

Intention Formation Process for the Use of Tracheostomy and Invasive Ventilation in Patients with Amyotrophic Lateral Sclerosis

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Abstract

Background: Little is known about the intention formation process regarding the use of tracheostomy and invasive ventilation (TIV) in amyotrophic lateral sclerosis (ALS) patients in the course of disease progression. **Objective:** To clarify the intention formation process in the use of TIV in ALS patients for the purpose of providing decision-making support. **Methods:** We conducted a follow-up study of 14 patients using semi-structured interviews, participant observation, and medical records review. **Results:** The patients' various intentions regarding the use of TIV were formed as their symptoms progressed (e.g., declining motor, swallowing, and respiratory functions). Other factors influencing their decision were their considerations, such as their ability to communicate after receiving TIV treatment, the degree of support they would receive from professionals after TIV treatment, palliative care for physical distress, value of life after TIV treatment, and to what degree they would be a burden on their families. **Conclusion:** Patients' intentions regarding the use of TIV were diverse and changeable. The decision of whether or not to use TIV was made out of conviction as well as considering individual experiences of symptom progression and quality of life after TIV use.

Keywords

Amyotrophic Lateral Sclerosis, Tracheostomy and Invasive Ventilation,

1. Introduction

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease for which there is currently no cure. Patients with ALS die due to respiratory failure, usually 2 - 5 years after onset because of irreversible progression of symptoms such as muscle weakness [1]. Noninvasive ventilation (NIV) and tracheostomy and invasive ventilation (TIV) are used to treat respiratory disorders and can improve survival time [2] [3] [4]. The use of NIV or TIV has been reported to improve the prognosis of ALS patients [5] [6].

The TIV utilization rate in ALS patients is around 0.5% - 30% worldwide [7], and many patients, including Japanese, do not undergo TIV at present [7]. Factors affecting the varying rates of TIV use in patients with ALS are due in part to differences in health insurance systems [8], religious views, and cultures [8]. Patients also have concerns about the burden of care on families [9], symptom progression [9] [10], and the impossibility of withdrawal after mechanical ventilator use [11], which affect their assessment of TIV use.

Decision-making is a process in which one selects, from the available options, a solution to a problem [12]. ALS patients need to consider the options and eventually make a decision about TIV use. There has been a tendency to emphasize on only the final decision, *i.e.*, accept or decline, in these patients [8] [9] [13] [14] [15] [16]. On the other hand, it has been shown that their decision could change over time [15] [16]. The thought process behind the decision about TIV that takes place over the course of disease progression, and when the decision is formed and changed, however, is unknown. Furthermore, factors that influence intention formation also are unknown. This knowledge is important for the health care professional who provide care and treat ALS patients who consider TIV use.

The aim of this research was to clarify how ALS patients form and change their intention about TIV use, and what factors influence their intentions.

2. Methods

2.1. Design

We conducted a follow-up study from February 2016 to January 2017 in patients with ALS. We used case study research design [17], *i.e.*, gathering and examining information from multifaceted viewpoints and integrating it into a theoretical framework, to conduct a survey. We also conducted based on the qualitative approach and made use of semi-structured interviews, participant observation, and a medical records review. The survey was conducted at two institutions: University Hospital A in Tokyo, Japan, which mainly aims to diagnose and treat ALS patients in inpatient and outpatient settings, and Outpatient Clinic B in Chiba,

Japan, which specializes in neurology and internal medicine and provides visiting care support to ALS patients.

2.2. Participants

We used purposive sampling [18] to recruit patients of varying levels of functioning, based on the ALS Functional Rating Scale-Revised (ALSFRS-R) [19] [20], which measures decline in physical functioning specific to ALS. The highest possible score is 48 points, as higher would indicate independence in activities of daily living.

Criteria for inclusion in the research were as follows: 1) adult patients 2) diagnosed with definite ALS or probable ALS according to the revised El Escorial criteria [21], 3) the patients who are not using TIV, and 4) having no significant cognitive dysfunction or mental disorders. We recruited patients who were hospitalized or who visited the outpatient clinic according to inclusion criteria. Participants who decided to introduce TIV within the research period were withdrawn from the research.

