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ORIGINAL ARTICLE

Long-Term Independent Brain-Computer Interface Home Use Improves Quality of Life of a Patient in the Locked-In State: A Case Study

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Abstract

Objective: Despite intense brain-computer interface (BCI) research for >2 decades, BCIs have hardly been established at patients' homes. The current study aimed at demonstrating expert independent BCI home use by a patient in the locked-in state and the effect it has on quality of life.

Design: In this case study, the P300 BCI-controlled application Brain Painting was facilitated and installed at the patient's home. Family and caregivers were trained in setting up the BCI system. After every BCI session, the end user indicated subjective level of control, loss of control, level of exhaustion, satisfaction, frustration, and enjoyment. To monitor BCI home use, evaluation data of every session were automatically sent and stored on a remote server. Satisfaction with the BCI as an assistive device and subjective workload was indicated by the patient. In accordance with the user-centered design, usability of the BCI was evaluated in terms of its effectiveness, efficiency, and satisfaction. The influence of the BCI on quality of life of the end user was assessed.

Setting: At the patient's home.

Participant: A 73-year-old patient with amyotrophic lateral sclerosis in the locked-in state.

Interventions: Not applicable.

Main Outcome Measure: The BCI has been used by the patient independent of experts for >14 months. The patient painted in about 200 BCI sessions (1−3 times per week) with a mean painting duration of 81.86 minutes (SD=52.15, maximum: 230.41). BCI improved quality of life of the patient.

Results: In most of the BCI sessions the end user's satisfaction was high (mean=7.4, SD=3.24; range, 0−10). Dissatisfaction occurred mostly because of technical problems at the beginning of the study or varying BCI control. The subjective workload was moderate (mean=40.61; range, 0−100). The end user was highy satisfied with all components of the BCI (mean 4.42−5.0; range, 1−5). A perfect match between the user and the BCI technology was achieved (mean: 4.8; range, 1−5). Brain Painting had a positive impact on the patient's life on all three dimensions: competence (1.5), adaptability (2.17) and self-esteem (1.5); (range: −3 = maximum negative impact; 3 maximum positive impact). The patient had her first public art exhibition in July 2013; future exhibitions are in preparation.

Conclusions: Independent BCI home use is possible with high satisfaction for the end user. The BCI indeed positively influenced quality of life of the patient and supports social inclusion. Results demonstrate that visual P300 BCIs can be valuable for patients in the locked-in state even if other means of communication are still available (eye tracker).

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Brain-computer interfaces (BCIs) enable persons with severe motor paralysis (eg, from amyotrophic lateral sclerosis [ALS], stroke, spinal muscular atrophy) to communicate and control devices. Several studies have demonstrated that patients with severe motor impairments can control a visual P300 BCI for communication,[1,2-5] entertainment,[6-8] environmental control,[9] and e-mailing and Internet surfing.[1,10] For reviews see Mak[11], Kübler,[12] Kleih,[13] Sellers,[14] and colleages.

Despite intense BCI research for >2 decades, studies with end users are sparse compared with studies with healthy subjects.[15,16] Moreover, BCIs have hardly been established at the patient's home. To our knowledge there are only 3 studies that demonstrate independent BCI home use in locked-in end users

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diagnosed with ALS. One user surfed the Internet by regulating slow-cortical potentials[17,18] and another user used the P300 BCI for writing e-mail, speech generation, environmental control, and pursuing his science career for >2.5 years.[10] However, quantitative data were not reported. Patients with ALS who are locked-in may wish to be able to pursue other satisfying leisure activities that enhance quality of life.

In the present study, the BCI-controlled application Brain Painting was implemented for independent home use in 1 patient in the locked-in state. Brain Painting was developed and improved in an iterative user-centered development process,[1,19,20] including proof of principle,[21] testing by healthy subjects and end users,[6] and redesign. Then, usability metrics were defined[1,22] and BCI prototypes were tested and evaluated by end users.[1,7,8] These studies showed that severely disabled end users expressed a high degree of satisfaction with the BCI devices.[20] However, for daily life use, end users requested easier adjustment of the electroencephalogram (EEG) cap/electrodes, small number of electrodes, dry electrodes, wireless EEG, and higher functioning of the BCI in terms of accuracy and speed. Ease of use was indicated as the most important aspect of a BCI device and a prerequisite for independent BCI home use.[1,7,8] Highest satisfaction was expressed for the Brain Painting application, and 3 of 4 end users reported that they would like to use the Brain Painting application in their daily life, 1 to 2 times per week.[7]

