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BrainShare: A Glimpse of Social Interaction for Locked-in Syndrome Patients

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ABSTRACT

Locked-in syndrome (LIS) patients are partially or entirely paralyzed but fully conscious. Those patients report a high quality of life and desire to remain active in their society and families. We propose a system for enhancing social interactions of LIS patients with their families and friends with the goal of improving their overall quality of life. Our system comprises a Brain-Computer Interface (BCI), augmented-reality glasses, and a screen that shares the view of a caretaker with the patient. This setting targets both patients and caretakers: (1) it allows the patient to experience the outside world through the eyes of the caretaker and (2) it creates a way of active communication between patient and caretaker to convey needs and advice. To validate our approach, we showcased our prototype and conducted interviews that demonstrate the potential benefit for affected patients.

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CCS CONCEPTS

• **Human-centered computing → Human computer interaction (HCI)**; *Interaction paradigms*; Mixed / augmented reality;

KEYWORDS

locked-in syndrome; brain-computer interaction; augmented reality; social interaction.

INTRODUCTION

Locked-In Syndrome (LIS) is a medical condition where conscious patients remain in full possession of their cognitive abilities yet are unable to produce any kind of speech or move their face or limbs [6]. This results in a patient who is aware and can perceive the surrounding environment but cannot move and has minimal interaction capabilities. LIS patients' primary way of communication is through their eyes, as they can produce vertical eye movements and blinks [10].

Holt-Lunstad et al. [3] analyzed the results of 148 studies with 308,349 participants, showing that poor social relationships ranks top among mortality risk factors. Hence, the goal of this work is to provide means to support and enhance social relationships.

Several approaches have been developed to facilitate the interaction of the patients and their caregivers. Some use non-technical ways [11], while others employ techniques, such as Brain Computer Interaction (BCI) [12] and eye gaze detection [5]. Although the usability of eye gaze is superior to BCI [9], BCI is more practical in cases where patients suffer from a Complete Locked-In Syndrome (CLIS), as they also lose control over their gaze [4]. Previous approaches aim to ameliorate interaction techniques to the best of our knowledge none of them focuses on improving patients' social interaction.

In this paper, we present BrainShare a system that seeks to mitigate the social interaction challenges of LIS patients. In our system, we make use of a human proxy (i.e., caregiver) that acts on behalf of the patient. This new concept grants the patient the chance to be involved in the daily activities and social interactions of the proxy as well as creating a direct way of communication to convey all of the patients' needs and requirements. In particular, the patient can select items representing a need or a demand and receive feedback through a display that shows the proxy's real-time view while wearing Augmented Reality (AR) glasses.

We designed and built a proof-of-concept prototype of the BrainShare system: the communication between patient and proxy occurs through a P300 BCI system on the patient's side, and the targeted commands are displayed on AR glasses (Microsoft HoloLens) on the proxy's side. Additionally, there is a display on the patients' side, continuously showing live feedback from the proxy.

Early insights complement our work. In particular, we conducted interviews with two doctors that had previous experience with LIS patients and report on their recommendations.

Figure 1: A Locked-In Syndrome (LIS) patient conveys a need from a grid (i.e., cup of water) using P300 system to the caregiver wearing AR glasses. The patient receives live feedback through the caregiver view (i.e., caregiver bringing a cup of water).

CONCEPT

According to Lugo et al. [7], the communication means for LIS patients should be motivating, and grant the patient a chance to send and receive information. Based on that we designed a concept that not only aids LIS patients to express themselves, but also to receive live feedback.

Our concept is composed of three main entities (Figure 1), enabling a patient to ask the proxy to perform a particular task while receiving real-time feedback. The first entity is a display on the patient's side. A live stream of the proxy view is shown, involving the patient in all the actions that the proxy is doing. The second entity is a pair of Augmented Reality (AR) glasses worn by the proxy (i.e., caregiver). The AR glasses are the patients' window to the external world. The third entity is a brain-computer interaction system, measuring a P300 Event-Related Potential (ERP). This helps the patient to select from among a set of commands (i.e., asking for a cup of water).

IMPLEMENTATION

In 1964, Chapman and Bragdon [1] discovered that the ERP responses to visual stimuli are affected by how meaningful the stimulus is. They presented the participants two numbers and asked them to decide which one was smaller than the other. The amplitude of the ERP response resulting from the targeted stimulus was higher and appeared around 300 ms after the stimuli. The appearance of this effect was further examined [13, 14] and became known as P300 BCI systems.

