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A half-day education program for healthcare students on communication support for people with amyotrophic lateral sclerosis

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ABSTRACT

Background: Augmentative and alternative communication (AAC) requires on-going support but few studies describing AAC training for healthcare professionals were found.

Method: We developed a short-term education program on amyotrophic lateral sclerosis communication support for undergraduate students in multiple healthcare disciplines. The program comprised lectures plus practice of three AAC methods. Participants were 58 students from four courses at four Japanese universities who completed the program twice, at 6-month intervals. Effects of the program on 'Beginners' (taking the program for the first time) and 'Experienced' (repeating the course 6 months later) were evaluated using pre-test/post-test scores, number of letters transmitted in 5 min, subjective burden indicated on visual analogue scale (VAS) before and after each AAC trial, and free-text comments.

Results: An increase in scores was shown from the first to the second pre-test. Number of letters generated in 5 min was higher for the Experienced group than for Beginners with the exception of one AAC device. VAS change rate for the Kuchimoji method was lower in the Experienced group than for Beginners. Text-mining of participants' comments showed lower eyestrain reported in the Experienced group.

Conclusions: This study suggests that participants' knowledge of AAC for communication support of people with ALS was retained 6 months after completing the short training program, and hands-on AAC experience helped them develop their skills and reduce the perceived subjective burden.

KEYWORDS
Amyotrophic lateral sclerosis; augmentative and alternative communication; education program; text-mining

Introduction

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease. Upper and lower motor neuron dysfunction causes progressive loss of voluntary muscle activity, including bulbar impairment (dysarthria and dysphagia) [1]. The latest data indicate 9,636 registered patients with ALS in Japan in 2017 [2]. ALS respiratory failure directly affects prognosis; most patients with ALS without ventilation support cannot live beyond 2–5 years from onset. In Japan, the percentage of tracheostomy and invasive ventilation (TIV) is higher (28%–33%) than in other countries (1%–17%) and there are some long-term survivors [3,4].

ALS involves symptoms that impair speaking, writing and physical expression. Communication is fundamental for patients, family, and healthcare professionals. The ability to communicate and understand affects patient participation in decision-making and symptom relief [5,6].

Augmentative and alternative communication (AAC) is any type of support for patients with spoken or written communication disorders, and involves communication strategies (e.g. hand gestures and signs) and/or devices to enhance or replace residual vocalization and communication functions in individuals with language and speech impairment [7]. AAC use varies greatly depending on ALS functional state. AAC support is essential for patients with TIV because they cannot speak [8]. TIV use in ALS is 1%–14% in the USA, 3% in Germany, 2%–5% in France and 11% in northern Italy. TIV is rarely used for ALS in the UK [9]. An analysis of survival time until death/TIV for patients followed by a university hospital in Japan showed that 52 of 160 consecutive patients (33%) underwent TIV in 1990–2010 [10].

In Japan, AAC has been used mainly for patients with ALS. The Rehabilitation Engineering Society of Japan conducted a survey in 2008 and 2009 on national communication support provision [11]. ALS ranked first for dissemination of communication devices by disease (62%), followed by cerebrovascular disorders (10.6%) and cerebral palsy (7.6%). ALS

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accounted for 90.2% of requests for communication device repairs (i.e. replacing switches), reflecting voluntary motor function decline. Communication support was mostly associated with neurodegenerative disorders, especially ALS.

Makkonen et al. [12] reported that 60% of Finnish patients with ALS retained adequate speech for an average of 18 months from the first bulbar symptoms. They recommended focusing on first bulbar symptom onset when assessing AAC need. Nakayama et al. [8] examined communication status in 76 patients with TIV in Japan (17.2% were totally locked-in). Communication ability stage progression was associated with several factors, including TIV need and development of overt oculomotor limitation. Development of the latter within 24 months post-onset affected progression to Stage V (unable to communicate by any means) [13]. However, some patients maintained communication >10 years after TIV. The authors emphasized that about 80% of patients with ALS using TIV can communicate with AAC devices [8,13].

Imura [14] surveyed the Japanese ALS Association patients and family members who use AAC. The 'stand-by group', that did not yet use AAC, had little experience in using information technology (IT) such as personal computers. In addition, little support was available for the 'aborted group', which discontinued AAC use. The results suggested the need to provide incentives for the stand-by group to use IT devices, and support for the aborted group to use new AAC. The use of AAC in patients with ALS requires continuous support.

The introduction and continued use of AAC requires ongoing support from multidisciplinary healthcare teams [15]; however, general undergraduate healthcare studies provide few opportunities to acquire AAC expertise in Japan. For example, the medical and nursing education model core curriculum presented by the Ministry of Education, Culture, Sports, Science and Technology in Japan only provides basic communication with patients and team communication, and does not mention support for patients with communication disorders [16,17]. Therefore, most healthcare professionals need to learn about AAC support after graduation, given their need to care for patients with ALS and the difficulties with communication experienced by these patients. Some institutes and patients' associations in Japan have their own resources to support such learners [18], but there are differences among individual healthcare professionals in terms of level of AAC support [19]. It is therefore essential that undergraduate education in this field is effective even if limited, as it is a fundamental opportunity for students to gain exposure to AAC.

