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Communication Method Based on Pupil Diameter Changes for Amyotrophic Lateral Sclerosis (ALS) Patients: A System Designed for Adaptation to Symptom Progression

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Abstract— **Patients with severe physical disabilities owing to amyotrophic lateral sclerosis (ALS) typically have normal cognitive function; however, they often experience difficulties with speech, writing, and oculomotor functions as their symptoms progress. There is a need for a consistent communication system that can adapt to these progressing symptoms. The ability to modulate pupil diameter remains intact in patients who experience difficulties with eye movements, speech, and writing owing to ALS. This study focuses on the behavior of changes in pupil diameter when attention is directed to a target with periodic changes in light intensity. The purpose of this study is to develop a communication system that consistently adapts to the progression of symptoms, based not on eye movement but on changes in pupil diameter, enabling patients with severe disabilities due to ALS to communicate daily, even when their eye movement symptoms worsen. Additionally, the study aims to confirm the feasibility of the developed system for communication that reflects the intentions of patients with ALS. We developed a wearable communication system with a head-mounted display (HMD) that can be used in any situation. Users can express "Yes" or "No" to their surroundings without moving their gaze, directing attention solely to the target. Targets are displayed on the HMD and flicker periodically in different phases. The intention-estimation algorithm determines which target the user selects based on the pattern of changes in pupil diameter. To evaluate the system's performance, an experiment was conducted with one patient with ALS who has difficulty with speech and writing. The results showed that the accuracy of intention estimation for yes/no responses was 100 %, and the average time to estimate the intention was 6.88 s. In conclusion, we confirmed the feasibility of a daily communication system based on pupil diameter for patients with severe disabilities because of ALS.**

I. INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive neurodegenerative disease characterized by the selective loss of motor neurons in the brainstem and spinal cord. This progression gives rise to a diverse array of signs and symptoms, including extremity paralysis, muscle atrophy, dysphagia, dysarthria, and impaired respiratory function [1-3]. As a characteristic of ALS, patients' sensory and cognitive functions are typically preserved. Patients can perceive pain, urination, and bowel movements, and can receive and decipher information from their environment [4]. However, patients encounter severe communication impairments in speaking and writing because of the progressive loss of voluntary motor function. Thus, it is essential to enhance their quality of life through a communication system that assists with interactions with others, employment, and writing, ultimately fostering vibrant lives free from social alienation [5-8].

Patients with disabilities because of ALS often use various alternative communication methods instead of speech and writing, utilizing eye movements that are preserved until the disease progresses [4]. We previously proposed and developed new interfaces that allow communication through written information based on eye movements [9]. This is known as Augmentative/Alternative Communication. With symptom progression, eye movement function gradually declines. It has been reported that eye movement input systems are difficult to use because of the significant burden of moving the eyeballs during calibration, which is essential for eye movement estimation and fixing the gaze point for a certain period to input text. Regarding intention estimation by caregivers, only highly skilled caregivers are capable of capturing text information and yes/no intentions by eye movements. Therefore, even when visual eye movements are possible, the use of this system is limited and depends on skilled caregivers. Caregiver proficiency and one-on-one assistance are required; however, there are limitations to 24-hour support by a highly skilled caregiver [10]. When symptoms also affect eye movements, few widely used methods are available, and those that have been studied are mostly based on EEG and other methods [11]. Therefore, patients with eye movement disorders because of ALS and their caregivers must seek alternative communication methods and try EEG-based systems once eye movement-based systems become difficult to use owing to the progression of symptoms. As switching communication systems requires caregivers and patients to select, purchase, install, test, and train on equipment, which can be a significant burden, a unified communication system capable of adapting to the progression of symptoms is essential. To achieve this, it is necessary to develop a communication method that is not based on eye movements, but can be integrated into the eye movement-based interfaces we have proposed and developed.

For a communication system that can consistently adapt to the progression of symptoms, a system based on eye information, which is prevalent among patients with severe

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ALS, is desirable. The remaining ocular function of patients with ALS who experience difficulty with both eye movements and communication, including speech and writing, is the ability to modulate pupil diameter. The autonomic nervous system regulates pupil dilation and contraction. Therefore, the system may be applicable to many patients with ALS whose autonomic nervous system remains unaffected [12]. In this study, we focused on a method to induce changes in pupil diameter by directing attention to a target with periodic changes in light intensity [13]. A previous study showed that users can select a target by focusing their attention independently of eye movements and discriminating user selection based on changes in pupil diameter synchronized with the light intensity of the selected target. However, the system has only been verified in a laboratory environment with controlled room luminance and has not yet been implemented in practical settings.

