Clinical desires to catch signals of human expression

–assisting communication of severely disabled patients with neurodegenerative disorders–

Yugo Narita*,**, Mio Kato ***, Natsumi Nishii ****, Rui Makî *****, Takeo Manabe ****** and Keiko Fukuroku *

* 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
*** Department of Nursing, Daido Hospital, 9 Hakusui, Minami-ku, Nagoya-shi, Aichi 457-8511, Japan
**** Department of Nursing, Komatsu Hospital, 6-45 Maehama-dori, Minami-ku, Nagoya-shi, Aichi 457-0058, Japan
***** Department of Nursing, Mie University Hospital, Mie University, 2-174 Edobashi, Tsu-shi, Mie 514-8507, Japan

Abstract: The authors present clinical desires to catch signals of human expression, and then ask opinions on communication support for severely disabled patients with neurodegenerative disorders from specialist members of the International Society of Affective Science and Engineering. Two aims were considered. One aim was to detect patients’ expressions as a trigger to a switch for an augmentative and alternative communication device and to accumulate facial signals conveying demented patients’ good or no-good expressions using a tool that is typically used for providing palliative care for non-cancer patients. The other aim was to determine the examined tool’s possibility for evaluation in normal subjects. The knowledge and skills required for communicating with severely disabled patients, especially with amyotrophic lateral sclerosis (ALS), needs to be shared among colleagues in the form of vocational education. In the clinical fields, health-care professionals and undergraduates are too busy to make sufficient time to gain such knowledge and skills. With regard to the proposed tool, we raised the unusual question about whether our desires to catch signals of human expression are too idealistic and infeasible.

Keywords: human expression, communication, neurodegenerative disorders

1. INTRODUCTION

The number of patients with neurodegenerative disorders increases steeply in accordance with the aging population [1,2]. These diseases include, among others, Parkinson’s disease (PD), dementia with Lewy body (DLB), multiple system atrophy (MSA), amyotrophic lateral sclerosis (ALS) and Alzheimer’s disease (AD) [2]. Many clinical professionals and families have tried to obtain a signal from severely disabled patients with demented disorders or ALS on a mechanical ventilator with tracheostomy. However, these signals have been too subtle on occasion, especially at the advanced stage, to determine delivery of suitable care and to evaluate care appropriateness to each patient. All’s well that ends well. The question arises, “How can we judge whether each care is suitable or not without an accurate signal?”

Two considerations may be supposed. First, the technology can be applied to tools. For example, for advanced-stage ALS without dementia, regardless of how subtle the signal is, even if it is detectable, the signal can be connected to an augmentative and alternative communication (AAC) device [3,4]. For another example, regardless of how demented a patient is, if we can apply a tool to accumulate their facial signals for good or no-good expressions for a period of time, we may be reassured of what services we have provided.

Second, vocational education can be considered. We need to share knowledge and skills required for communicating with severely disabled patients with ALS among colleagues. However, in the clinical fields, health-care professionals and undergraduates are too busy to make sufficient time for acquiring knowledge and for becoming familiar with new skills.

Here, we present clinical desires to obtain signals of human expression, with the aim to ask opinions on communication of severely disabled patients from specialist members of the International Society of Affective Science and Engineering. We also discuss whether or not our desires to catch signals of human expression are too idealistic and infeasible.