Nagayoshi et al. [20] examined nursing students' use of communication boards. They reported that time to transmit randomly set *hiragana* letters or numbers improved more for students with 10 days of training compared to students who practiced only two or three times, but there was no evaluation of long-term knowledge retention. Kavanaugh et al. [21] assessed a 5-hour training program for young caregivers (8–18 years) of patients with ALS. Training comprised <1 h on communication support and did not address communication in patients with TIV. Evaluation involved participant impressions but not robust qualitative methods, such as text-mining.

In the intensive-care field, Radtke et al. [22] reported the experience and perceptions of nurses regarding communication intervention: a basic communication skills training program and introduction of AAC strategies. While the nurses' opinions about their experiences showed the benefits of training, they pointed out the small proportion of nurses trained or knowledgeable about best patient communication practices in the intensive care unit (ICU). Dithole et al. [23] conducted a workshop with scenarios including communication during intubation, suctioning and tracheostomy care, especially focusing on assessment of a patient's ability to communicate in order to check which AAC devices would be appropriate. The study indicated that AAC can improve nurse-patient communication in the ICU and the authors suggested the implementation of communication skills training for intensive-care nurses.

In other fields, Banfai et al. [24] assessed a training program on knowledge and skills of automatic external defibrillators and basic life support (BLS) for 7–14-year-old students. Four months post-training, students retained some knowledge and skills. Kovács et al. [25] examined the long-term effects of BLS training for medical students using different training conditions. Students who took a practical exam 3 months post-training showed greater skill retention after 5 months. Parikih et al. [26] evaluated retention of palliative care communication skills training one year later in medical students using simulated patients. Although participants felt that communication skills training was important, there was no quantitative measure of knowledge and skill retention.

Previous research indicated educational effectiveness of training. However, few studies have evaluated the effects and retention of training programs on communication support for patients with ALS. We developed a short-term ALS communication support education program for undergraduate students in multiple healthcare disciplines: medicine, nursing, rehabilitation and education.

The research objective was to examine how AAC knowledge, skills and subjective burden were affected by a half-day education program, and to describe the change that occurred in these aspects over a 6-month period.

Methods

This study was conducted from March 2018 to September 2019. The Mie University Faculty of Medicine Research Ethics Committee approved the study (#3245).

Materials

The program content was adapted from Imura's Guidebook for AAC, through discussions among the authors [27]. The program comprised three 90-minute units of lectures plus practice of three AAC methods.

At the orientation session, we described the program, checked materials (guidebooks and worksheets) and explained how to complete the worksheets. After a pre-test, the program began (Table 1).

Session 1 contained three lectures, the first of which was a 20-minute lecture on ALS, followed by a 9-minute video of a person with TIV, a group discussion on the need for communication, and an overview of AAC. Session 2 comprised AAC practice. Session 3 comprised five lectures on the AAC system for maximizing usage period, and subsequent group discussions. The program ended with a post-test and retrospective comments on the worksheets. Participants brought back the guidebooks and worksheets used in the program.

Table 1. Program outline.

	Contents	Time (min)
Opening	Orientation	15
	Pre-test	10
Session-1 (90 min)	Lecture: ALS and care • Understanding ALS	20
	Movie 'Gisoku' (case of patient)	10
	Review	10
	Lecture: Chapter 1 Concept of support • Social resources & multiple disciplines	25
	Review	10
	Lecture: Chapter 2 Communication types and choices • Letter board, Kuchimoji	15
Session-2 (90 min)	Watching video material: Communication board method	5
	Practice: Communication board	30
	Watching video material: Kuchimoji method	10
	Practice: Kuchimoji	30
	Review	10
	Lecture: Continuation of Chapter 2 • Bell, Dedicated devices	5
Session-3 (90 min)	Lecture: Communication devices (Let's Chat)	5
	Practice: Let's Chat	5
	Lecture: How to adjust the speed	5
	Practice: Let's Chat after adjustment	5
	Lecture: Continuation of Chapter 2 Utilize PC, How to select devices etc.	10
	Lecture: Chapter 3 Public support system • Physical resources • Human resources	10
	Review	5
	Lecture: Chapter 4 • ALS stage-specific approach to the introduction of communication devices • Summary	30
Closing	Review	5
	Post-test	10

Notes: Each session took 90 min. In the practice session, participants conducted transmission practice using the three designated AAC methods. The number of transmitted letters in each practice was evaluated for 5 min. Gisoku: the title of a 9-minute video produced by the broadcasting club at Nissei Gakuen Daiichi High School. Its copyright has been managed by the Mie ALS Association. ALS: Amyotrophic lateral sclerosis.

The pre-test/post-tests were the same. All topics were extracted from the guidebook summary. They comprised ten questions with participants selecting two of five choices [28].

The practice exercises used a transparent flick-type communication board (Flick, ICT rescue team, Tokyo), the Kuchimoji communication method, and the Let's Chat® (Panasonic Inc., Tokyo) communication device. The communication board presented a Japanese syllabary, allowing the patient to communicate with the caregiver using eye contact to select letters. The Kuchimoji method uses a combination of oral shapes and eye-blinking for communication [28]. After a video explanation of how to use each AAC method, a 5-minute practice was performed. In the communication board and Kuchimoji sessions, participants were asked to practice three roles (patients, caregivers and observers), with the order rotated each time so that each participant was able to take on each role once.