2.3. Data Collection

2.3.1. Interviews

We used semi-structured interviews [18] to outline the themes of experiences from the diagnosis of ALS to the present and the concerns about TIV use. Interviews were conducted each time the participants were hospitalized or visited one of the institutions during the research period. The corresponding author (WS) asked participants open-ended questions. Example questions were as follows: “What has happened since you were diagnosed with ALS?”; “What did you think about TIV use when diagnosed with ALS?”; “Have your thoughts about TIV use changed?”; “What do you think about changing your thoughts?” These questions were used as a guide for the first interview, which was developed by the corresponding author. New questions were added to the interview guide according to the data analysis, which was ongoing at that time. The face-to-face interviews lasted 30 to 60 minutes in a private room in each institution and were digitally recorded and transcribed verbatim. In cases in which participants had dysarthria, written communication or communication boards were used.

2.3.2. Medical Records

The following information was collected from medical records: 1) basic personal information (age, family structure), 2) medical history (onset data, diagnosis data, changes in symptoms, course of ALSFRS-R, experiences of and reasons for hospitalization or emergency outpatient consultation, presence of dyspnea, presence of oxygen therapy, presence of NIV, presence of TIV, and performing suction). Information on participants’ intentions of TIV use, TIV-related questions, and decisions on TIV use were also collected. To determine results, the information collected from medical records was verified by the physicians or nurses in charge.

2.3.3. Participant Observation

The corresponding author observed and noted details of the medical care received, as well as the verbal expressions and behaviors of the participants during their outpatient visits or hospitalizations. Participant observation was used to supplement of the interview. The corresponding author took the position of observer, *i.e.*, as a participant [18] not participating in medical treatment or nursing.

2.4. Data Analysis

In order to clarify the intention formation process of TIV use in ALS patients, we conducted a time-series analysis [22]. The interview data were analyzed in individual and overall analyses. Then the interview data and medical records data were integrated. We followed a series of steps in our analysis. First, in the individual analysis, we focused on any indications of a change in intention regarding the use of TIV and thoughts about TIV, as well as changes in symptoms, from each participant's transcripts and coded them in short sentences. Second, in the overall analysis, codes based on the results of the individual analyses collectively were classified the same way, and then subcategories were created.

An analysis of medical records data was conducted simultaneously with the individual analysis. The medical records data, specifically past records by physicians and nurses, were evaluated in chronological order to determine ALSFRS-R scores and the progression of symptoms, and the descriptive process of TIV use was elucidated by an individual analysis. The subcategories created in the overall analysis were derived from combining the results of the analysis using medical records data and sorting them as common patterns emerged. Categories sharing the same features were combined into an aspect. Then we used the results of the interview and analysis of the medical record to schematize the relationship between aspects and categories.

2.5. Rigor

Reliability was evaluated based on the Lincoln and Guba criteria of trustworthiness [23]. During the interviews, we assessed the agreement between the participants' intent and the researchers' interpretation by asking them as much as possible. We also received evaluations of our data collection, data analysis, and results from five experts in the fields of ALS nursing, neurology, and qualitative research. For transferability purposes, we tried to make our descriptions clear so that the reader can judge whether or not the results of this research are transferable to different settings. To establish dependability, we undertook audits from the supervisor and tried to clearly describe the research process. To establish confirmability, we recorded the research in writing to show evidence of what we accomplished in the research.

2.6. Ethical Considerations

This research was conducted with the approval of the ethics review committee of

Tokyo Medical and Dental University Medical Hospital (approval number M2000-2323). In consideration of the possibility of the progression of dysarthria, we conducted a survey to evaluate physical conditions to be administered by the attending physicians or nurses. All participants were informed that there was no disadvantage of participation/nonparticipation/refusal to participate in this research. This research was conducted with the written consent of the participants.

3. Results

3.1. Participant Characteristics

There were 14 patients (University Hospital A: 10 patients, Outpatient Clinic B: 4 patients) who agreed to participate in the research and were able to start the investigation. No participants were withdrawn, as none underwent TIV during the research period. All participants' background data are shown in **Table 1**.