The purpose of this study was to develop a communication method that consistently adapts to the progression of symptoms, based not on eye movement but on changes in pupil diameter, to enable patients with severe disabilities because of ALS to communicate daily, even when their eye movement symptoms change, and to confirm the feasibility of the developed system for reflecting the communication, intentions of patients with ALS.

II. MATERIAL AND METHODS

This section describes the presentation of visual stimuli designed to induce changes in pupil diameter based on the user's choice and the research and development of algorithms to estimate the user's selection.

A. System Configuration

An overview of the proposed system is presented in Fig. 1. An interface usable on a daily basis by people with disabilities caused by ALS requires no restrictions on the conditions of use. Because people with disabilities routinely receive assistance, such as massage, transfers, and bathing, a system that requires a screen monitor or sensor to be fixed in front of the patient's face cannot be used during these interventions, thereby limiting its usability. Therefore, the system was designed as a wearable solution that does not require fixation in front of the patient's face. The hardware of the developed system is the VIVE Pro Eye (HTC), an HMD integrated with a pupil diameter measurement sensor, and gaze estimation sensor (Fig. 2)[14]. The use of an HMD eliminates the need to maintain constant light intensity in the room because the system's video presentation delivers light only to the eyeballs and is unaffected by changes in ambient light. The VIVE Pro Eye operates at a frame rate of 90 fps and has display resolution of 2880 × 1600 pixels.

B. The Method of Inducing a Pattern of Cognitive Pupil Diameter Changes in Response to User Selection

This section describes the visual stimuli used to induce pupil diameter changes based on the target selected by the user. It is known that pupil diameter changes due to cognitive factors, in addition to the regulation of the amount of light entering the retina (pupillary light reflex) and changes in the perspective of the gazing target (accommodation reflex)[15]. In this study, visual stimuli were presented under conditions in which the light intensity of the screen displayed on the HMD was kept constant to prevent the occurrence of a light reflex. Therefore, pupil diameter changes in response to the target selected by the user occur because of cognitive factors alone. If the target to which the user is directing their attention is white (bright), the pupil diameter decreases; if the target is black (dark), the pupil diameter increases. Similarly, pupil diameter increases when the target color changes from white to black over time, and it decreases when the target color changes from black to white over time. Thus, it is possible to induce two distinct patterns of pupil diameter changes in response to user selection by presenting two targets with color changes set in opposite phases.

C. Selection-discrimination System GUI

The target arrangement of this system is shown in Fig. 3. The GUI consists of four targets: A, B, C, and D. Target C changes in the same way as target A, and target D changes in the same way as target B. Target A displays “No” and Target B displays “Yes” in Japanese. When the user wants to express “No,” they select target A; when they want to express “Yes,” they select target B. Although there are four targets (A to D), only targets A and B are selectable. This design is based on a

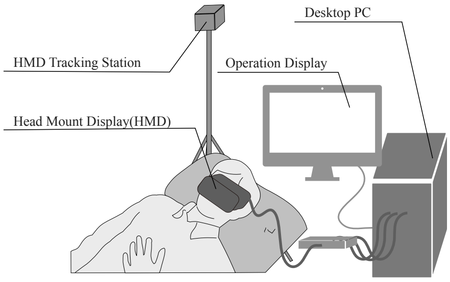

Figure 1. Overview of the Developed System

Figure 2. VIVE Pro Eye

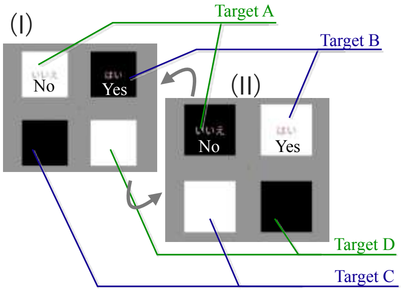

Figure 3. Target Arrangement in the System

previous study [13], which reported that estimation accuracy increased when four targets were placed, with only the upper two being selectable. Regarding the size and spacing of the targets, preliminary experiments by the developer determined an arrangement with high estimation accuracy: the spacing between targets was 21 °, and each side of the target square measured 42 °. These parameters were adjustable to facilitate user attention, considering individual differences in viewing angle.

