Managing Communication for People with Amyotrophic Lateral Sclerosis: The Role of the Brain-Computer Interface

Gaye Lightbody, Brendan Allison and Paul McCullagh

> *Leave no stone unturned*
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> EURIPIDES, Heraclidae

Abstract Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative neurological condition categorized as an orphan disease and at present the primary treatment is managing symptoms. It leads to severe paralysis, resulting in the need for the patient to use assistive technologies to support them in their daily activities. When the condition is severe, mainstream technologies may no longer offer the support required, due to the need for reliable residual movement. Brain computer interfaces (BCI) have the potential to become a powerful assistive technology for some individuals with the most severe of neuromuscular disorders. With only 'thought' as an input medium the user could harness control and communication. Undoubtedly, the availability of such technology could have a major positive impact on the life of a patient with ALS, supporting their inclusion in the world and contact with people around them. However, despite decades of research and development, BCIs are still not commonplace. Many recent advances have been

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G. Lightbody (✉)
School of Computing and Mathematics, University of Ulster, Jordanstown campus,
Shore Road, Newtownabbey, Northern Ireland, Antrim, BT37 0QB, UK
e-mail: g.lightbody@ulster.ac.uk

B. Allison
Visiting Scholar, Cognitive Science Dept, UC San Diego, 9500 Gilman Drive,
La Jolla, CA 92093, USA
e-mail: ballison@ucsd.edu

P. McCullagh
Computer Science Research Institute, School of Computing and Mathematics,
University of Ulster, Jordanstown campus, Shore Road, Newtownabbey,
Northern Ireland, Antrim, BT37 0QB, UK
e-mail: pj.mccullagh@ulster.ac.uk

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made but some factors still prevent widespread deployment of BCI. This chapter will introduce the background of BCI and provide a short discussion about the problems associated with BCI technology, balanced with thoughts about its potential, challenges and hopes for the future.

Introduction

There are many conditions or injuries that can lead to paralysis, such as stroke, brain trauma or Multiple Sclerosis, with the level of severity varying widely. One such lesser known condition is Amyotrophic Lateral Sclerosis (ALS). It is a neurodegenerative neurological condition that leads to severe paralysis and is often referred to as Motor Neuron Disease (MND) or sometimes Lou Gehrig's disease, after the celebrated baseball player who contracted it (Gehrig 2013) and brought it to the consciousness of the general public. It is a rare orphan disease that affects in the region of 1–2 in 100,000 people (GARD 2013; ALSA 2013a, b), although statistics vary regarding its incidence. In the UK it is estimated that 5,000 people have the ALS form of MND, with around 2 people in 100,000 developing it each year (Patient 2013).

ALS is an aggressive disease that progresses rapidly in most cases. It affects the nerves for establishing movement. These nerves, known as motor neurons link the brain to the spinal cord and onto the peripheral nerves for function control. Degeneration of these nerves leads to a decline in voluntary muscular movement of the limb and trunk (ALSA 2013a; Orphanet 2013). For some sufferers, eye muscles may be affected but not in all cases (Birbaumer and Cohen 2007). It is non-contagious and the cause is unknown but it is estimated that about 5–10 % of those with the condition have an inherited form of the disease. Variations of ALS exist. 'Spinal ALS' has initial symptoms which start with muscle weakness in the arms and legs, leading to paralysis in these regions which then progresses to the neck and head. The symptoms of 'Bulbar ALS' start within the neck and mouth regions and then progresses to other parts of the body. Progressive Muscular Atrophy (PMA) and Primary Lateral Sclerosis (PLS) are less severe forms with a better prognosis.

