



Developing brain-computer interfaces from a user-centered perspective: Assessing the needs of persons with amyotrophic lateral sclerosis, caregivers, and professionals



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ARTICLE INFO

Article history:

Received 25 March 2014

Accepted 11 March 2015

Available online 31 March 2015

Keywords:

Amyotrophic lateral sclerosis

Brain-computer interfaces

User-centered approach

ABSTRACT

By focus group methodology, we examined the opinions and requirements of persons with ALS, their caregivers, and health care assistants with regard to developing a brain-computer interface (BCI) system that fulfills the user's needs. Four overarching topics emerged from this analysis: 1) lack of information on BCI and its everyday applications; 2) importance of a customizable system that supports individuals throughout the various stages of the disease; 3) relationship between affectivity and technology use; and 4) importance of individuals retaining a sense of agency. These findings should be considered when developing new assistive technology. Moreover, the BCI community should acknowledge the need to bridge experimental results and its everyday application.

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1. Introduction

Amyotrophic lateral sclerosis (ALS) is an inexorably progressive disease that leads to the neurodegeneration of the motor system, causing severe physical disabilities that involve all limbs, swallowing, breathing, and speech. The life expectancy of persons with ALS generally varies between two and four years following diagnosis. Nevertheless, there is high interindividual variability, which makes predictions of life expectancy very difficult (Chiò et al., 2002; Czaplinski et al., 2006).

A small proportion of ALS patients have been estimated to use mechanical invasive ventilation. Although such devices increase life expectancy, they lead to total dependence on electromedical equipment (O'Toole et al., 2008). ALS patients who forgo this

apparatus die in a relatively short time due to respiratory complications.

During its progression, ALS causes the complete loss of oral communication and a significant reduction in nonverbal communication (Hecht et al., 2002; Kübler et al., 2005; Young and McNicoll, 1998). The ability to correspond with family members and caregivers is critical in maintaining a patient's quality of life. Persons with ALS often consider this ability to be more important than retaining strength and physical mobility (Simmons et al., 2000). In an assessment of quality of life using the Schedule for the Evaluation of the Individual Quality of Life (SEIQoL) in 120 patients with ALS, Felgoise et al. (2009) reported that relational and psychological factors were more critical than health and physical aspects. Thus, the loss of communication and relational factors with the environment severely impacts the quality of life of people with ALS and their caregivers.

The ALS Specific Quality of Life-Revised (Felgoise et al., 2007), a questionnaire that measures quality of life specifically in persons with ALS, includes a subscale to assess interaction with others and the environment, emphasizing the impact of such aspects on their

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life. As observed by [Blain-Moraes et al. \(2012\)](#), the ability to maintain autonomy and independence by controlling the environment (e.g., switching television channels, regulating the temperature of a room, turning lights on and off) helps persons with ALS to retain agency and subjectivity, defined in relation to technology by [Moser \(2006\)](#) as a position of consciousness, knowing, thinking, or feeling.

Assistive technology (AT) that meets the needs of persons with ALS could establish new communication and environmental control channels, significantly improving their quality of life. Conventional AT, however, requires a certain degree of muscular control, thus losing its effectiveness once the disease has evolved to the point at which all muscular function is lost. Noninvasive brain-computer interfaces (BCIs) can provide ALS patients a communication channel that is independent of muscular activity, exploiting electroencephalographic (EEG) signals and extracting specific features that are then classified and translated into external commands ([Birbaumer and Cohen, 2007](#); [Cincotti et al., 2008](#)).

BCIs have been used for various purposes, of which two major clinical applications are movement restoration in patients who have been affected by spinal lesions or stroke ([Cincotti et al., 2012](#); [Daly et al., 2009](#); [Kaiser et al., 2011](#); [Pfurtscheller et al., 2003](#); [Ramos-Murguialday et al., 2013](#)) and a communication system for those with motor impairments ([Birbaumer et al., 1999](#); [Donchin et al., 2000](#); [Furdea et al., 2009](#); [Kübler et al., 2009, 2001, 2005](#); [De Massari et al., 2012](#); [Nijboer et al., 2008](#); [Riccio et al., 2012](#)). Other uses include the control of robots and wheelchairs ([Tonin et al., 2011](#); [Carlson and Millán, 2013](#); [Millán et al., 2009](#); [Galán et al., 2008](#); [Tonin et al., 2010](#); [Leeb et al., 2013](#)), internet browsing ([Bensch et al., 2007](#); [Mugler et al., 2010](#); [Mugler et al., 2008](#); [Riccio et al., 2011](#); [Zickler et al., 2011](#)), and gaming ([Bos et al., 2010](#); [Gürkök et al., 2013](#); [Nijholt et al., 2009](#); [van de Laar et al., 2013](#); [Holz et al., 2013](#)).

