revealed that medical professionals with fewer years of medical experience tended to rate their experience as “positive.” The most frequent response was five years of medical experience, which was provided by 18 medical professionals. As shown in the graph, the proportion of positive self-evaluations gradually decreased as the number of years of experience increased. Mixed self-evaluations were notable in those with 15–35 years of experience, peaking at 20–30 years of medical experience, whereas no responses were received for those with 5–10 years or over 40 years of experience. The highest frequency

of negative self-evaluations was observed among participants with 20 years of medical experience.

Next, we analyzed the answers from the rehabilitation staff (Fig. 3), who had the largest number of occupations (Table 3). The Fisher’s exact test ( $p = 0.0034$ ) revealed a significant relationship between “years of ALS medical experience” and “intention to continue ALS clinical care (Table 4). In addition, the effect of “years of medical experience” on “self-evaluation of ALS clinical care practice experience” was examined using the Kruskal-Wallis test, but no significant difference was observed ( $p = 0.322$ ). The effect of “years of medical experience” on “intention to continue ALS clinical care” was further examined using the Kruskal-Wallis test, yielding no significant correlation between groups ( $p = 0.664$ ). Further, the effect of “years of ALS medical experience” on “self-evaluation of ALS clinical care practice experience” was examined using the Kruskal-Wallis test, and a significant difference was observed ( $p = 0.0263$ ). Furthermore, when the p-value adjustment method was applied using Holm’s proce-



**Fig. 3** Percentage of self-evaluation of ALS clinical care practice experience, and percentage of medical professionals who expressed intent to continue ALS clinical care, as assessed from the responses of the rehabilitation staff (n = 64).

**Table 3** Characteristics of participating rehabilitation staff (survey respondents) (n = 64)

	average	Universal standard deviation	0%	25%	50%	75%	100%
Years of medical experience (years)	12.1	8.6	1	5	10	17	34
Years of ALS medical experience (years)	9.4	7.4	0.16	2	5	10	32

**Table 4** Correlation between “self-evaluation of ALS clinical care practice experience” and “sustaining to continue ALS medical care” among rehabilitation staff (n = 64)

Self-evaluation of ALS clinical care practice experience	sustaining to continue ALS clinical care					
	I think so	I somewhat think so	Neither one nor the other	I don't think so very much	I don't think so	I don't think so
Positive	29 80.6%	6 60%	6 37.5%	0 0%	0 0%	0 0%
Both positive and negative	1 2.8%	0 0%	0 0%	0 0%	0 0%	0 0%
Negative	6 16.7%	4 40%	10 62.5%	2 100%	0 0%	0 0%

measure, a significant difference was observed in the median “years of ALS clinical care practice experience” between rehabilitation medical staffs who rated their experience as “positive” or “both positive and negative” self-evaluations ( $p = 0.034$ ). The effect of “years of ALS medical experience” on “intention to continue ALS clinical care” was further examined using the Kruskal-Wallis test; however, no significant associations were observed ( $p = 0.76$ ). Regarding the association and distribution, the “self-evaluation of ALS medical experience” was rated as “both positive and negative” after 20 years of ALS medical experience.

### DISCUSSION

This study aimed to examine the association between duration of medical experience and self-appraisal. We examined the overall responses of multidisciplinary medical professionals and rehabilitation medical practitioners, observing the same trend for the number of “years of ALS medical clinical care experience” and “self-evaluation of ALS clinical care.” In the questionnaire, two options were provided (positive and negative) but many of the professionals responded by writing “both positive and negative” in the answer column. This was an unforeseen but valuable insight into the feelings of medical professionals.

Medical professionals with up to 5 years of medical experience demonstrated a significant inclination to rate their experience as positive or negative. Although the proportion of medical professionals who rated it negatively peaked at 20 years of age, positive ratings still outnumbered negative ratings. After 15 years of medical experience, a mix of both positive and negative appraisals became evident, with this response most frequent in those with 20–30 years of experience. The reason for this trend was that, by increasing the duration of their medical experience, medical professionals were able to accumulate expertise in the medical field, reflect on their practice, and make self-appraisals. Moreover, they gained invaluable experience from their daily interactions with ALS patients, and demonstrated that they had amassed many experiences that could be appraised as “both positive and negative.”

