The Experience of Augmentative and Alternative Communication on a Half-Day Training Program on Communication for Support of People with Amyotrophic Lateral Sclerosis

– Text mining the free-text comments of students from multiple healthcare disciplines –

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Abstract: Amyotrophic lateral sclerosis brings various communication disorders. Augmentative and alternative communication (AAC) strategies can provide effective solutions but require ongoing support from the multidisciplinary team. We planned a repeating half-day training program on communication support and delivered it to healthcare students at 4 Japanese universities. We investigated the difference in perceived burden of using AAC between “Experienced” participants who had completed training 6 months prior and “Beginner” participants using AAC for the first time, as revealed in their written comments left after AAC use. KH Coder® data mining software was used to identify “characteristic” words in the comments. Fifty-eight participants (completing 105 training sessions) participated in the program. The text mining revealed that “eyestrain” was less frequently expressed by Experienced participants than by Beginners, suggesting that a single prior AAC training experience could reduce the burden of use.

Keywords: Amyotrophic lateral sclerosis, Augmentative and alternative communication, Education program, Text mining.

1. INTRODUCTION

Amyotrophic lateral sclerosis (ALS) brings various communication disorders, including in speaking, writing, and body expression [1]. Communication is fundamental for—people (patients and family) and healthcare professionals alike—for patient participation in decision-making and for achieving symptom relief [1,2].

Augmentative and alternative communication (AAC) is used to support patients with spoken or written communication disorders. AAC refers to the use of communication strategies (e.g. hand gestures and signs) and/or devices to enhance or replace residual vocalization and communication functions in individuals with language impairment [3].

The introduction and continued use of AAC requires ongoing support from the multidisciplinary healthcare team [4]; however, in general undergraduate healthcare studies, there are sparse opportunities to acquire expertise in AAC.

Nagayoshi et al. (2017) examined the use of communication boards (an AAC tool) by nursing students. They reported that 3-letter-transmission time was improved for the students who had >10 days of training on communication board use; however, the researchers did not see any longitudinal effectiveness of the training [5].

Previously, the study authors developed a half-day training program on communication support for patients with ALS, for students in the healthcare disciplines [6]. For the purpose of reinforcement and the study evaluation, the training was designed to be repeated (by each participant) after a 6-month interval. To evaluate the program, we previously investigated the immediate and retained training effect, and we reported our quantitative results on improvement of word transmission by AAC [7]. Herein we further report on our corroborating qualitative analysis of free-text comments left by the student participants in the training program.

2. OBJECTIVE

In the present work, we aimed to evaluate the differences in perceived burden of using AAC between first-time learners and those repeating training after 6 months.

3. METHOD

3.1 Study design

This study was conducted from March 2018 to September 2019 and used a wait-list control design with a
6-month delay interval.

3.2 Training program

The program content was adapted from Imura’s Guidebook for AAC, through discussions among the study authors [8]. The training program consisted of lectures plus practice of 3 AAC methods.

For the practice exercises, we chose a transparent flick-type communication board, the Kuchimoji communication method, and the Let’s-Chat® (Panasonic Inc. Tokyo) communication device. The communication board presented Japanese syllabary, allowing the patient to communicate with the caregiver by using eye contact to select letters. The Kuchimoji method used a combination of oral shapes and eye-blinking for communication [6].

3.3 Participants

Participants were asked to leave their impressions and comments on study worksheets after practicing each of the methods.

The participants consisted of a convenience sample of paid volunteer students recruited from the undergraduate faculties of Medicine, Nursing, Rehabilitation and Education (Clinical Psychology stream) at 4 Japanese universities. Participants completed the program twice, at half-year intervals. Participants taking the course for the first time were labeled as the “Beginners”, while participants repeating the course after having taken it a first time 6 months prior were labeled as “Experienced” (Figure 1).