Eleven of the 14 participants (79%) were male and 3 (21%) were female. The median age was 61 years (range: 32 - 79 years). At the time of the first interview, the median number of months from the diagnosis of ALS was 11 (range: 3 - 178 months). The mean \pm SD number of interviews per participant was 3.5 ± 1.2 , for a total of 49 interviews. The ALSFRS-R scores at the first interview were as a

Table 1. Demographic characteristics of participants.

ID	Sex	Age	Duration (months)			ALSFRS-R ^a		Length of interview (min)	Attendant caregivers ^b		Communication tools ^c
			From onset to diagnosis	From diagnosis to first interview	Total interview investigation	At first interview	At last interview		At first interview	At last interview	
1	Male	74	49	13	10	44	42	76	0	0	Verbal
2	Male	32	34	9	5	43	43	200	0	0	Verbal
3	Male	62	115	23	7	21	19	120	1	1	Verbal
4	Male	70	4	9	3	35	34	96	0	1	Verbal
5	Male	54	18	9	3	34	30	60	1	1	Verbal
6	Male	57	11	5	5	42	35	158	0	1	Verbal/AAC
7	Male	62	8	4	4	42	25	59	1	1	Verbal
8	Male	65	9	27	4	28	27	101	1	1	Verbal
9	Male	64	9	7	2	31	25	80	1	1	Verbal
10	Female	56	10	33	4	15	6	40	1	1	AAC
11	Female	61	22	57	10	24	15	280	1	1	Verbal
12	Female	79	71	3	4	23	16	220	1	1	Verbal
13	Male	55	14	18	3	17	10	90	1	1	Verbal
14	Male	60	12	178	2	8	8	100	1	1	AAC

a. ALSFRS-R: ALS functional rating scale; b. 0: Absence, 1: Presence; c. AAC: Augmentative and Alternative Communication.

total of 49 interviews. The ALSFRS-R scores at the first interview were as follows: four participants scored 40 - 48, three participants scored 30 - 39, four participants scored 20 - 29, two participants scored 10 - 19, and one participant scored less than 10. Seven of these participants were classified as independent (ALSFRS-R score 30 or higher).

3.2. Interview Data

We identified 102 codes, 29 subcategories, and 8 categories. These were integrated into one of two aspects: intentions regarding the use of TIV, and factors affecting intentions regarding the use of TIV. Each of these is described below.

3.2.1. Intentions Regarding the Use of TIV

Intentions regarding the use of TIV were composed of six categories, and changed as symptoms progressed. The six categories are shown below.

A: *I am not sure whether or not to use TIV now.*

Of all of the participants, 11 (ID: 1, 3, 4, 5, 7, 8, 9, 10, 11, 12, 13) said that at the time of their diagnosis they were not sure whether or not they would use TIV in the future, and could not think about it. Their concerns regarding TIV use were uncertain and vague.

“(On diagnosis) I heard from my physician, there are individual differences in ALS. It is difficult to predict the speed of the progress now. So my family and I talked to each other. It may slightly progress but I think there is no problem in daily life in 5 or 10 years, because I trained my body enough.” (ID: 13)

B: *I do not want to think about whether or not to use TIV.*

Six participants (ID: 3, 7, 8, 12, 13, 14) said they did not want to think about whether or not to use TIV. They felt uneasy about any deterioration in their condition that could lead to the use of TIV and were aware of the progress of their symptoms. Therefore, in order to eliminate anxiety in their everyday lives, these participants intentionally did not think about TIV.

“From looking at books and the internet, it is written that muscles will be worse. I have not progressed yet, but I think this situation means progression of ALS. I’m depressed when I think about TIV; I do not want to think about it.” (ID: 7)

C: *I want to use TIV, but I have not decided it.*

Two participants (ID: 12, 13) said that they would like to use TIV, but they did not want to commit to TIV use yet in order to not regret their decision. They needed more information about TIV use and consent from family members about TIV use before they finalized their decision.

