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Student participants' free comments after a short-term session of augmentative and alternative communication for patients with amyotrophic lateral sclerosis

– comparison between novice and experienced students using text-mining –

Takemasa ISHIKAWA*, ** Yugo NARITA **, ***, Keiko FUKUROKU **
Erisa TAKAHASHI **** and Chihiro MIZUMOTO ****

* *Department of Nursing, Mie University Hospital, Mie University, 2-174 Edobashi, Tsu-shi, Mie 514-8507, Japan*
** *Course of Nursing Science, Graduate School of Medicine, Mie University, 2-174 Edobashi, Tsu-shi, Mie 514-8507, Japan*
*** *Department of Neurology, Mie University Hospital, Mie University, 2-174 Edobashi, Tsu-shi, Mie 514-8507, Japan*
**** *School of Medicine, Faculty of Medicine, Mie University, 2-174 Edobashi, Tsu-shi, Mie 514-8507, Japan*

Abstract: Augmentative and alternative communication (AAC) has been used for amyotrophic lateral sclerosis (ALS) patients with severe communication difficulties. We planned a brief educational course for students in multiple healthcare disciplines. In 2018 we held 2 sessions more than 5 months apart. We set out to test a preliminary hypothesis that there would be a difference between novice students and an experienced group of students who had already attended the session once, especially in terms of their ease in managing the AAC. We compared data from the second training session between 6 students (experienced group) who had attended the same session twice in March and August, and 6 new students (novice group) who had never experienced AAC before August. We measured the number of letters obtained by each AAC method and the participants' perceived burden before/after using AAC evaluated by a visual analog scale (VAS). We also asked the participants to write comments after using AAC. We compared the number of letters and the subjective burden between the two groups. Free-text comments were processed by text-mining software (KH Coder®). The burden of the Flick type of communication board was lower for the experienced group (p=0.034). Comparison of Difficulty/Ease of the two groups with KH Coder® suggested less difficulty in the experienced group (p=0.002). Text-mining of the free comments suggested some difference on Difficulty/Ease between the 2 groups with and without the experience of the educational course.
Keywords: *Augmentative and alternative communication, Text-Mining, Amyotrophic lateral Sclerosis (ALS), Education*

1. INTRODUCTION

Communication failure sometimes occurs after severe neurological disorders such as cases of brainstem stroke or neurodegenerative diseases [1,2]. In Japan many patients with amyotrophic lateral sclerosis (ALS) are living on assisted mechanical ventilation with tracheostomy even after respiratory failure [3,4]. The disease progression involves all voluntary muscles including not only verbal communication but also hand writing or pointing. This situation makes it a challenge for patients to express themselves [5-7].

Communication is fundamental and essential, not only for patients but also for healthcare professionals, for patients' participation in society, making decisions and achieving symptom relief [2,8,9]. Augmentative and alternative communication (AAC) has been used as a support for patients with communication difficulties [10]. Patients may be able to maintain effective, functional communication with AAC support [8]. Imura (2015), however, reported that AAC has not always been used for ALS patients in appropriate and adequate ways [11]. There is a lack of knowledge and experience of AAC among most healthcare professionals, who need to get more familiar with the potential of AAC [2].

We had planned a short-term educational session on AAC for ALS patients with students in multiple healthcare disciplines (Figure.1) [10]. We had held 2 sessions in 2018 with nearly half a year interval in between them.

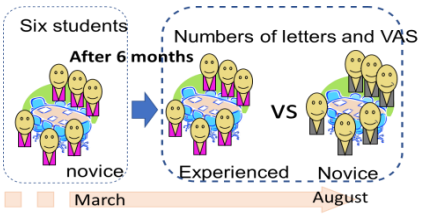

Figure 1: Schema of a short-term session for students to learn AAC and its evaluation strategy

2. AIM

Our aim was preliminary testing of the hypothesis that there is a difference between novice students and experienced students who had attended the session once already, especially in terms of difficulty/ease of managing with AAC.

3. METHOD

3.1 Study design

This study used a case-control design with a delayed interval of nearly half a year (5 months and 10 days).