![Figure 1: Study Design](image)

3.4 Ethical approval

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

3.5 Analytical method

All of the free-text comments left on the worksheets were processed using KH Coder® (http://khcoder.net/en/) text mining software. KH Coder® is free software developed by a Japanese researcher in 2001. The program has been used in more than 1,500 studies published in Japan and elsewhere [9]. In 2016, Higuchi proposed a two-step approach for quantitative content analysis of text data using KH Coder® [10,11].

Based on the work of Higuchi, we followed the following two-step approach to analyze the content of the free-text comments: First, we extracted words from the free-text comments using KH Coder® and then compared “characteristic” words used by the Beginner and Experienced participants. After this, we created a coding rule for extracting words related to the burden and the ease of use, and finally, compared the frequency with which these concepts occurred in the 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. A co-occurrence network was created by KH Coder® based on the frequency and pattern of the extracted words. Strongly related words were connected by lines, and the degree of co-occurrence between words was indicated by the Jaccard coefficient, as shown in the figure. The Jaccard coefficient was calculated as the number of sentences containing A and B, divided by the number of sentences containing A or B.

4. RESULTS

Fifty-eight students participated in the program. All participants attended the program twice, except for 11 students who took the course only once due to limitation of the study period. Thus, there were 105 trials in total.

Table 1 shows the demographic characteristics of the participant sample, which consisted of 35 (60.3%) nursing students, 9 (15.5%) medical students, 9 (15.5%) rehabilitation students, and 5 (8.6%) clinical psychology students.

<table>
<thead>
<tr>
<th>Table 1: Participant Demographic Characteristics (N = 58)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Group</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
<tr>
<td><strong>Age (yrs), mean (±SD)</strong></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Faculty, n (total)</strong></td>
</tr>
<tr>
<td></td>
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<td></td>
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<td></td>
</tr>
</tbody>
</table>
The KH Coder® extracted 15,287 Japanese words from the comments. Some of the words (mainly of particles, adverbs, and symbols) were excluded if they lacked any semantic content of their own. Words such as “think” and “feel” were also excluded from the analysis because these would be meaningless in the analysis. This left 6,018 tokens in use. There were 1,261 types of words in total and 1,018 types of words in use. The frequency (mean ± standard deviation) of each word in use was 5.9 ± 18.0.

### Table 2: Coding for the 4 Extracted Concepts

<table>
<thead>
<tr>
<th>Eyestrain</th>
<th>Technical Burden</th>
<th>Time Burden</th>
<th>Ease</th>
</tr>
</thead>
<tbody>
<tr>
<td>(“blink” &amp; “tough”)</td>
<td>(“understandable” &amp; “able”)</td>
<td>(“understandable” &amp; “difficult”)</td>
<td>(“smooth” &amp; “easy”)</td>
</tr>
<tr>
<td>(“blink” &amp; “hard”)</td>
<td>(“practice” &amp; “need”)</td>
<td>(“get used to” &amp; “need”)</td>
<td>(“get used to” &amp; “need”)</td>
</tr>
<tr>
<td>(“eye” &amp; “tired”)</td>
<td>(“ transmitting” &amp; “able”)</td>
<td>(“transmit” &amp; “difficult”)</td>
<td>(“get used to” &amp; “need”)</td>
</tr>
<tr>
<td>(“eye” &amp; “dry”)</td>
<td>(“make mistakes” &amp; “many”)</td>
<td>(“make mistakes” &amp; “not few”)</td>
<td>(“frustrating” &amp; “not increase”)</td>
</tr>
<tr>
<td>(“eye” &amp; “hard”)</td>
<td>(“small”)</td>
<td>(“miss” &amp; “make”)</td>
<td>(“frustrating” &amp; “not disappear”)</td>
</tr>
<tr>
<td>(“dry-eye”)</td>
<td>(“frustrating” &amp; “not disappear”)</td>
<td>(“wait” &amp; “hard”)</td>
<td>(“frustrating” &amp; “not disappear”)</td>
</tr>
<tr>
<td>(“frustrating” &amp; “not disappear”)</td>
<td>(“frustrating” &amp; “not disappear”)</td>
<td>(“frustrating” &amp; “not disappear”)</td>
<td>(“time” &amp; “not long”)</td>
</tr>
<tr>
<td>(“frustrating” &amp; “not disappear”)</td>
<td>(“frustrating” &amp; “not disappear”)</td>
<td>(“frustrating” &amp; “not disappear”)</td>
<td>(“time” &amp; “not long”)</td>
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<td>(“frustrating” &amp; “not disappear”)</td>
<td>(“frustrating” &amp; “not disappear”)</td>
<td>(“frustrating” &amp; “not disappear”)</td>
</tr>
</tbody>
</table>