“When I came to the hospital, I was shocked by the sudden hospitalization and tracheotomy. In the end it will be comfortable; I would like to use TIV. But I was anxious just the same. If possible, I wanted time to think about using TIV.” (ID: 12)

D: *I do not want to use TIV, but I have not decided not to do it.*

Ten participants (ID: 2, 4, 5, 6, 7, 8, 9, 10, 11, 14) said that they would not like

to use TIV, but that it was not a final decision. Many of the participants were trying to decide whether to use TIV based on the information they had available to them on the advantages and disadvantages of the treatment, and based on the progression of their symptoms.

“After TIV, it is almost impossible to move all the way, in the end with the progression, I can move only my eyes, right? So, I do not think I want to live until that point. However, now I will keep my muscles while they are functioning. I am stretching them. I do what I can do now to change.” (ID: 6)

E: I have already decided not to use TIV.

Participant (ID: 14) had previously already decided not to use TIV. The participant made the decision when the physician told him that his respiratory condition had worsened. A family member of the participant agreed with his opinion not to use TIV.

“My physician asked my intention about TIV, I said I decided not to use TIV. And my wife also agreed with my decision, and that became a couple’s will.” (ID: 14)

F: I have already decided to use TIV.

Two participants (ID: 12, 13) said that they had already decided to use TIV. The participants had limited respiratory function. They had already discussed their decision with family members, friends, and health care professionals.

“I was thinking about whether to use TIV or not. I heard from my physician about health care professionals who care for me and my family member, after TIV, and then I came to decide to use TIV.” (ID: 12)

3.2.2. Factors Affecting Intentions Regarding the Use of TIV

The participants’ intentions regarding the use of TIV was found to be influenced by experiences of symptom progression which many participants talked about, and considering what their lives would be like after using TIV. This is explained in more detail below.

A: Experiences of symptom progression

Experiences of symptom progression were composed of four subcategories. Participants were aware of the progression of their symptoms due to a decrease in motor, swallowing, and respiratory functions and loss of respiratory function. Declining motor function was evident to the participants when they had difficulty raising their upper and lower limbs, going up and down stairs, and stumbled while walking on flat ground. Declining swallowing function was evident to the participants when they had difficulty swallowing and painful feelings due to aspiration, and felt in danger of choking to death. Declining respiratory function was evident to the participants when they coughed repeatedly or started oxygen therapy or NIV for dyspnea. Finally, participants were told by a physician that their respiratory functioning was limited (**Table 2**).

The experience of symptom progression had a pattern in which the speed of progression felt fast and one in which it felt slow. The participants who felt that the progression was fast were unable to adapt to the speed of the symptoms’

Table 2. Experience of symptom progression and sample quotations.

Symptom progression	Sample quotations
Declining motor function	I couldn't turn over in my bed. When I woke up, I was so scared of the situation as I could not move. (ID5; 8 months after diagnosis; ALSFRS-R: 34) Because I fall when I try to get up. Even when I wake up in the morning, I cannot stand up without my wife's help. I'm good, just sitting on a wheelchair, but it has become too difficult to walk to the toilet. (ID9; 7 months after diagnosis; ALSFRS-R: 31)
Declining swallowing function	(Coughing while speaking) Perhaps, it is time to use TIV as I cannot eat. But in my case, I believe that the reason I may die is not because my limbs do not move, but because of pneumonia. (ID6; 7 months after diagnosis; ALSFRS-R: 38) It went down the wrong way. Although I recovered by suction, I choked on my saliva. I was in a lot of pain. (ID10; 27 months after diagnosis; ALSFRS-R: 15)
Declining respiratory function	Last week, my SpO ₂ level drastically decreased, and my husband called a visiting doctor. I couldn't stop coughing up sputum, and it seems to be getting worse. I started using oxygen. With oxygen, SpO ₂ was 92%, 94%, without oxygen or moving on toilet, SpO ₂ was 85%. It was a sudden event. (ID11; 67 months after diagnosis and receiving 2 L of oxygen; ALSFRS-R: 15)
Loss of respiratory function	Everyone's life has a limit. As for me, it looks like I am at my limit now. (ID12; 4 month after diagnosis and using NIV ^b for 24 h; ALSFRS-R: 23) I just could not move at all and I had difficulty in breathing. My physician said it is time to decide what to do. So, in this situation, I would like to be hospitalized soon. (ID13; 18.1 months after diagnosis, after using NIV for 24 h; ALSFRS-R: 10)

a. ALSFRS-R: ALS functional rating scale; b. NIV: Noninvasive ventilation.

progression, and felt symptom progression to be unstable. The participants who felt that progression was slow were able to understand the progression of symptoms, change the means of transport and the living environment appropriately, and felt that symptom progression was stable.