Participants were asked to discuss improvements associated with their roles after each practice in the group. They did not have the opportunity for discussions with the other group as the groups were physically distanced. In the Let's Chat® session, participants first used the set scanning speed (labeled 'default') of level 7 (scanning-speed range: 1 (slowest) – 13 (fastest)), then attempted the same text again using their preferred scanning speed (labeled 'adjusted'). The contents to be transmitted were randomly changed and presented at each practice, so that the same message was not communicated twice.

Participants

Participants were a convenience sample of paid self-selected students recruited from the undergraduate faculties of medicine, nursing, rehabilitation and education (Clinical Psychology stream) at four Japanese universities. Inclusion criteria were 20–60 years old, able to participate in the program both initially and 6 months later, and no similar educational opportunities. All participants provided written informed consent.

Participants completed the same program twice, over a 6-month interval. Those taking the course for the first time were labeled 'Beginners' and those repeating the course 6 months later were labeled 'Experienced'. The cohorts were kept away from each other so that there was no mixing between groups. A waiting-list control design with a 6-month delay interval was used to compare the two groups (Figure 1).

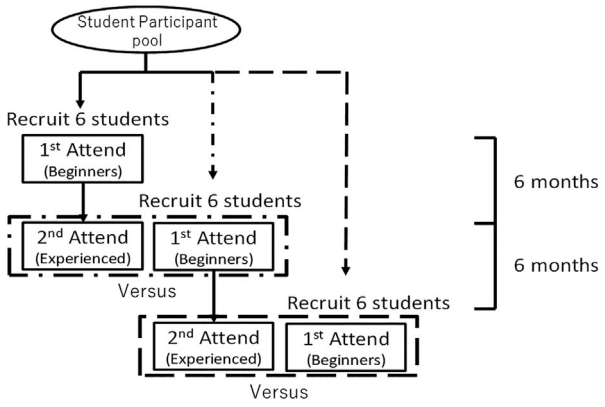

Figure 1. Study design: a waiting-list control design.

Notes: This figure shows the flow of the study at one university. Here, implementation was conducted with one group of six participants at one university (The full study was conducted at four universities using the same flow). All participants, except for those in the last group, completed the same program twice at 6-month intervals. The effect of the education program was evaluated by comparing the outcomes between the first attendance (Beginners) and second attendance (Experienced).

The number of participants was settled at 6 per group in each program of this trial due to the limited capacity of the research members at individual universities.

Analyses

Effects of the program were evaluated using four outcomes: pre-test/post-test scores; number of letters transmitted using each AAC in 5 min; subjective burden of AAC using visual analogue scale (VAS) values before and after each AAC trial; and free-text comments on impressions and awareness. Data were analysed using R version 3.5.0 (R Foundation for Statistical Computing, Vienna, Austria). Statistical significance was set at $P < 0.05$.

Participants were asked to mark their level of burden using VAS by marking a straight line with a highlighter pen at the subjective level perceived, where level 0 meant no burden and level 100 meant the highest burden. Just before the task, they were asked to mark the expected level of burden. Soon after the AAC trial, they were requested to do ratings again on another VAS with the same criteria, based on the actual burden experienced.

Free-text comments on the worksheets were processed using KH Coder® (https://khcoder.net/en/) text-mining software. In 2016, Higuchi proposed a two-step approach for quantitative content analysis of text data using KH Coder® [29]. This two-step approach was used for analysis of the content of the free-text comments. First, KH Coder® extracted words from the comments and then 'characteristic' words used by Beginners and Experienced participants were compared. Coding rules were created for extracting words related to burden and ease of use, and finally KH Coder® compared the frequency with which these concepts occurred in Beginner and Experienced participant comments.

In KH Coder® analysis, 'Token' indicates the total number of words in the text. 'In use' indicates the number of words KH Coder® recognizes as analysis targets. KH Coder® created a co-occurrence network based on the frequency and pattern of the extracted words. Strongly related words were connected by lines. Degree of co-occurrence between words was indicated by the Jaccard coefficient.

Results

Of 58 students (16 males and 42 females) who participated in the program, 11 took the course only once owing to study period limitations, resulting in 105 total trials. All the participants were older than 19 years (mean ± standard deviation: 20.8 ± 1.6). There were 35 nursing students, 9 medical students, 9 rehabilitation students and 5 clinical psychology students.

Pre-test/post-test

Table 2 shows percentage of correct answers for each question in each test. In questions 2, 7 and 8, the correct answer rate was accurately selected by less than half of the participants, with question 2 the lowest of them all. For most questions (except question 6) the percentage of correct answers increased or remained the same before and after the program. The percentage of correct answers decreased by about 20% for both the Beginner and Experienced group in question 6.

Test scores for each group were normally distributed as determined using the Shapiro–Wilk test. The Beginners' pre-test and post-test scores were compared using the paired t-test (Table 3). Their mean post-test score was 1.79 points higher ($P < 0.001$ $n = 58$) than at pre-test.