Takushima *et al.* conducted a study to evaluate the quality of nursing practice by comparing it with years of clinical experience and age [7]. Overall, a significant difference was found between nurses with less than 3 years of experience and those with more than 10 years of experience. Additionally, they inferred that this skill was acquired through the accumulation of experience. Nanke *et al.* also found that “care that prepares the living environment” and “facing patients” with nursing practice skills in expert nurses were strongly correlated with more than 10.1 years of clinical experience [8]. Although these previous studies were conducted only in nurses, we hypothesized that multidisciplinary medical professionals must develop the ability to self-appraise after 10 years. Given that the option “both positive and negative” in self-appraisal appeared after 15 years of medical experience, we inferred that medical professionals with over 10 years of experience had acquired the ability to self-appraise their clinical practice while enhancing their practical skills.

Additionally, we examined the association between self-evaluation and the intention to continue ALS clinical care. Approximately 96.6% of medical professionals expressed their intention to continue ALS clinical care, even those who rated their experience as negative, chose “I think so,” “I somewhat think so,” or “neither one nor the other.” The remaining 3.5% of the medical professionals who selected “I don’t think so very much” or “I don’t think so” reflected on their clinical care practice in the questionnaire, and expressed their commitment to enhance ALS care by acknowledging negative self-evaluations. Some medical professionals explicitly stated no intention to continue sharing experiences involving a patient with juvenile ALS who understood their symptoms and visited an outpatient clinic, but whose thoughts remained unknown. Owing to the anonymous nature of the free-entry format, a detailed exploration of this experience was not possible. However, this experience underscores the sincere engagement of medical professionals with ALS patients and their earnest efforts to understand them. For nurses, which were among medical professionals who responded in this study, Kudo *et al.* argued that professional commitment and self-fulfillment are integral to the preservation of lives and health. Nurses who are satisfied with their profession tend to stay in their workplace, displaying a strong determination to contribute to society by showcasing their expertise [9].

Ando *et al.* further investigated the relationship between burnout and personal attributes among nurses caring for patients with intractable neurological diseases, which was related to the number of years of experience with intractable neurological diseases. This past study suggested that the unique stressors associated with the care of patients with intractable neurological diseases may affect burnout, and that burnout occurs earlier than in other departments. However, in the present study, many multidisciplinary medical professionals indicated their intentions to continue ALS treatment. This sentiment is shared among other medical professionals, all medical professionals hold profound respect for their patients and continually contemplate ways to enhance clinical care by applying their expertise. The multidisciplinary medical professionals involved in this study were affiliated with hospitals and had extensive experience. Schein discussed the need for individuals to reconcile work situations that contribute to personal growth as a fundamental aspect of career development [10]. In particular, Schein emphasizes the challenges of evaluating one’s own reactions and coping strategies, while diagnosing oneself. Gaining insight and understanding is of paramount importance in constructive coping. Schein argued that self-insight arises from accumulating various experiences and that awareness of the impact of one’s attitudes is crucial for self-evaluation and learning. With more than 15 years of medical experience, Schein has cultivated a variety of experiences a wealth of experiences through continuous engagement in clinical care within their fields. Medical professionals can evaluate themselves, value all relationships, while evaluating themselves both positively and negatively. The willingness to continue with ALS care despite a self-assessment of experience as negative reflects a profound respect for patients.

This study revealed the commitment of medical professionals to persist in the treatment of ALS, despite rating their experiences as adverse. These professionals leverage diverse clinical care experiences with patients with ALS as catalysts to reflect on their engagement. Medical care is defined as “the treatment of disease by medical techniques” [11]; however, this approach is challenging in patients with intractable diseases. The Japanese government defined the optimal framework for medical care under such conditions under the Intractable Diseases Law. Healthcare professionals must therefore endeavor to accommodate the individual needs of patients with ALS. To achieve this, we posit that fostering motivation through self-awareness, rather than relying solely on critical self-assessment of the current quality of medical care, is imperative. By attaining self-awareness, it is feasible to transform negative experiences into valuable insights and foster a sustained dedication to ALS medical care.

#### **Limitations and challenges of the research**

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 of these centers accepts patients with ALS and provides specialized medical care; however, as they are not wards that specialize in caring for patients with ALS, the frequency of interaction with patients with ALS, which is a rare disease,

is less than that in hospitals and wards that specialize in intractable diseases. In the future, it will be necessary to conduct surveys to investigate the attitudes of medical staff at specialized medical institutions. Given the influence of sociocultural context on healthcare provision in each region, it is imperative to broaden the scope and conduct further surveys in the future to validate and expand upon our findings. To elucidate the commonalities and discrepancies among medical professionals, substantial data categorized according to professional roles should be collected and examined for possible correlations. Furthermore, as patients are the ultimate recipients of healthcare, the significance of this study will be enhanced by complementing the survey of patients and incorporating qualitative research methods, such as interview content, in addition to quantitative analysis to construct a “mixed study.”

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#### 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