Lugo et al. [8] used the elicited signals retrieved from P300 BCI systems to instantiate a way of somatosensory communication for LIS patients using a vibrotactile oddball paradigm. The system was tested on six LIS patients. All participants elicited a P300 wave, yet the accuracy with correspondence to the triggered stimuli differed across the participants. In a recent study by Guy et al. [2], 20 Amyotrophic Lateral Sclerosis (ALS) and locked-in patients tested a P300 based speller with word prediction. About two-thirds of participants achieved an accuracy of more than 95 %.

To create a prototype of our proposed concept, we used a state-of-the-art P300 based speller by the G.TEC Medical Engineering company. The elements that can be selected from the interface are arranged in a grid and are highlighted in quick succession to the BCI user. Simultaneously, the P300 signal, which is related to decision-making [1], is measured and used to distinguish which of the elements the user is focusing on. We configured a grid layout to show context-related actions to the BCI user (Figure 2). Therefore, we implemented four different sets of actions: navigation, food, indoor, and outdoor. Which set of actions is active and available for selection depends on the location and context of the caregiver. Despite the displayed grid being always the same, we can use the context information to decrease selection errors. Therefore, the grid is arranged in a way that actions belonging to the same context are never direct neighbors. Hence, if a user selects an icon that is not available due to the current context, the active neighbor action is selected.

Figure 2: The grid of the P300 speller that is shown to the LIS patient.

On the proxy side, we used AR glasses to display selected items. We implemented our application for the Microsoft HoloLens, using the Unity engine as a platform. The speller already integrates a network interface which was used to send the selected elements to the proxy. The application receives the message and is able to display the selected item that is then sent via TCP to the HoloLens application. Those actions are then shown to the proxy in the form of a three-dimensional arrow object or as an icon. This object is displayed in the wearer's field of view for three seconds, every time an element is sent.

Simultaneously, we used the HoloLens Device Portal to show a live-stream of the proxy's view to the BCI user. This allows for experiencing and following the social interactions of the active user.

PROOF-OF-CONCEPT & EVALUATION

We tested our system in two different scenarios to communicate different tasks. We asked one participant to operate the P300 system (hence simulating the patient side) and another participant was wearing the HoloLens (hence simulating the proxy).

The first testing scenario was to ask the proxy to head to a park and use the system to navigate through the park (see Figure 3). In this scenario, the static participant chose the park symbol and various arrows to point out the direction. The second testing scenario was to convey a need, where the proxy was in a kitchen and the patient requested a drink.

Procedure. We video-recorded the participants while using our system. Later, we showed the video to two neurologists (i.e., D1 & D2). We gathered their feedback using a semi-structured interview. In the interview, we asked them to provide feedback regarding the utility of the system, potential activities that the patients might be interested in, and general recommendations.

Results. Both doctors appreciated the general concept and design of the system. In particular, they stated that designing such a system *"that can enhance the communication for this patient would be great"* (D2). They found the system valuable because *"locked-in people are usually in some kind of an institute where they would need social interaction"* (D1).

D1 highlighted that, currently, communication is limited to eye movements, where a specific direction indicates 'yes' and another indicates 'no'. Furthermore, D1 elaborated that such a system would *"give the patient the opportunity to choose a question or an idea from among a set of options instead of a yes/no action"*. In addition, it would be interesting for use by *"a family or a friend"* (D2). D2 pointed out that one major challenge such patients face is the speed of communication. He suggested to focus on this aspect and try to make the interaction as fast as possible.

Finally, D2 raised one concern, which is the social acceptance. He is concerned that caregivers may experience the system as too *"invasive"* in case the glasses are worn too extensively.

Figure 3: A static person operating the P300 interface to communicate navigational directions with the proxy through augmented reality glasses (i.e., HoloLens).

RESEARCH CHALLENGES

The current work represents a first step towards designing a novel social interaction technique for Locked-In Syndrome (LIS) patients and their caregivers, where the patients are continuously involved in the caregivers' activities. Our results highlight three main aspects for further investigation.

Interaction Speed

As D2 pointed out, the communication speed is of utmost importance for patients. As a result, future work could look into how this can be further enhanced. For example, our approach could employ different technologies, such as BCI and eye gaze, based on the severity of the patient's condition [4] or even combine them. Future work could also look into how the number of possible options to choose from can be reduced by learning and predicting the most likely request of the patient.

System Design and Social Implications

Further work could focus on the design of the user interface of our system. One aspect is how to visualize requests in the visual field of view of the caregiver and how to convey urgency. The system could take into account the current activity of the caregiver and adjust accordingly. In addition, it is unclear yet, how to adjust, modify, or cancel requests by patients.