2. Technology

2.1. Caring for the totally locked-in state of ALS

The totally locked-in state (TLS) has been defined as a state whereby a patient’s thought has been well preserved, but surrounding people have no method to detect any signal of the patient’s thought [5-8]. This situation occurs in 10% or more of advanced-stage ALS patients with...
tracheostomy and positive pressure ventilation (TPPV). The longer one lives with TPPV, the higher prevalence of TLS is estimated. Far less patients choose TPPV support in the USA or UK, while nearly 30% of ALS patients currently live with TPPV in Japan [9,10]. The function of voluntary movement of extra-ocular muscles is well preserved even through to the latest stage of ALS. However, at the end of the trajectory, the function disappears in some cases [11]. Many kinds of tools have been invented to detect subtle voluntary signals, including detecting pattern changes on electroencephalography (EEG) or functional near-infrared spectroscopy (fNIRS) [11-14]. Regardless, the meaningful use of this tool among patients is extremely rare in clinical settings. Reports on brain-machine-interfaces (BMI) have failed to show good results for complete TLS patients with no applied method, including BMI [11-14]. In contrast, their caregivers have on occasion stated that they have been able to catch a positive or negative sign from the TLS patient. No clinician knows what factors contribute to this so-called “signal”, even if the caregiver can describe it, because there are no objective methods to confirm such claims. A tool to objectively catch signals of human expression could therefore be useful.

2.2. To detect human expression

Ideally, a tool for catching signals of human expression would be able to detect a patient’s voluntary expression, not only immediately, but even after collecting several factors over a period of time. Such signals could be in the form of good or no-good expressions on the patient’s face or any part of their body. The tool might bring about reassurance not only for patients, but also for carers and health-care providers with regard to ensuring each patient’s comfort and dignity. Severely ill patients, especially with dementia, seldom show constant good or no-good signals. Furthermore, palliative care for cancer patients has gradually become common. Regardless, for non-cancer patients, especially for demented patients, palliative care has just stood on the start, because no scale to detect patients’ subjective comfort exists [2].

Another question to consider is, “How precisely are we able at present to evaluate normal people on their subtle change of human expression?” A tool that can detect and evaluate such change would be good for vocational education in terms of learning clinical skills.

For example, learning how to use letter boards for severely disabled patients with ALS is considered to be difficult among health-care professionals who have never had such knowledge and experience [15]. We therefore sought to measure the speed and emotional burden of nursing students’ use of a letter board in a simulation of treating ALS patients. We attempted this via an educational trial about how to use letter boards at the school of nursing, the faculty of medicine, Mie university in 2016.

Participants: Five adult students (20–35 years of age, mean 24.2±4.9 years, comprising two men and three women) were selected among applicants after a call for paid participants from the school of nursing. The participants were taught how to play the role of a severe ALS patient without cognitive impairment. They followed the trial protocol of responding with only eye movements using three different types of letter boards (Grid type, Flick type and Kuchimoji).

![Fig. 1: Letter board: Grid type: 50-letter board (shown in original Japanese letters on the left and in translated alphabetical notations on the right)](image)

![Fig. 2: Flick type: cross-shape board (shown in original Japanese letters on the left and in translated alphabetical notations on the right)](image)

Kuchimoji comprises an oral shape and eye-blink method without a board. Participants acting as patients were allowed to express oral shapes for five different vowels in Japanese: “A”, “I”, “U”, “E” and “O”. Formerly even in Japan, there were many vowels with some differences especially in local accents. But only these 5 vowels have been converged and merged by the Ministry of Education after the WWII. There are subtle variances in expression of each vowel among people. But most of the oral shape (expression) would be identifiable in patients with moderate to severe disability. Intentional eye blink with sufficient length and times (twice or 3 times) is a good way to show “yes” or “no” in ALS.
patients even with severe disability. For example, when the patient tried to convey "Ke", the participant read the "E" shape with the patient's mouse, then the participant read aloud the "E", "Ke", "Se", "Te", "Ne" and so forth. The participant could catch the patient's signal of intentional eye blink at "Ke".

Protocol: Three students received letters from the participants acting as patients in a 60-minute session for 5 consecutive days. (fig.3)

During each session, a scenario composed using 200 Japanese letters was provided to the participant acting as a patient. They were shown the scenario for the first time during preparation for each session. They were told it was unnecessary to use sonant marks (dots added to kana symbols).

The passages were selected from the daily newspaper column “Tensei-Jingo” (the Asahi Shinbun) from 2015. One of the research member RM prepared all of the scenario passages without showing anyone else. No same passage was used twice.