The color transitions for each target are shown in Fig. 4. In the preliminary experiments of this study, it was observed that changes in pupil diameter synchronized with the target's color transitions occurred approximately 1 s after the color change. Therefore, the target color was continuously presented for 1 s, and 0.25 s were allocated for the color transition. Each cycle was set to last 2.5 s. During each cycle, the target colors change as follows: For Targets A and D, the color transitions from white to black between 0 and 0.25 s. The color remains black from 0.25 to 1.25 s. From 1.25 to 1.5 s, the color transitions from black to white, and it remains white from 1.5 to 2.5 s. For Targets B and C, the color transitions from black to white between 0 and 0.25 s. The color remains white from 0.25 to 1.25 s. From 1.25 to 1.5 s, the color transitions from white to black, and it remains black from 1.5 to 2.5 s. Each target continuously changes its color in cycles from the start of the system operation until the termination command is executed. The results of the user's choice, as determined by the system, are communicated to the user and surrounding environment, as shown in Fig. 5, with a "Yes" (Fig. 5(a)) or "No" (Fig. 5(b)) on the screen and sound, depending on the determination result when the process is complete.

D. Selective Target-detection Algorithm

This section describes the algorithm developed to estimate the target selected by the user and to which the user is directing attention based on changes in the pupil diameter. Let $PS_F(i)$ denote the pupil size during the first half (Pupil Size First-half) of each frame 1 to 1.25 s after the start of each cycle, and $PS_L(\hat{i})$ denote the pupil size during the latter half (Pupil Size Latter-half) of each frame 2.25 to 2.5 s after the start of each cycle. For each trial, let PS_F be the overall average of $PS_F(i)$and let PS_F be the overall average of $PS_L(\hat{i})$. If $PS_F > PS_L$, the pupil diameter in the first half of the cycle is smaller. Therefore, we can assume that the target the user is paying attention to in the first half of the cycle has changed from white to black in the second half. Because the Target A changes to white in the first half of the cycle and black in the second half, we can determine that the user selected and paid attention to Target A. Similarly, if $PS_F < PS_L$, the user selects Target B.

III. BASIC PERFORMANCE EXPERIMENT

A performance evaluation experiment was conducted to confirm that the developed system is capable of supporting daily communication by the user based on induced changes in pupil diameter. The experiment was conducted with a male patient with ALS who exhibited difficulty communicating through speech and writing. Regarding the eye movement symptoms of the participant, the system that tracks eye movements to type letters is difficult to use, and only skilled caregivers can read letters using the eye transfer (ETRAN) board through eye movements. The ETRAN board is a communication tool widely used by people with speech and writing difficulties. In this method, a caregiver moves a transparent board with characters or prepared phrases written in advance in front of the user's face, and the user's choice of letters is identified based on the user's and caregiver's gazes. The range of possible eye movements was limited, and it was difficult to calibrate eye tracking to see the edges of the screen, for example. To verify the correctness of the system's intention-estimation results in communication, the participant was able to communicate daily with the ETRAN board [16] by highly skilled caregivers.

The experiment consisted of four tasks: A. Steady state of the participant's pupil diameter, B. Confirmation of the optical reflex, C. Intention estimation using the developed system while maintaining attention on the target for 30 s, and D. The participant responded by expressing "Yes" or "No" to their surroundings using the system. An overview of the experimental environment is shown in Fig. 6. The operator manipulated the screen projected onto the HMD and instructed the caregiver to attach it after confirming that the HMD projection was completed successfully. The caregiver manually placed the HMD on the participant's face. The start time was when the experimental operator determined that the participant had put on the system and was ready.

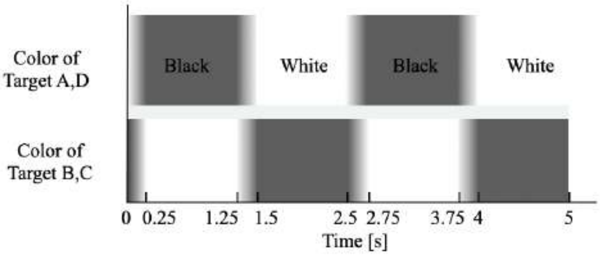

Figure 4. Relationship between Target colors and duration times.