First attendance post-test scores and second attendance pre-test scores of the same student were

Table 2. Correct answer percentage for each question in the pre-test/post-test.

Question number		1	2	3	4	5	6	7	8	9	10
Beginners	pre-test	71.4	17.9	51.8	57.1	73.2	53.6	41.1	37.5	64.3	51.8
	post-test	67.9	71.4	69.6	87.5	94.6	37.5	44.6	60.7	82.1	69.6
Experienced	pre-test	70.3	43.2	67.6	67.6	89.2	45.9	54.1	62.2	83.8	54.1
	post-test	73.0	75.7	81.1	89.2	97.3	27.0	64.9	67.6	94.6	59.5

Notes: The table shows correct answer rate (%) of pre-test/post-test for each question for Beginner ($n = 58$) and Experienced ($n = 47$) groups.

Table 3. Mean pre-test/post-test scores for each group.

	Test	Score (out of 10)
Pre-test	Beginners	5.1 ± 2.0
	Experienced	6.0 ± 2.1
Post-test	Beginners	6.9 ± 1.9
	Experienced	7.2 ± 1.8
		(mean ± s.d.)

Notes: The table shows the pre-test/post-test scores for the Beginner (n = 58) and Experienced (n = 47) groups. Numerical data are shown in the style of mean ± standard deviation (s.d.) in the group.

compared using the paired t-test (excluding 11 participants who took the course only once). The mean second attendance pre-test score was 0.89 points lower than the first attendance post-test score (P = 0.028, n = 47). Pre-test scores of Beginners and post-test scores of Experienced students were compared using unpaired t-test. The mean Experienced group score was 2.04 points higher (P < 0.001, n = 47) than the mean score of the Beginners.

Pre-test scores of Beginners and Experienced students were compared using the unpaired t-test. The mean Experienced group score was 0.88 points higher (P = 0.031, Beginners: n = 58, Experienced: n = 47) than the mean score of the Beginners.

Number of letters

A scanning-speed adjustment in the Let's Chat® session was introduced after researcher discussion following the first implementation in each university. No adjustment was made for participants of the first implementation (24 students). Therefore, 34 Beginners and 38 Experienced students used the adjustment.

The number of letters in each group was normally distributed based on results of the Shapiro–Wilk test. We compared the mean number of letters transmitted in 5 min using each AAC by the Beginners and Experienced groups using unpaired t-tests (Table 4). The number of letters used by the Experienced participants was higher than by the Beginners, except in the Let's Chat® default condition. The Experienced students transmitted more letters in 5 min: 8.7 (Flick), 5.6 (Kuchimoji) and 6.8 (Let's Chat with adjusted speed) letters than the Beginners did (Table 4).

Table 4. Number of letters transmitted in a 5-minute period for each AAC system by group.

AAC		Beginners	Experienced	P value
Flick		29.5 ± 9.1	38.2 ± 9.9	<0.001*
Kuchimoji		27.4 ± 7.2	33.0 ± 10.4	0.004*
Let's Chat	default speed	14.2 ± 1.9	14.1 ± 2.7	0.827
	adjusted speed	25.7 ± 5.0	32.5 ± 9.2	0.001*
P value (default-adjusted)		<0.001*	<0.001*	
				(mean ± s.d.)

Notes: The table shows the number of letters transmitted in 5 min using each AAC by the Beginner (n = 58) and Experienced (n = 47) groups. For each AAC method the number of transmitted letters was compared between Beginners and Experienced by t-test. In Let's Chat® sessions, the numbers before and after adjustment to a suitable scanning speed were also compared between the default-speed group and the adjusted-speed group for Beginners and Experienced using paired t-test.
Notes: Numerical data are shown in the style of mean ± standard deviation (s.d.) in the group. The asterisk * shows significance (P < 0.05). AAC: augmentative and alternative communication

Table 5. VAS change rates by AAC.

AAC	Role/speed setting	Beginners	Experienced	P value
Flick	Patient	2.0 (1.4–4.1)	1.6 (0.8–2.4)	0.154
	Caregiver	1.6 (0.9–4.5)	1.1 (0.8–2.2)	0.34
Kuchimoji	Patient	1.6 (1.0–1.9)	1.0 (0.6–1.3)	0.001*
	Caregiver	1.2 (0.8–1.9)	0.9 (0.7–1.1)	0.054
Let's Chat	default	1.5 (4.5–1)	1.9 (1.1–2.7)	0.858
	adjusted	1.0 (0.6–2.5)	1.2 (1.0–2.3)	0.337
		[median (lower quartile–upper quartile)]		

Notes: The VAS change rate was defined as the ratio of the two VAS scores just after to just before using each AAC. This was used to evaluate the change in the subjective burden for each AAC. Mann–Whitney U tests were used to compare the two groups (34 Beginners, 38 Experienced). The column 'role / speed' shows the role of practicing AAC in Flick and Kuchimoji, and the setting of the speed in Let's Chat®. Numerical data are shown in the style of the median from lower quartile to upper quartile in the group. The asterisk* shows significance (P < 0.05). AAC: augmentative and alternative communication

The change in the number of letters from the default to the adjusted conditions was also compared between the Beginners and the Experienced using the paired t-test. In both groups, the number of letters increased with adjustment.