Another critical aspect revolves around the question, how the system could create an active and easy-to-use way of communication while at the same time respecting the caregiver's privacy. One possible direction for future work could be to investigate who should be given how much control of when to initiate or restrict social interaction through our system.

Application Areas

Finally, application areas could be investigated in more detail. In particular, challenges may arise from the fact that the patients' needs and preferences may change. This will create the need to include novel types of requests. It is yet unclear, how an interface to edit possible requests will look like and who would be the users. Notably, in cases where caregivers are non-experienced relatives, this becomes a significant challenge to be addressed.

CONCLUSION AND FUTURE WORK

With our work, we took a first step towards enhancing social interactions of LIS patients. Our preliminary investigation revealed many interesting directions to follow up on our work. We hope to spark discussions in the community and to obtain valuable feedback on how to further develop and adapt the concept.

REFERENCES

[1] Robert M Chapman and Henry R Bragdon. 1964. Evoked responses to numerical and non-numerical visual stimuli while problem solving. *Nature* 203, 4950 (1964), 1155.

[2] Violaine Guy, Marie-Helene Soriani, Mariane Bruno, Theodore Papadopoulo, Claude Desnuelle, and Maureen Clerc. 2018. Brain computer interface with the P300 speller: Usability for disabled people with amyotrophic lateral sclerosis. *Annals of physical and rehabilitation medicine* 61, 1 (2018), 5–11.

[3] Julianne Holt-Lunstad, Timothy B Smith, and J Bradley Layton. 2010. Social relationships and mortality risk: a meta-analytic review. *PLoS medicine* 7, 7 (2010), e1000316.

[4] Veronica Johansson, Surjo R Soekadar, and Jens Clausen. 2017. Locked Out: Ignorance and Responsibility in Brain–Computer Interface Communication in Locked-in Syndrome. *Cambridge Quarterly of Healthcare Ethics* 26, 4 (2017), 555–576.

[5] Ki-Young Kwon, Jae-Yong An, Sung-Wook Shin, Se-Jin Yoon, and Sung-Taek Chung. 2016. Communication Board and Visual PerceptionTraining Contents with Gaze Tracking for Augmentative and Alternative Communication (AAC). *Indian Journal of Science and Technology* 9, 45 (2016).

[6] Miriam Kyselo and Ezequiel Di Paolo. 2015. Locked-in syndrome: a challenge for embodied cognitive science. *Phenomenology and the cognitive sciences* 14, 3 (2015), 517–542.

[7] Steven Laureys, Frédéric Pellas, Philippe Van Eeckhout, Sofiane Ghorbel, Caroline Schnakers, Fabien Perrin, Jacques Berre, Marie-Elisabeth Faymonville, Karl-Heinz Pantke, Francois Damas, et al. 2005. The locked-in syndrome: what is it like to be conscious but paralyzed and voiceless? *Progress in brain research* 150 (2005), 495–611.

[8] Zulay R Lugo, Javi Rodriguez, Alexander Lechner, Rupert Ortner, Ithabi S Gantner, Steven Laureys, Quentin Noirhomme, and Christoph Guger. 2014. A vibrotactile p300-based brain–computer interface for consciousness detection and communication. *Clinical EEG and neuroscience* 45, 1 (2014), 14–21.

[9] Emanuele Pasqualotto, Tamara Matuz, Stefano Federici, Carolin A Ruf, Mathias Bartl, Marta Olivetti Belardinelli, Niels Birbaumer, and Sebastian Halder. 2015. Usability and workload of access technology for people with severe motor impairment: a comparison of brain-computer interfacing and eye tracking. *Neurorehabilitation and neural repair* 29, 10 (2015), 950–957.

[10] Eimear Smith and Mark Delargy. 2005. Locked-in syndrome. *Bmj* 330, 7488 (2005), 406–409.

[11] Sinikka Söderholm, Monica Meinander, and Hannu Alaranta. 2001. Augmentative and alternative communication methods in locked-in syndrome. *Journal of rehabilitation medicine* 33, 5 (2001), 235–239.

[12] Vignesh Sureshkumar and Kumar Saravana. 2014. A computer based communication aid for paralytic patients using EEG. *Engineering Sciences International Research Journal* 2 (2014).

[13] Samuel Sutton, Margery Braren, Joseph Zubin, and ER John. 1965. Evoked-potential correlates of stimulus uncertainty. *Science* 150, 3700 (1965), 1187–1188.

[14] Samuel Sutton, Patricia Tueting, Joseph Zubin, and E Roy John. 1967. Information delivery and the sensory evoked potential. *Science* 155, 3768 (1967), 1436–1439.