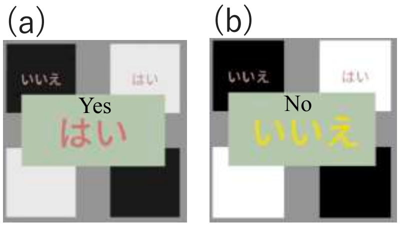

Figure 5. Video displaying the results of the system's estimation of the user's intention

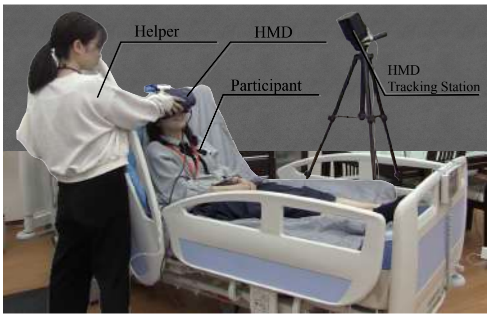

Figure 6. Overview of experiment environment

This study was approved by the Research Ethics Committee of the Graduate School of Systems and Information Engineering, University of Tsukuba. Informed consent was obtained from all participants. (Approval number: 2024R883)

A. Steady State of the Participant's Pupil Diameter

The participant watched a gray, unchanging screen for 30 s in a relaxed state. After 30 s, the experimental operator instructed the caregiver to remove the HMD. To reduce the burden on the participant, the task was completed once if the steady state was confirmed, and twice otherwise.

B. Confirmation of the optical reflex

To confirm the participant's ability to contract their pupil diameter, a visual stimulus with light intensity changing every 3 s was presented on the HMD. The participant viewed the images displayed on the HMD in a relaxed state for 30 s. To minimize the burden on the participant, the experiment was completed after a single trial if the change in pupil diameter in response to the presented light intensity was confirmed, or after a second trial otherwise.

C. Intention Estimation Using the Developed Interface

The participant alternately selected “Yes” and “No” twice using the system. In Task C, the experimental operator specified the target to be selected for each trial. Changes in pupil diameter and eye-opening rate while using the interface were measured, and the developed algorithm was used to estimate the participant's choice. Fig. 3 shows the screen projected by the HMD. The participant directed their attention to the designated target while viewing the interface for 30 s. To measure changes in pupil diameter while looking at the interface, measurements continued for 30 s, even if the algorithm's estimation of the participant's choice ended earlier. The algorithm that estimates whether the user has selected "Yes" or "No" uses the pupil diameter of either the left or right eye. The experimental operator determined which eye's pupil diameter to use based on the results of Tasks A and B, and configured the system accordingly. Because the developed system does not require eye movements for target selection, the operator does not provide any instructions regarding the position of the gazing point but only instructed the participant to direct their attention to the target.

D. Expressing Yes/No to the Surroundings Using the System

The participant used the interface to communicate their "Yes" or "No" intentions to those around them in response to questions, enabling free communication. Intention estimation was performed four times. The experimental operator determined which eye's pupil diameter is used for estimation based on the results of Tasks A, B, and C, and configured the system accordingly. Fig. 3 shows the screen projected by the HMD. After listening to the questions, the participant wore the system and responded by directing their attention toward the target to be selected. The operator did not provide any instructions about the participant’s gazing position during the intention estimation, only asked them to direct attention to the target. When communicating with the participant, the system was used to respond to questions from their surroundings, and then the highly skilled caregiver received the answers using the ETRAN board, which the user usually uses, to confirm the answers. The results of the estimation were displayed by the system to the user and others on the screen shown in Fig. 5, as well as by a voice indicating “Yes” or “No.” The caregiver removed the HMD after the estimation results were displayed.

IV. RESULT

Figs. 7 and 8 show representative results from Task A, illustrating changes in the participant's eye-opening rate and pupil diameter without visual stimulation. The average percentages of eye openness, with the fully open state defined as 100 %, were 87.7 % and 25.9 % for the left and right eyes in Trial 1, respectively; 41.9 % and 10.6 % in Trial 2; and 47.2 % and 8.7 % in Trial 3.