B: Considerations regarding quality of life after TIV

The intention of TIV use was influenced by the following consideration: "Whether or not there is a guarantee of good living even after TIV." It consisted of five subcategories, and its contents were related to the ability to communicate after TIV, the degree of support offered by professionals after TIV, palliative care for physical distress, the value of life after TIV, and the burden on their family members. There was no regular order of these ideas that participants used to consider the quality of life after TIV. The five subcategories were ideas that were being considered repeatedly and continually (Table 3).

The result of considerations regarding quality of life after TIV had a pattern, either unconvinced or convinced. Participants showing the unconvinced pattern felt strong anxiety about symptom progression and had uncertain and vague concerns regarding TIV use. Conversely, participants showing the convinced pattern were actively trying to resolve the question of whether or not to use TIV. Their method was to gather information through discussions with family members and professional staff.

3.3. Medical Records Data

In the survey of medical records, analysis of commonalities in symptom progression of each participant was carried out. Even though the participants'

Table 3. Considerations regarding quality of life after TIV^a and sample quotations.

Contents of Considerations regarding quality of life after TIV	Sample quotations
Ability to communicate after TIV	At present, I don't want to use TIV. Well, I think that I want to talk, but I do not know whether I can after using TIV. (ID2; 9 months after diagnosis; ALSFRS-R ^b : 43) If I use TIV, I cannot speak... (says nothing more). I lose my voice, right? Once I used my eyes to communicate. I did not seem to be able to move my eyes either. Even now, I do not understand it. (ID11; 65 months after diagnosis; ALSFRS-R: 18)
Degree of support offered by professionals after TIV	I am worried about my family's anxiety and my family's life after using TIV. I hope the nurse can join us in addition to my family, if possible. (ID12; 4 months after diagnosis; ALSFRS-R: 23) In future, if I use TIV, someone has to care for me all the time. Of course, I have heard that there will be professionals to look after me. Can they begin support soon, like tomorrow? I don't know if it's possible. (ID13; 18 months after diagnosis; ALSFRS-R: 17)
Palliative care for physical distress	After using TIV, the difficulty I had with breathing finally stopped, so I thought it was good that I used TIV. (ID12; 4 months after diagnosis; ALSFRS-R: 23) It's not clearly defined, as it's not good to use TIV (even if I use a respirator). Because my disease will continue to progress, I do not know what to say... (ID11; 65 months after diagnosis; ALSFRS-R: 18)
Value of life after TIV	If I come to the hospital with a mechanical ventilator machine behind the wheelchair and my wife pushing the wheelchair, we will not have fun. Would you? (ID4; 10 months after diagnosis; ALSFRS-R: 36) As for me, sometimes, if I am just bedridden, there is no way to use TIV. (ID9; 7 months after diagnosis; ALSFRS-R: 31)
Burden on family	At this time, death with dignity is not possible. If I use TIV, it means I will impose endless invisible burden on family members. At first, it might be nice, but eventually my family members will start to think "Why did you choose TIV?" I wonder if the ventilator tube can be removed while I am not aware, for example, during night-time. It is sad to make them think like that. (ID14; 178 months after diagnosis; ALSFRS-R: 9)

a. TIV: tracheostomy and invasive ventilation; b. ALSFRS-R: ALS functional rating scale.

symptoms differed at the time of diagnosis, the order of decline in, first, motor function, and then swallowing function, followed by respiratory function, and, finally, the loss of respiratory function, were the same.