3.2 Sessions and Participants

We had the first session with six students consisting of 4 medical students (male) in their 2nd to 3rd grade and 2 nursing students (female) in their 3rd grade on 22nd March. Mean age of students was 21.3 +/- 0.75 years (mean +/- standard deviation). We held the second session with the same contents and time frames on 30th August with 12 students: the same 6 students from March (experienced group) and 6 new students that had never experienced AAC (novice group). The novice group consisted of 2 medical students (male) in their 2nd to 3rd grade and 4 nursing students (female) in their 4th grade, whose age was 21.7 +/- 0.94 years old (mean +/- standard deviation). In the sessions, participants practiced how to use a cross-shaped (Flick type) communication board with letters, Kuchimoji (in Japanese) and Let's Chat® as one of the Japanese Scanning Communication Aids (JSCA). Kuchimoji comprise an oral shape and eye-blink method without a board [10]. Let's Chat® is an electronic blinking communication board with voice guidance. It works by choosing one letter at a time through single input-equipment (switch). We measured the number of letters obtained in the designated five minutes by each AAC and asked the participants to evaluate the burden before/after using each method by visual analogue scale (VAS) [10]. We also asked the participants to write down their thoughts about AAC and awareness of it after the training.

3.3 Ethical approval

This study was approved by the Research Ethics Committee of the Faculty of Medicine, Mie University (No.3245, March 2018).

3.4 Analytical Method

We compared the number of letters and the subjective burden (VAS) between the novice and experienced groups. Data analysis was performed using a statistical application, R version 3.1.0 (R Core Team 2014).

The free-text comments were processed using text-mining software (KH Coder, http://khcoder.net/en/).

KH Coder® is free software created and published by a Japanese researcher in 2001 and has already been used in more than 1000 studies published both in Japan and elsewhere as of November 2016 [12]. Higuchi (2016) proposed the following two-step approach for quantitative content analysis of text data by KH Coder® [12].

Step 1: Extract words automatically from data and statistically analyze them to obtain the whole picture and explore the features of the data while avoiding the prejudices of the researcher.

Step 2: Specify coding rules, such as "if there is a particular expression, we regard it as an appearance of the concept A", and extract concepts from the data. Then, statistically analyze the concepts to deepen the analysis.

In accordance with the approach, we attempted to analyze the contents of the free comments in Japanese.

For step 1, we extracted words from the free comments using KH Coder® and then compared feature words between the novice and experienced groups.

After step 1, we created a coding rule for extracting the difficulty/ease in Japanese, then compared the appearance of each code of the novice group with the ones of the experienced group. We checked synonyms of every word using the Weblio® thesaurus available on the web in Japanese and English (https://thesaurus.weblio.jp/), when we created the coding rule.

4. RESULTS

4.1 Number of letters in 5 minutes and burden by VAS

Comparing the two groups on the number of letters in 5 minutes and the burden (VAS) for each AAC, we found the burden of the experienced group was significantly lower only for the Flick type ($p=0.034$, Student's t test). In other types of AAC, there was no significant difference between the two groups (table 1).

There was no significant difference in the number of letters obtained in 5 minutes between the two groups (table 2).

We examined the difference for each AAC by one-way ANOVA. Results showed a significant difference in the number of letters between each AAC in both groups (the novice: $F(2,15)=34.20$, $p=0.00002$, the experienced: $F(2,15)=11.04$, $p=0.001$). In multiple comparison using Tukey's test, the number of letters of the Flick type was significantly larger in the experienced group than for the

other AAC (Flick-Kuchimoji: p=0.003, Flick-Let's Chat: p=0.00001). In the novice group, the number of letters for the Flick type was significantly larger than that of JSCA (p=0.0008).