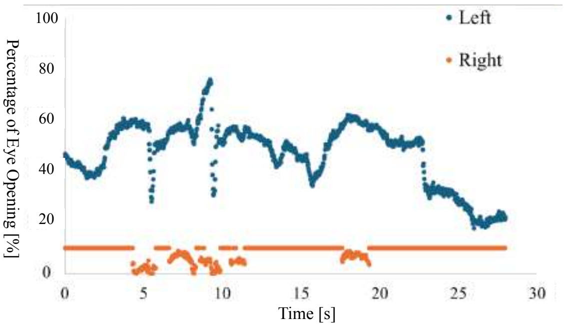

Figure 7. Task A: Changes in eye-opening rate without visual stimulation

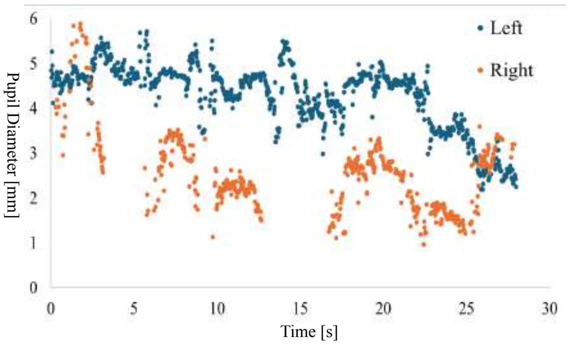

Figure 8. Task A: Changes in pupil diameter without visual stimulation

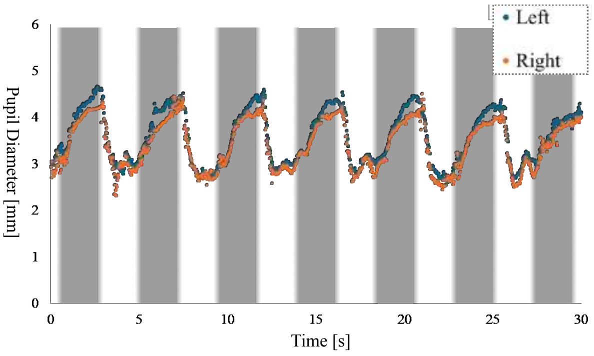

Figure 9. Task B: Changes in pupil diameter when visual stimuli with periodically changing light intensity are presented.

TABLE I. User selections, system estimation results, processing time for estimation, maximum and minimum pupil diameters (left eye), and average eye openness across all trials of Tasks C and D.

Trial	Task C				Task D			
	1	2	3	4	5	6	7	8
User's Choice	Yes	No	Yes	No	Yes	Yes	Yes	No
System's Answer	Yes	No	Yes	No	Yes	Yes	Yes	No
Time taken to estimate [s]	6.983	7.094	7.201	7.117	6.768	6.399	6.078	7.365
Maximum pupil diameter of left eye [mm]	4.948	4.618	4.836	4.843	5.302	5.481	5.642	5.038
Minimum pupil diameter of left eye [mm]	3.949	3.615	3.900	3.476	4.414	4.539	4.381	3.966
Average degree of left eye openness	99.4%	98.7%	93.2%	96.2%	100%	95.1%	98.9%	99.2%
Average degree of right eye openness	99.9%	99.3%	86.3%	90.8%	100%	68.3%	99.6%	98.3%

The changes in pupil diameter in Task B are shown in Fig. 9. The black-masked area in the graph represents the time periods when darker images are presented. The maximum pupil diameter in Task B was 4.66 mm, and the minimum was 2.55 mm, resulting in a maximum pupil diameter change of 2.11 mm owing to visual stimulation. Table I shows the participants' choices for all trials of Tasks C and D, the results of the system's estimation of the participant's intention, the time required to estimate the participant's choice, the maximum and minimum pupil diameters, and the average percentages of the left and right eyes open during the estimation. Because the left eye was used for intention estimation in Tasks C and D, based on the results from Tasks A and B, the maximum and minimum pupil diameters shown in the table correspond to the left eye. The developed system correctly estimated the participant's choices in all trials. Representative results of the changes in the participant's eye-opening rate in Tasks C and D, and the change in pupil diameter, are shown in Figs. 10 and 11. The average time used by the system to estimate the participant's choices in Tasks C and D was 6.88 s. Figs. 9 and 11 show that the difference between the maximum and minimum pupil diameters was 0.57 mm smaller when the visual stimuli of varying light intensity were presented than when the intention estimation interface was used.