VAS

As subjective burden showed large individual variation, VAS values were compared using change rates. The change in VAS values before and after using each AAC method was expressed as the after/before score rate (Table 5). The data were non-normally distributed (Shapiro–Wilk test). The VAS score rates for Beginners and Experienced groups were compared using Mann–Whitney U tests. The change rate of Kuchimoji for the Experienced participants acting as patients was 0.6 lower than for the Beginners (P = 0.001).

Free-text comments

KH Coder® extracted 15,287 Japanese words from the comments. Some words (mainly particles, adverbs and symbols) were excluded if they lacked any semantic content of their own. Words such as 'think' and 'feel' were also excluded, as these would have been meaningless in the analysis. This left 6,018 tokens in use. There were 1261 types of words in total and 1018 types of words in use. The frequency (mean ± standard deviation) of each word in use was 5.9 ± 18.0.

The co-occurrence network was created from the text by KH Coder® (Figure 2). Co-occurrences of words related to 'time burden' (circle A, e.g. 'time' and 'wait'), words related to 'technical burden' (circle B, e.g. 'transmit' and 'difficult'), and words related to 'eyestrain' (circle C, e.g. 'eye', 'tired' and 'blink') were

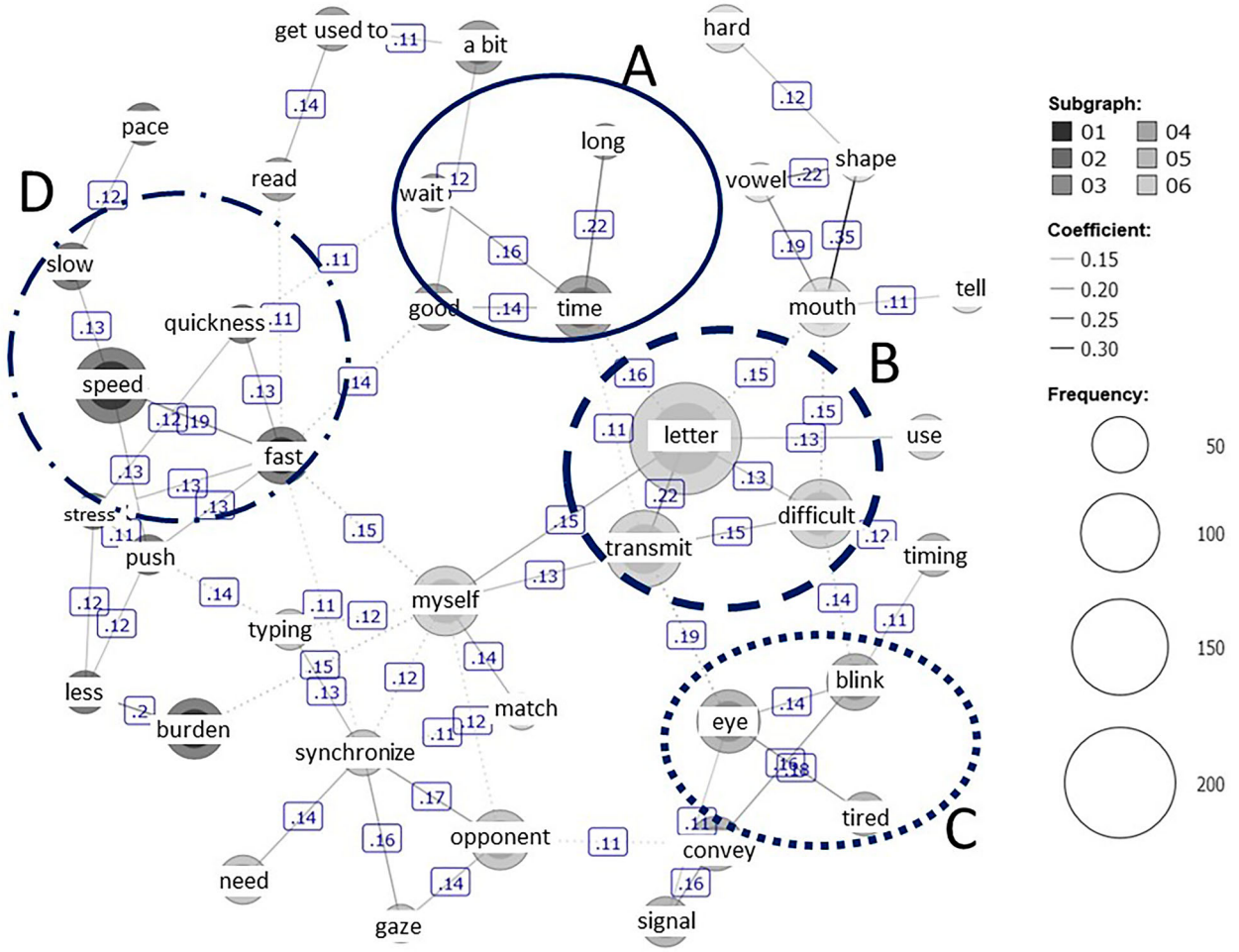

Figure 2. Co-occurrence network.