		Flick		Kuchimoji		Let's chat	
		before	after	before	after	before	after
novice	max	90.0	80.0	90.0	96.0	80.0	70.0
	min	50.0	20.0	70.0	20.0	10.0	0.0
	mean	60.0	55.0	70.0	80.0	45.0	45.0
	ave	65.0	49.0	76.7	72.7	43.3	39.0
	S.D.	15.0	21.1	9.4	24.3	21.3	29.4
experienced	max	60.0	62.0	90.0	100.0	60.0	90.0
	min	25.0	20.0	50.0	30.0	20.0	20.0
	mean	45.0	45.0	70.0	85.0	40.0	45.0
	ave	43.3	43.0	70.3	80.0	41.7	48.3
	S.D.	12.8	15.9	13.2	23.8	14.6	24.1
	p value	0.034*	0.623	0.403	0.640	0.888	0.595

(Student's t test)

Table 1: Burden for each AAC by visual analog scale

		Flick	Kuchimoji	Let's Chat
novice	max	57.0	39.0	16.0
	min	20.0	19.0	12.0
	mean	37.5	26.0	15.0
	ave	39.7	26.8	14.3
	S.D.	13.0	6.8	1.4
experienced	max	61.0	48.0	20.0
	min	38.0	19.0	11.0
	mean	56.5	35.0	15.5
	ave	52.8	34.8	15.5
	S.D.	8.4	8.6	2.8
	p value	0.087	0.134	0.416

(Student's t test)

Table 2: The number of letters obtained by each AAC

4.2 Free comments by KH Coder®

Step1

From the free comments, a total of 965 words were extracted and 350 different words (average frequency of appearance 2.76 +/- 4.45) were obtained by KH Coder®.

We created a co-occurrence network from contents of the novice (figure 1) and experienced (figure 2) groups. The numbers on the connecting lines in the figure were Jaccard indices, which represented the degree of co-occurrence. The larger the value was, the stronger the degree of co-occurrence was [11]. When we checked the co-occurrence of "a" and "b", the Jaccard index could be obtained (figure 4).

The experienced group: Regarding the Flick type, "practice (Jaccard: 0.08)" was extracted three times and used in the context of "I can do it if I practice". "fast (Jaccard: 0.08)" was extracted twice and "smooth (Jaccard: 0.17)" four times. Words relating to Kuchimoji were "mouth (Jaccard: 0.18)" – three times; "shape (Jaccard: 0.18)" – three times and "forget (Jaccard: 0.12)" – twice. The word "forget" was used in the context "I forgot Japanese syllabary". For JSCA, "speed (Jaccard: 0.29)" and "slow (Jaccard: 0.33)" were both extracted twice.

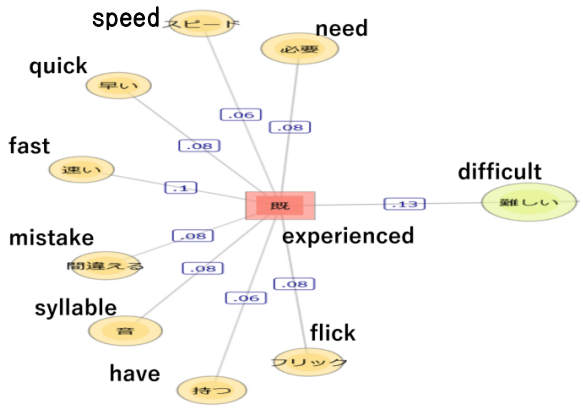

Figure 2: Co-occurrence network in the novice group

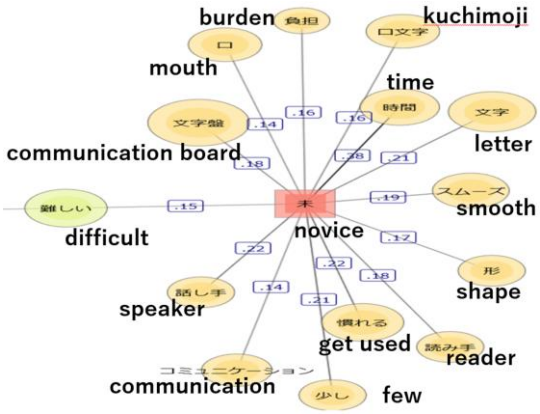

Figure 3: Co-occurrence network in the experienced group

$$\frac{A \wedge B}{A \vee B}$$

A=Number of sentences including "a"
B=Number of sentences including "b"

Figure 4: Equation for the Jaccard indices

The novice group: similar to the experienced group, "smooth (Jaccard: 0.33)" was extracted seven times and "understand (Jaccard: 0.31)" three times with regards to the Flick type. In contrast, "time (Jaccard: 0.32)" was extracted five times and used in the context of "take some time". "getting used (Jaccard: 0.5)" – nine times; and "fatigued (Jaccard: 0.15)" – twice; were also extracted and used in the context "I got fatigued until I got used to use it".