### Step 1

As Figure 2 showed, Co-occurrences of words related to “time burden” (such as “time”, “wait”, and “slow”), words related to “technical burden” (such as “letter”, “transmit” and “difficult”), and words related to “eyestrain” (such as “eye”, “tired” and “blink”) were found and extracted as characteristic words.

### Step 2

From the group of extracted characteristic words, we created a code to extract the 4 concepts “eyestrain”, “technical burden”, “time burden”, and “ease” from among other related concepts (Table 2). The number of occurrences of each code was compared between the Beginner and Experienced participants, in a cross-tabulation table (Table 3). A difference was observed in the number of occurrences of “eyestrain” between the 2 groups (p=0.036).

### Table 3: Differences in Concept Occurrence in the Participant Comments

<table>
<thead>
<tr>
<th>Beginner</th>
<th>Experienced</th>
<th>Total</th>
<th>Eyestrain</th>
<th>Technical Burden</th>
<th>Time Burden</th>
<th>Ease</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>29</td>
<td>23</td>
<td>52</td>
<td>66</td>
<td>94</td>
<td>80</td>
<td>139</td>
<td>246</td>
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<tr>
<td>32</td>
<td>48</td>
<td>80</td>
<td>32</td>
<td>48</td>
<td>80</td>
<td>139</td>
<td>246</td>
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<tr>
<td>93</td>
<td>139</td>
<td>232</td>
<td>93</td>
<td>139</td>
<td>232</td>
<td>232</td>
<td>420</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 4.378^* \quad (p=0.036) \]
5. DISCUSSION

Text mining with KH Coder® has been performed in a range of contexts, such as in analysis of social science questionnaires and interviews [9]. In the present work, we obtained a chart showing strong co-occurrence with “characteristic words”, which consisted of objective words (e.g., “letter”, “speed”, “transmit”), body parts (“eye” and “mouth”), and subjective words (e.g., “difficult”, “tired”, “burden”). We then analyzed these characteristic words using a two-step approach in KH Coder®. The analysis showed that Experienced participants expressed “eyestrain” less frequently than did the Beginners, suggesting the effect of AAC practice 6 months prior was preserved, i.e., that participants had retained their AAC learning relatively well, perceiving AAC to be less challenging, especially on the eyes.

Lee et al. (2019) investigated the difference of emotional aspects about the development of generic skills in the clinical practice of nursing students, also using KH Coder®. The researchers administered an open-ended questionnaire to 216 third-year nursing students who had completed field-specific training, respectively, in project-based learning, development of the nursing process, or experiential learning. Text mining and co-occurrence analysis helped the investigators to detect the educational effects: They extracted 2,903 words and reported a learning effect on “ability to find problems” in the project-based learning group and on “ability to maintain behavior” in the experiential learning group [12]. In the present study, we were able to extract 6,018 words, a sufficient number to confirm the effectiveness of our program as experiential training.

6. CONCLUSION

We developed a half-day training program on communication support for people with ALS and implemented it with students in 4 healthcare disciplines at 4 universities. Text mining of the students’ free-text comments following AAC use suggested that a single experience of AAC training can make its use easier, supporting our earlier quantitative findings of this effect.

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