Although the application of BCIs is limited primarily to a laboratory setting, recent studies have examined the possibility of using BCI in everyday life for environmental control ([Aloise et al., 2011](#); [Babiloni et al., 2007](#); [Cincotti et al., 2008](#); [Kleih et al., 2011](#)). The challenges in bringing BCI technology to daily activities include the design of user-machine adaptation algorithms and the incorporation of human-computer interaction (HCI) principles to improve usability ([Millán et al., 2010](#)). Most research in BCI has focused predominantly on improving the technology—e.g., enhancing signal speed and the accuracy of classification—but more attention should be paid to human factors and the needs of potential users ([Blain-Moraes et al., 2012](#)). In their systematic review of EEG-based BCIs, comprising 127 articles, [Pasqualotto et al. \(2012\)](#) found that most studies concentrated on the development of new algorithms to improve the accuracy of brain signal classification. A user-centered perspective, however, was rarely considered.

Few studies exist on the specific needs of BCI users, as observed by [Blain-Moraes et al. \(2012\)](#) and [Zickler et al. \(2009\)](#), who reported on how extensively research on BCIs has focused primarily on improving technological aspects, such as speed and accuracy, whereas psychological aspects and usability have largely been ignored.

Surveying a focus group on the barriers and mediators of BCI technology in the ALS population, [Blain-Moraes et al. \(2012\)](#) found that relational factors have a significant influence on its acceptance, examining BCI user experience, priorities, and opinions in a group of persons with ALS and their caregivers. In our study, we extended this analysis to a more heterogeneous group to address these issues from various perspectives, generating a complete description of users' needs from the home to the hospital.

To this end, we recruited individuals who had a personal or professional relationship with ALS patients. As the disease

progresses, individuals with ALS become more dependent on those who are close to them (e.g. family members, caregivers, medical personnel), particularly regarding the use of technology. Thus, the experience of these groups must be considered. Specifically, we examined certain applications of BCIs in the communication and domestic domains, in addition to asking participants about their general concerns with communication issues and BCI systems.

In contrast to [Blain-Moraes et al. \(2012\)](#), the participants in our focus group did not have direct experience with BCIs, allowing us to better understand the expectations and needs of new potential end-users. Our chief goal was to determine the needs of persons with ALS and their relatives, and caregivers and professionals who work with ALS with respect to BCI technology.

2. Methods

2.1. Focus group

To gain insight into the needs of ALS patients in terms of AT for communication and control, we implemented the focus group method. This qualitative approach is designed to obtain opinions and feedback on specific topics ([Morgan, 1996](#)), permitting direct examination of individual perception and experience on a topic or problem. It also allows one to consider various opinions and accumulate a more detailed and greater body of data ([Ward et al., 1991](#)), complementing other standardized quantitative methods. As observed by [Blain-Moraes et al. \(2012\)](#), the focus group method enables researchers to describe the perspective of participants “in their own words,” rather than relying solely on numerical data from predetermined rating systems. This tool allows researchers to ask questions that are more relevant to the personal and environmental contexts of the individuals who are involved.

Focus group participants find the experience more stimulating compared with more structured approaches and thus might be more candid in their responses ([Bristol and Fern, 1996](#)). The focus group allows participants to think out loud, modify their opinion, and comment on each other's points of view, often challenging each other and revealing dynamics that are unlikely to emerge in more controlled settings ([Kidd and Parshall, 2000](#)).

The focus group was led by two experienced psychologists: a moderator and an assistant who took notes. The session was video-recorded.

2.2. Participants

We recruited nine participants through the ALS Center of “Policlinico Umberto I” General Hospital, Sapienza University, and the nonprofit association Viva la Vita Onlus, which comprises persons with ALS and their relatives. We included different people who had experience with ALS: a person with ALS, a person who lived with a relative with ALS, a non-cohabiting family member of someone with ALS, a certified assistant, an in-home nurse, a hospital nurse, an occupational therapist, a communication aids expert (e.g., a person who worked for an organization that provides communication aids to those with disabilities), and a medical doctor. The rationale of this diverse sample was to obtain various perspectives on the requirements of a BCI for communication and control and to encompass the spectrum of issues regarding ALS and BCI. This selection was consistent with [Zickler et al. \(2011\)](#) who argued for the importance of including caregivers, family members, and other assistants in evaluating BCI technology, because these individuals have specific ideas and requirements that should be considered.

Potential subjects were informed about the opportunity to take part in a focus group that was centered on BCI, facilitation of

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