Declining motor function was seen in 12 participants (ID: 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14) who experienced a fall a median of 8.5 months (range: 1 - 60 months) after their diagnosis. Indicating declining swallowing function, experiences of aspiration were experienced by nine participants (ID: 6, 7, 8, 9, 10, 11, 12, 13, 14) a median of 26 months (range: 2 - 61 months) after their diagnosis. Declining respiratory function was seen in seven participants, who experienced difficulty breathing (ID: 8, 9, 10, 11, 12, 13, 14) a median of 27 months (range: 3 - 67 months) after their diagnosis. A loss of respiratory function occurred in three participants (ID: 12, 13, 14) a median of 19 months (range: 4 - 66 months) after their diagnosis. Moreover, three participants made a decision about the use of TIV after experiencing the loss of respiratory function.

3.4. Intention Formation and Factors Affecting Intention Formation on TIV Use

The integration of the interview survey and the medical records survey revealed

that a process was formed by the experience of the symptom progression and considerations regarding quality of life after TIV. The relationship between the order of progressing symptoms, changes in intentions regarding the use of TIV, and considerations regarding quality of life after TIV were schematized (Figure 1).

At the time of diagnosis, 11 of 14 participants did not know whether or not to use TIV; three participants did not want to use TIV, but they had not decided not to do it. These intentions surrounding TIV use changed as the participants experienced their symptoms progressing: declining motor function, declining swallowing function, declining respiratory function, and the loss of respiratory function. And three participants' decisions about TIV use, both for and against, could be ultimately explained as resulting from experiences of progressing symptoms, and consideration regarding quality of life after TIV. The only time this happened was when they had experiences of losses of respiratory function. There were no participants who never changed their intention about the use of TIV from the time of diagnosis until the time of their decision.

4. Discussion

This research showed diverse and shifting attitudes regarding TIV use in ALS patients. Decisions about using/not using TIV were the results of process to convince their own accompanied by experiences of symptom progression and consideration regarding quality of life after TIV.