The aims of the present study were to prove the concept of independent BCI home use, evaluate the usability of the BCI for independent home use, and quantify the influence of the BCI on the end user's quality of life.[23] To face the challenges of independent BCI home use, we simplified the BCI application, trained the family members and caregivers to set up the system, used an easy setup EEG cap and a small number of electrodes, provided continuous remote supervision, and evaluated every session.

Methods

Participant

The participant is a 73-year-old woman with ALS (spinal form) in the locked-in state with only residual eye movement. She is artificially ventilated and fed and is able to communicate with eye movements in the partner-scanning mode or with an eye tracker. She lives with her family and full-time caregivers. Painting had been her favorite hobby. Because she has had no application for creative expression, Brain Painting awoke her interest, and her family contacted the Brain Painting team of the University of Würzburg. The study was approved by the Ethical Review Board of the Medical Faculty at the University of Tübingen.

List of abbreviations:

ALS	**amyotrophic lateral sclerosis**
AT	**assistive technology**
ATD PA	**Assistive Technology Device Predisposition Assessment**
BCI	**brain-computer interface**
EEG	**electroencephalogram**
ERP	**event-related potential**
Extended QUEST 2.0	**Extended Quebec User Evaluation of Satisfaction with Assistive Technology version 2.0**
VAS	**visual analog scale**

Easy-to-use Brain Painting application

In Brain Painting (further details are available in Zickler et al[7]), the user can select different tools for painting from a 6×8 P300 matrix (fig 1). A second monitor displays the digital painting constituting the number of selections from the P300 matrix (fig 2). For independent home use, the BCI-2000 based Brain Painting application[a] was embedded into an interface program (Python 2.7; python.org[b]) that enabled the user to simply open Brain Painting and automatically load individual parameters. The BCI application could be handled with a few clicks (eg, open, select painting, start, end, evaluate, close). With every use, the end user could choose a new painting or continue an existing one. Six evaluation questions and a comment query were automatically presented to the end user. There was automatically initiated transmission and storage of BCI data to a remote server for each session.

Onsite support at the end user's home

The Brain Painting application was installed at the end user's home, an initial calibration was performed (calibration 1), and the family was trained to set up the BCI. After 6 weeks an update of the BCI program, including extended evaluation, was installed via remote control. After 2 months there was a second visit to improve stability of the program. Additionally, a second calibration was conducted (calibration 2). After 9 months, the classic flash stimulation was replaced with a face overlay stimulation (Einstein Brain Painting) because face stimuli increase the signal-to-noise ratio of the recorded event-related potentials (ERPs), thereby enhancing the spelling bit rate.[5,24] At the same time, the system was recalibrated (calibration 3). Throughout the study, the end user and her family were using the BCI fully independently (see fig 2), while the BCI team was in close contact with the end user and family via phone and Internet. BCI experts monitored the BCI use on the basis of user evaluation data transmitted to the remote server. A remote desktop application was used enabling modifications and reinstallation (end user received a new personal computer) of the program or the end user's special requests (eg, parameter modification).

Signal acquisition and classification

Detailed information on calibration procedure, classification of signals, and BCI parameters are shown in appendix 1. The EEG was recorded with 8 active electrodes (gamma cap[c]) at the scalp positions Fz, Cz, Pz, P3, P4, Po7, Po8, and Oz[25] according to the International 10-20 system and amplified using a g.USBamp.[c] Signals were classified with the P300-GUI (BCI2000; http://www.bci2000.org).[26] In the first calibration, the end user had 100% accuracy after 8 flashing sequences. Taking noise/distraction into account, the number of sequences was set to 10 (minimum number of flashing sequences plus 2). After calibration with Einstein Brain Painting, 100% correct selections were reached after 3 sequences. Thereafter, the number of sequences was set to 5. ERPs from the electrode Cz from the first, second, and third calibration are depicted in figure 3.