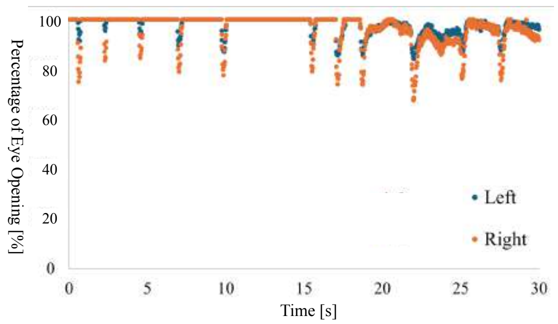

Figure 10. Task C: Changes in eye-opening rate during the use of the intention estimation interface in Trial 4 (selection: No).

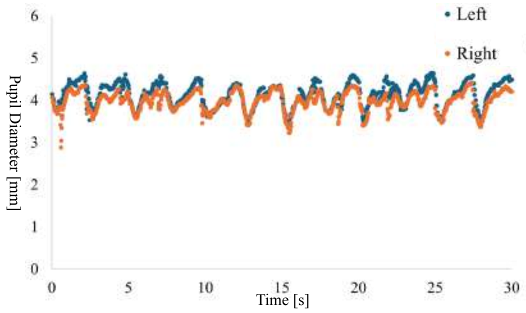

Figure 11. Task C: Changes in pupil diameter during the use of the intention estimation interface in Trial 4 (selection: No).

V. DISCUSSION

In this experiment, the participant, who was unable to speak and write and had difficulty with eye movements, was able to communicate their intentions to their surroundings with 100 % accuracy using the system. The results showed that the developed system could be used for daily communication by patients with severe disabilities caused by ALS. In addition to the experiment in which the developer specified "Yes" or "No" for the user, the system was also successfully used as a tool for expressing the patient's own intentions during conversation, indicating not only the successful estimation of intentions but also its potential as a communication tool in daily life. In Task B, the change in light intensity caused the pupil diameter to change from 2.55 mm to 4.66 mm, providing us with an upper and lower limit for the changes in pupil diameter that our system can induce. In Tasks C and D, the pupil diameter changed 1.06 mm in average when the interface was used, suggesting that the interface could be adjusted to induce even greater changes, thereby improving the system's accuracy. It has also been reported [17] that 37 % of the time, the system was able to correctly estimate the target even when the user was not looking directly at it, but instead in the peripheral field of view.

In terms of the eye-opening rate, Fig. 7 shows that participant's eyes were less open when measuring the pupil diameter without the system's interface. However, the system was able to capture changes in the pupil diameter, as shown in Fig. 8. When the interface was presented and attention was directed toward the target, the eye-opening rate increased, as seen in Fig. 10. Although the participant was not instructed to open their eyes, it is possible that their eye-opening rate increased when the target was placed in the upper half of the screen. It was also suggested that if the eye-opening rate needs to be improved during the system's usage, assistance could be provided using eyelid tape to assist eye-opening when using the system as well, as it is commonly used for eye-opening in communication between patients and caregivers. The developer briefly confirmed that the system could be used successfully when eyelid tape was applied.

The change in pupil diameter can be captured more accurately by considering less micro saccade movement owing to the symptomatic eye movements of the target user. This allows for intention-estimation based on small changes in pupil diameter. The white/black switching cycle of the interface was set it to 1.25 s, considering the responsiveness of the pupil diameter change [14]. The optimal time-change parameter could also be set using a mathematical model of pupil diameter to induce more accurate and larger pupil diameter changes, thereby improving the system's accuracy. Furthermore, the communication method developed in this study, based on changes in pupil diameter, could be integrated with our previously developed system for transmitting textual information [10]. The integrated system would be a communication tool that can consistently adapt to symptoms, regardless of eye movement functions, using a single system. This is expected to reduce the physical, financial, and time burden on users and caregivers when switching communication methods based on the user's changing symptoms. In the future, we plan to verify the feasibility of using the integrated system in daily life based on the user's eye movements with the cooperation of patients with ALS.

VI. CONCLUSION

We developed a communication method that consistently adapts to the progression of symptoms based on changes in the pupil diameter, enabling patients with severe disabilities because of ALS to communicate daily, even when their eye movement symptoms change. The developed system does not require eye movements, but only changes in pupil diameter. The system induces changes in pupil diameter and uses an algorithm to estimate the user's yes/no responses. In the experiment, a participant with a disability in speaking and writing caused by ALS was able to use the system to communicate responses to questions from his surroundings with 100 % accuracy. Consequently, the feasibility of the developed method for transmitting intentions by patients with disabilities caused by ALS with severe symptoms was confirmed.

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