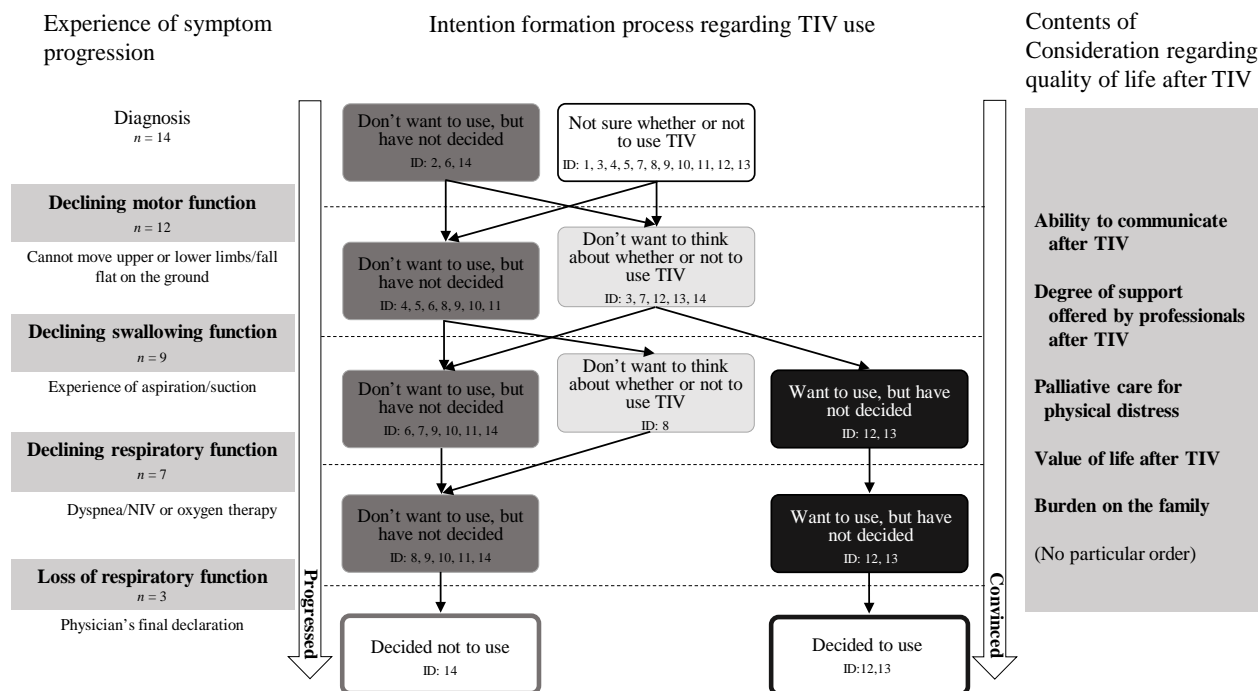


Figure 1. The structure of process in which intention is formed and factors affecting intention formation of TIV use. The left vertical axis represents experience of symptom progression after diagnosis (progression increases downward), and the right vertical axis represents contents of consideration regarding quality of life after TIV (conviction increases downward). The dashed lines in the center show when the deteriorations that are characteristic of progression (shown at left) are experienced.

convince their own accompanied by experiences of symptom progression and consideration regarding quality of life after TIV.

First of all, there were six different categories of intentions of TIV use. This indicates the diversity of ideas about TIV use in this population. In particular, there were four types of undecided intentions. The intentions surrounding TIV use in ALS patients was not limited to two types of ideas [8] [9] [13] [14] [15] [16], *i.e.*, using or not using TIV. Furthermore, the intention about TIV use changed with their symptom progression. This suggests that intentions concerning TIV use in ALS patients are not constant, and can change because of straying and conflicting about [24] [25] [26] using/not using TIV.

Second, the intentions regarding the use of TIV were formed by experiences of symptom progression. The experiences included declining motor function, declining swallowing function, declining respiration function, and the loss of respiratory function. The times when there are changes in physical function would be a trigger to consider the use of TIV. The decision regarding using/not using TIV was made only after experiencing the loss of respiratory function. ALS patients focused on their current physical function, and confirmed their intentions repeatedly when their symptoms progressed.

Third, considerations regarding quality of life after TIV indicate the imagining of a future that patients have still not experienced. Specific concerns patients expressed were the ability to communicate after TIV, the degree of support offered by professionals after TIV, the burden on family members, palliative care for physical distress, and the value of life after TIV. From these five items, we ascertained that ALS patient wished to continue to protect their dignity, as well as their own and others' security.

Finally, the decision regarding the use of TIV required a conviction resulting from experiencing symptom progression and considerations regarding quality of life after TIV. Convincing is defined as to bring to belief, consent, or a course of action [27]. The patients who were not convinced had vague ideas regarding the use of TIV, and they were anxious about symptom progression. Meanwhile, the patients who were convinced were trying to answer the question about TIV use by discussing it with family members and professionals. It was necessary for the ALS patients to have discussion with their families and medical staffs [28], as the method of gathering information, and the importance of these processes, were emphasized to support decision-making accompanied by conviction.

This research can be utilized to support decision-making concerning the use of TIV in ALS patients in the clinic setting as follows. First, through periodic observation from the time of diagnosis, using an item of decline in physical function as an indicator, it is possible to judge the timing of intention formation and the timing of change about TIV use for the patients with ALS. Second, it is possible to refer to the contents of various intentions at the time of declining physical function. Third, it is possible to establish five items regarding quality of life after TIV as a basic item of information provision.

In order to encourage self-decision regarding the use of TIV in ALS patients,

understanding the process of progressive symptoms on the part of the patient is essential. In addition, early patient education is necessary, in order to allow the patient to think about what meaning and value TIV use has for their life.

5. Limitations and Further Research

This research has some limitations. First, it used a small number of subjects from limited facilities. To generalize this result, increasing the number of subjects, lengthening the investigation period, and expanding the survey facilities would be necessary. Next, there is the possibility that the presence of family members during part of the interviews may have affected the contents of the patients' remarks. However, we tried to collect various data from many interviews on patients in different situations over the course of a 10-month follow-up study. We believe that it is meaningful to elucidate the intention formation process about the use of TIV and related factors in ALS patients. In order to provide more efficient support for decision-making about the use of TIV in patients with ALS, further research that also examines the medical staff and family members involved in the decision-making process is also needed.

6. Conclusion

Intentions about the use of TIV in ALS patients were diverse and changeable. The decision of using/not using TIV for patients with ALS was the result of the conviction process accompanied by experiences of symptom progression and consideration regarding quality of life after TIV use. Early patient education is required in ALS patients.

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