Receivers consisted of 3 research members other than RM. They were MK, NN and TM. Each of them took the same part of the session through the trial. They kept away from the scenarios until the completion of each trial.

The trial was held in the practical room of fundamental nursing at the school of nursing in August 2016. Vital signs were checked, and questionnaires with visual analogue scales to measure the participants' emotional burden were completed before and after each session. The inter-beat (R-R) intervals of electrocardiogram and heart rate changes of each participant during the 60 minutes from the beginning to the end of the session were also measured by using MemCalc/BonalyLight (GMS Co., Ltd. Tokyo, Japan 2015). Participants replied only with eye movement and blinking.

**Results**

Kuchimoji, the oral shape and eye-blink method was faster than the grid-type 50-letter board and the flick-type cross-shape board. (fig.4) Accuracy was the same across all three modalities as of the second day. (fig.5) Subjective emotional burden (stress ratio) markedly decreased by the second day. (fig.6)

However, no significant difference among participants or sessions was found on the LF, HF, and LF/HF ratio of the heart rate variability data.

The outcomes were the number of successful communicated Japanese kana letters in 5 minutes for each type of board. The emotional burden was measured by changing the R-R intervals of the electrocardiogram and visual analogue scale (VAS) before and after each session. The ratio of VAS values (after / before) was set as the stress ratio.

The IRB permission number was No. 3046 (August, 2016), Faculty of Medicine, Mie University.

**Fig. 4: Total number of received letters / 5 min. (average)**

**Fig. 5: Correct proportion of received letters (%)**

**Fig. 6: Stress ratio**
This trial was merely a pilot study, but it has potential in teaching knowledge and skills about communication for patients with ALS within a relatively short timeframe to students aiming to become health-care professionals. Additionally, the results of this investigation may apply to not only students but also people with ALS and health-care professionals. We need objective evidence on the effectiveness of such an education trial. We failed to show a significant difference of heart rate variability on this trial. We merely obtained subjective data of stress ratios from VAS values.

We pose an additional question, “Is there any possibility to catch signals of human expression in healthy people?” A tool to catch subtle changes in expressions may provide us with another chance to evaluate human stress.

3. Education

3.1. Trying to educate within a short timeframe

We are planning to design a half-day course for undergraduate students on methods and skills required for communicating with severely disabled patients with ALS. The effectiveness and maintenance of the course’s effect will be evaluated only according to the number of letters received within 5 minutes and the VAS scale stress ratio. These approaches mirror the aforementioned methods and will include an interval after 6 months of intervention and the same contents as showing on figure 7.

The proposed scheme includes a point of weakness. That is, it lacks necessary objective data in addition to heart rate variability. To address this weakness, a tool to catch signals of human expression would be a good candidate as an evaluation method.

In Japan, one third of ALS patients currently live with TPPV [9,10]. This high ratio alongside the Grant-in-Aid program for designated chronic diseases may be able to account for the high prevalence of complete TLS in Japan [1,9]. Therefore, communication support is essential for patients with ALS [2, 4-8]. Use of a letter board is the most common and convenient tool for communicating with severely disabled patients, even in situations where there is no access to electricity [4,15].

However, education is insufficient with regard to how to use a letter board or which AAC device should be applied, not only for undergraduate students but also for all health-care professionals who care for ALS patients [4,15]. Most patients and carers hope to maintain communication by use of tools such as BMI, even though ethical issues need to be considered [16]. However, in daily clinical and committee activity, we have never observed any model case in which BMI has been used meaningfully, with a successful attempt in patients. For this reason, we presented here an investigation into clinical desires to catch signals of human expression. Are our desires too idealistic and infeasible?

ACKNOWLEDGMENTS

This work was supported by Grant-in-Aid for Scientific Research (C) in Japan, 2017. We thank Edanz Group (www.edanzediting.com/ac) for editing a draft of this manuscript.

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