Notes: The figure was created with KH Coder® based on the frequency and pattern of words in free-text comments, without consideration of the analysts' intentions. Words with strong co-occurrence were arranged close together and connected with lines. Circle sizes corresponded to the frequency. The numbers on the lines indicated the Jaccard coefficients. Larger values suggest a stronger degree of co-occurrence. Words reflecting feelings of burden were separated into 'time burden' (circle A), 'technical burden' (circle B), and 'eyestrain' (circle C). The other group (circle D) directly reflected burden relating to 'speed'.

extracted as characteristic words and comprehensive burden on 'speed' was shown in the circle D.

From the characteristic words via KH Coder®, four concepts emerged as 'eyestrain', 'technical burden', 'time burden' and 'ease' (Table 6). A coding rule was agreed whereby a combination of the particular expressions shown in the table should be regarded as an appearance of the concept of the heading. The number of occurrences of each code was compared between the Beginners and the Experienced (Table 7). A between-group difference was observed in the number of occurrences of 'eyestrain' ($P = 0.036$).

Discussion

Pre-test/post-test scores

The participants had little knowledge related to some questions at the beginning of the program: 'communication board (No. 2)', 'AAC support in accordance with trajectory of the disease (No. 7)' and 'the role of healthcare professionals (No. 8)' at the first pre-test (Table 2). These scores increased through the program. In contrast, there was a question that showed no increase in correct answers (No. 6), suggesting that participants did not know when to introduce AAC and the nature of the team required to support it. Emphasis on the importance of AAC and the need to gain knowledge of AAC may have led to the misunderstanding that there is a need for specific healthcare professional support and early introduction regardless of stage. Lack of understanding of lecture content might have led to participants being confused about test items focusing on timing and support of AAC. In addition, they may have misunderstood items in the pre-test/post-test. This suggests a need to focus specifically on the topics of how and when AAC should be introduced. Ambiguous test items must also be revised for future training.

Beginners test scores increased after taking the program once, which may be an effect of single attendance (Table 3). The increase in the second pre-test scores compared to the first pre-test scores showed a slight retention of the learning effect.

Table 6. Coding table of the four extracted concepts.

Eyestrain
('blink' & 'tough')|('blink' & 'patience')|('blink' & 'confusion')|('blink' & 'hard')|('eye' & 'tired')|('eye' & 'burden')|('eye' & 'dry')|('eye' & 'tough')|('eye' & 'hard')|'dry-eye'
Technical burden
'difficult'|('understandable' & 'unable')|('understandable' & 'difficult')|('practice' & 'need')|('get used to' & 'need')|('get used to' & 'unable')|('transmit' & 'unable')|('transmit' & 'difficult')|('make mistakes' & 'many')|('make mistakes' and not 'few' and not 'small')|('miss' & 'make')|('miss' & 'much')
Time burden
'slow'|('time' & 'annoying')|('time' & 'long')|('time' & 'take')|('time' & 'need')|('frustrating' and not 'decrease' and not 'disappear')|('wait' & 'hard')|('wait' & 'tough')
Ease
'smooth'|'convenient'|'easy'|('get used to' and not 'unable')|('get used to' and not 'need')|('burden' & 'less')|('burden' & 'decrease')|'ease' |'not tired'|'wonderful'|'good'|'easygoing'|'fun'|'happy'

Notes: From the characteristic words extracted via KH Coder®, four concepts emerged: 'eyestrain', 'technical burden', 'time burden', and 'ease'. The coding rule was settled that a combination of the particular expressions shown in the table should be regarded as an appearance of the concept given in the heading, e.g. 'blink' and 'tough' in the same sentence without negative expression to 'eyestrain'.

Taylor et al. [30] examined the effects of pre-test/post-test scores on pre-class work and class recitation activities of biochemistry university students.

Students who performed these activities scored better than control participants who did not. However, the learning effect was not maintained after 8 months. In this study, participants' knowledge was retained 6 months later, even though they had attended only a single program. The learning effect on the test score was statistically significant, although the difference between scores was very limited. It was difficult to evaluate actual effectiveness using only test scores. Therefore, other evidence of learning was considered including number of letters, VAS, and analysis of free comments.

Number of letters

The results suggested that even a single AAC practice was effective in maintaining the skills of participants in using AAC (Table 4). The meaningful transmissions at an average of more than 25 letters in 5 min using three types of AAC were shown in this study. The retention of skills supported the necessity of AAC experience in healthcare-education curricula.

There was no difference in the Let's Chat® default condition, because the unified scanning speed was too slow for healthy persons to detect the difference in the number of transmitted letters. It was already reported that it is important to use AAC with suitable scanning speed for each patient [31].

Morris et al. reported a qualitative study of adult AAC users' experiences [32]. The interview study with 12 patients revealed that AAC users felt 'physicians were rushed and gave the impression that they did not have enough time to communicate'. The time barrier could be one of the factors that make healthcare professionals hesitate to communicate with patients: they are too busy for time-consuming communication. The speed at which letters are transmitted is important for communication with patients with communication disorders [32]. Nagayoshi et al. reported that effective communication required communication partners to become accustomed to using AAC [20]. In other words, it is necessary for healthcare professionals to acquire the skills to communicate efficiently with AAC so that they can be sensitive communication partners of people with ALS and know how best to provide practical support to those using AAC.