For Kuchimoji, "mouth (Jaccard: 0.28)" was extracted

nine times; and "shape (Jaccard: 0.36)" six times, as for the experienced group. "difficult (Jaccard:0.35)" was also extracted six times.

Regarding the JSCA, like the experienced group, some words related to scanning speed such as "speed (Jaccard: 0.29)" – three times; and "slow (Jaccard: 0.29)" – three times; were extracted. In addition, "easy-going (Jaccard: 0.33)" for communication was also extracted twice.

Step2

Based on the results of step 1, we created a coding rule with reference to the Weblio® thesaurus and compared the two groups. Table 3 shows the coding rule translated into English.

Difficulty	Be stressed | Burden and not Less | Burden and not Reduce | Hard | Tired | Tough | Demanding | Struggle | Difficult | Difficult (difference between Kanji and Hiragana in Japanese) | Need & Practice | Time | Frustrate | Worried | Exhausted | Not & Get used | Need & Get used | Loss | Need & Effort | Swamped | Frustrating | Uncomfortable | Irritation | Confusing
Ease	Not & stressed | Burden & Less | Burden & Reduce | Easy-going | Smooth | Passable | Useful | Easy | Get used and not Need | Great | Good | Early | Simple | Ease | Comfortable | Smoothly

Table 3: The coding rule translated into English

group	Difficulty	Ease	number of cases
experienced	20 (24.39%)	22 (26.83%)	82
novice	40 (48.19%)	26 (31.33%)	83
total	60 (36.36%)	48 (29.09%)	165
chi-square value	9.097**	0.216	

Table 4: The cross-tabulation table of codes

	novice		
	Difficulty	Ease	number of cases
Flick	12(36.36%)	16(48.48%)	33
Kuchimoji	19(61.29%)	4(12.90%)	31
Let's Chat	9(47.37%)	6(31.58%)	19
total	40(48.19%)	26(31.33%)	83
chi-square value	3.985	9.408*	
	experienced		
Flick	5(12.82%)	14(35.90%)	39
Kuchimoji	11(44.00%)	4(16.00%)	25
Let's Chat	4(22.22%)	4(22.22%)	18
total	20(24.39%)	22(26.83%)	82
chi-square value	8.090*	3.322	

Table 5: Comparison of AAC and Codes

Results of the chi-square test (table 4), show the difficulty was significantly higher for the novice group (p=0.002).

Both the novice (p=0.009) and experienced (p=0.018) groups suggested a high level of difficulty with Kuchimoji (table 5).

5. Discussion

Comparison of Difficulty/Ease of novice and experienced groups with KH Coder® showed a decrease in difficulty of experienced people (table 4). The burden of the Flick type was low for the experienced group (table 1). There was no difference in the number of letters between the two groups (table 2). The number of letters obtained by Flick type was not significant but seemed to be more than for the other AAC (table 2). This result was concordant with the highest frequency of ease in Flick type in text-mining (table 5). From the extracted words of the novice group, difficulties, such as "fatigue" accumulating until students had "got used to" the method, were found. However, these challenges were not seen in the experienced group. In other words, results suggested that once students had some experience with AAC, difficulties faced by the participants remained low even after an interval of more than 5 months. Due to the small number of samples in each cell (Table 5), this inference was not robust. However, it could also be seen that the degree of difficulty was lower for the more experienced people.

In a survey conducted by Nagayoshi et al. (2017) for nursing students, students who had experienced using a communication board showed significantly faster communication speed than students who had never experienced it [14]. Although there was no difference in the number of letters obtained in our study, it may have been due to a sample size effect. We expected some difference might be shown with an increase in the number of samples, because these semi-annual training sessions have been taking place at 4 universities simultaneously.

Limitation of this study: This report was limited to analysis of data obtained from a very small number of subjects of 2 groups of 6 participants each. Our next step will be to aim for more robust results with sufficient sample size.

6. Conclusion

By using text-mining for the free comments, it was possible to confirm the difference in Difficulty/Ease depending on participants' experience of AAC use.

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