Table 7. Difference in the number of coded concepts between the groups.

	Eyestrain	Technical burden	Time burden	Ease	(total)
Beginners	29	66	32	93	174
Experienced	23	94	48	139	246
(total)	52	160	80	232	420
Chi-square value	4.378* (*P = 0.036)	0.000	0.026	0.271	

Notes: Number of occurrences of each coded concept was tabulated and compared between groups by Chi-square test, which showed a significant decrease in eyestrain of the Experienced group (P = 0.036).

VAS

Contrary to the authors' expectation that the AAC experience would reduce the subjective burden on participants, the results showed a decrease only in the Kuchimoji practice (Table 5). This may have reflected the small sample size and some sense of competition in the 5-minute practices of all the participants, even Experienced ones.

Andou [33] described a relationship between social skill and burnout in nurses who care for patients in the neurological and neuromuscular ward. This study pointed out that caring for patients who have difficulty communicating was one of the stressors for young nurses. Decreasing the perceived burden of using AAC was thought to promote the communication of healthcare professionals with patients with communication disorders.

Decreases in Let's Chat® VAS rates after adjustment to preferred scanning speed in both groups suggested that a speed suitable for each user reduced participant burden, as well as improving the number of letters. The perceived burden after adjustment was lower than the other results. This suggested that the participants realized how important to touch a device even once and to adjust it by each situation, even though all of them were young and very good at handling digital equipment and furthermore the communication device, Let's Chat® has been recognized easy to use without special skills compared to other AAC.

Free-text comments

Our analysis of characteristic words showed that the Experienced participants mentioned 'eyestrain' less frequently than the Beginners did, suggesting that participants retained the effect of AAC practice for 6 months and perceived AAC as less challenging, especially on the eyes (Table 7). The results were also considered to be related to the improvement in the number of letters in the AAC, when using the eyes, such as the Flick and the Kuchimoji. In contrast, the 'time burden' was still noted by the Experienced group. Huggins et al. reported patients with ALS expected to be able to transmit 15–19 letters/minute via AAC [34]. Even the improved number of letters may not be as fast as students in the Experienced group expected. In addition, more AAC experience may be needed to improve 'technical burden' and 'ease'.

Overall, these findings demonstrated the effectiveness of this communication-support program and indicate some retention of knowledge and skills. It was considered effective to have a program focusing on communication support for patients with ALS incorporated into medical and nursing curricula.

Limitations and future directions

This study was conducted with a limited sample size in four universities and four faculties. Participants were only those who voluntarily participated in this program. However, test scores increased slightly and participants were clearly able to acquire AAC skills through the program. It will be necessary to recruit a larger and more varied student sample in future to examine the learning effect.

Undoubtedly, further experience and training would be needed for healthcare professionals to provide a high level of personalized clinical support for AAC users. However, the program described in this paper provides an opportunity for participants to increase their awareness and familiarity with AAC, as a start to further development in this regard. We believe that this approach will contribute to supporting the younger generation, in other words, the next generation of clinical workers, supporting patients with communication disorders related to ALS.

Terry et al. [35] reported that face-to-face instruction combined with online training was effective in the retention of learning effect among undergraduate nursing students. Having demonstrated the effectiveness of the program, the next strategy would be to provide the program in a more readily accessible format to a wider audience. One solution would be to deliver the training by e-learning, needless to say which should be investigated if it could provide the same effect of the face-to-face program. In the era of covid-19, the demand for e-learning is increasing. Whether e-learning is equivalent to face-to-face instruction requires further study. While the five-hour, face-to-face program provided the benefit of direct learning, participants were required to remain in the same location for an extended period of time, potentially leading to impact on attention spans.

Conclusion

We developed a half-day education program on communication support for patients with ALS and implemented it with students in healthcare disciplines at four universities. The study design over a 6-month interval suggested student knowledge was maintained and the AAC experience improved and helped develop students' AAC skills and reduced some of the perceived burden. Communication support for patients with ALS should be included in the curriculum even if the training is limited to only half a day. The impact of this training may be significant for healthcare workers and the patients with ALS with whom they communicate.

Disclosure statement

No potential conflict of interest was reported by the author (s).

Ethical approval statement

The Mie University Faculty of Medicine Research Ethics Committee approved the study (#3245).

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Data availability statement

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Appendix 1. Pre-test/post-test

All topics were extracted from the guidebook summary (28). They comprised ten questions with participants selecting two of five choices. Each asterisk showed correct answers. Participants answered the test at the beginning and end of the program in 10 min. The pre-test/post-tests were the same.

1		**Choose two correct statements from the following five items about concepts of communication support for patients with neuromuscular disease.**
	a	Support with adjusting input equipment (switches) connecting to Japanese scanning comunication aids (JSCA) is a top priority.
	*b	Supporting communication for patients with neuromuscular disorder requires making them familiar with the use of methods.
	*c	Supporting communication for patients with neuromuscular disorder requires a support team along with all people involved and the family.
	d	The patients's own QOL is more important than the carer's.
	e	The carer's own QOL is more important than the patient's.
2		**Choose two correct statements from the following five items about communication methods with letter boards for patients with neuromuscular disease.**
	*a	Precise information can be delivered using a communication board (with letters) method.
	b	Japan Industrial Standard (JIS) provides arrangements for communication boards (with letters).
	c	It takes about 1 month to become familiar with using a communication board with letters.
	*d	There is a method of communication that does not involve using a communication board.
	e	Communication board methods are not popular these days.
3		**Choose two correct statements from the following five items about communication methods that do not use IT devices for patients with neuromuscular disease.**
	*a	Methods that do not use IT devices are convenient alternatives and are available anytime and anywhere.
	*b	Methods that do not use IT devices are beneficial in learning how to employ Japanese scanning comunication aids (JSCA).
	c	Methods that do not use IT devices require electricity.
	d	Methods that do not use IT devices make it difficult for lay people to master the necessary techniques.
	e	Methods that do not use IT devices take considerable time and are impractical.
4		**Choose two correct statements from the following five items about communication methods that use IT devices for patients with neuromuscular disease.**
	a	When people use IT devices, a dedicated device should be selected where possible.
	*b	If people cannot obtain a dedicated product, a general personal computer can be substituted.
	c	If people use a personal computer, it is not necessary to consider what is suitable for their needs or living environment.
	*d	Some applications are available on computers, tablets, or smartphones to enable a patient's communication.
	e	When a patient uses an IT device, it is not always necessary to adjust time or spatial resolution to match the patient's ability.
5		**Choose two correct statements from the following five items about selecting communication methods for patients with neuromuscular disease.**
	*a	Each patient's needs should be considered.
	b	When people choose a method, the patient's living environment is not a high priority.
	*c	It is necessary to avoid excessive burden for the family or carers.
	d	A method exists that uses a transparent communication board with letters as an IT device.
	e	A method exists that uses *kuchimoji*, an oral shape and eye-blink method without a board, as an IT device.
6		**Choose two correct statements from the following five items about introducing communication aid equipment for patients with amyotrophic lateral sclerosis (ALS).**
	a	It is better to introduce AAC to the patient early on, regardless of the stage of illness.
	b	Support by a small number of people at the beginning is suitable for the patient to avoid changing members as the disease progresses.
	*c	There are no problems in changing supporting members and systems according to the stage of illness.
	d	It is efficient to provide patient support that is limited to specific professional categories and coworkers.
	*e	Support is better delivered by a multidisciplinary team, with many kinds of health-care professionals than by specified health-care professionals or particular individuals.
7		**Choose two correct statements from the following five items about introducing communication aid equipment in accordance with the trajectory of the disease.**
	a	At the stand-by stage (still no need to use CA devices and products), support is considered after an actual need appears.
	b	At the using stage, consider maintaining support with the present equipment.
	c	At the difficult stage (unable to use existing support), withdrawal of support should be considered.
	*d	Upon introduction of CA devices and products, physical residual function and needs of each patient should be considered.
	*e	On introduction of CA devices and products, improving the patient's total environment, including daily living, should be considered.
8		**Choose two correct statements from the following five items about attention points for all health-care professionals providing services and support for communication with patients with neuromuscular disease.**
	a	All health-care professionals should become able to provide communication support and adjust input equipment (switches) connecting to JSCA as AAC products.
	b	Any health-care professional who cannot help directly should not enter the support team and should keep away from discussions on communication help.
	*c	A coordinator is necessary for the multidisciplinary team. The role should not be restricted to a medical doctor but open to any health-care professional able to fulfill the role.
	*d	It is useful for people who learn about communication aid devices and products to cooperate with the IT support center for the disabled.
	e	Enhancing courses on communication support for patients with neuromuscular disease should be encouraged in undergraduate education programs.
9		**Choose two correct statements from the following five items about institutions and their support of communication for patients with neuromuscular disease.**
	*a	In Japan, support is available both to obtain AAC and the human resources for learning how to use it and keep patients communicating.
	b	Government institutions as public support system for patients with difficulty communicating are uniform in Japan.
	c	Government institutions as public support system for patients with difficulty communicating seldom change over time.
	*d	The legislation of Act on Comprehensive Supports for Persons with Disabilities exists in Japan; it covers support for devices and products.
	e	No institution for patients is affected by a municipality's financial condition.

10 **Choose two correct statements from the following five items about institutions to support communication for patients with neuromuscular disease.**

*a As product support, the specific communication aid also covers Japanese scanning comunication aids (JSCA), as defined by the prosthetic device expense subsidy system.

*b As product support, the specific communication aid covers portable voice output communication aids (VOCA), defined in the class of daily living products for disabilities.

c As support for devices and products, the specific communication aid does not cover information and communication aids, defined in the class of daily living utensils.

d Patient rehabilitation is not defined as regaining communication using a communication aid device.

e In Japan, it is not allowed for doctors to prescribe rehabilitation support with a specific communication aid device through the medical insurance system or long-term care insurance system.