ALS is classified as an orphan disease. There is limited scope for drug intervention (Orphanet 2013), although Riluzole was approved in 1995 by the Food and Drug Administration (FDA). This drug has been shown to slow the progress of ALS, leading to a possible modest increase in survival time (ALSA 2013b). At present the "primary treatment is managing ALS symptoms" (Ensrud 2005). The expected lifespan of an individual diagnosed with ALS varies, with up to 20 % of people living beyond 5 years and 10 % of people living beyond 10 years (ALSA 2013a). Life expectancy is strongly linked to the patient's choice to accept (or decline) life supporting treatment such as artificial respiration when the paralysis has become severe enough to prevent breathing (Nijboer and Broermann 2010).

Against this outcome, the fear of losing the ability for interaction is a key concern for the individual, as highlighted by Blain-Moraes et al. (2012). The authors stated that, "the existence of the human self hinges on successful interaction with others … those who cannot engage in communicative interaction are, consequently, at risk of not being accorded personhood by others."

Nijboer and Broermann (2010) discussed the difficulty that ALS patients have in deciding whether or not to write a living will, detailing their wishes to accept or decline life-prolonging treatment. They highlighted the importance of the patients' expected quality of life in making these decisions and stressed that often there is not sufficient information made available to the patients in terms of life-sustaining treatment and communication technologies. Hayashi and Oppenheimer (2003) reported that 24 % of the patients in their study survived 10 years past respiratory decline due to artificial ventilation. At this extreme of the disease, paralysis will have extended to the point that the person will be in a Locked-In State (LIS). With cognitive function often remaining intact the healthy brain is effectively trapped inside the immobile body. A range of assistive technologies, from eye trackers (Calvo et al. 2008) to sip switches (Jones et al. 2008) can offer a reasonable form of communication, but only when residual muscular movement exists. Jean-Dominique Bauby, a French journalist struck down by a massive stroke in 1995 that left him with only residual movement of his left eye, authored his memoir, 'The Diving Bell and the Butterfly` (Bauby 1998), using only eye blinks in response to a repeatedly recited alphabet by his carer. In this book he gave an insight into the life of a person with LIS. Bauby wrote "Other than my eye, two things aren't paralyzed, my imagination and my memory." The book has since been interpreted as a major movie to critical acclaim (Thomas 2008).

As the severity of the condition of an ALS sufferer progresses, other assistive technologies that rely on some level of residual movement will no longer offer the pathway for communication. Those at the most severe levels of paralysis are considered to be in a Completely Locked-In State (CLIS). Can interfacing directly with the brain through the use of recording brain signals and using computers "bridge the gap between the inner and outer world"? This was the question asked by Nijboer and Broermann (2010), who applied such technology to try to help those in a LIS or CLIS state. Such a mechanism is commonly termed a Brain Computer Interface (BCI). It is important to note however, that "BCIs are not treatment for the disease; they do not affect a person's health or the progression of ALS in any way. They are an assistive technology that can potentially make a significant difference in the quality of life for people with ALS" (Ourand 2004).

BCI has been studied in electrophysiology laboratories for over 30 years (Wolpaw and Wolpaw 2012; Allison et al. 2013) and significant progress has been made regarding accuracy, speed, robustness and mobility. The questions we pose in this chapter are: can BCI offer the mechanism to enhance social inclusion and empowerment through communication and control? And if so, what hindrances are there in making it readily available for those that would benefit most? In order to first understand the role and potential impact of BCIs, it is important to present some background information on how relevant information within the brain can be harnessed to enable communication without the necessity of motor movement.

Brain Power

A BCI is a device that can potentially facilitate communication without the need for voice articulation or peripheral movement. A common misconception of brain computer interfacing is that the computer is literally reading the mind of the subject. This next section aims to explain some of the underpinning anatomy and physiology of the brain that enables interaction to occur when all other assistive technology fails. How is it possible to exploit the power of the brain?

Regions within the brain are associated with and responsible for cognitive, sensory and motor actions, as shown in Fig. 1. Application of BCI technology relies upon the understanding of the human brain function and has used this knowledge to develop ways for a person to convey information. It is not simply a case of random thoughts being translated into actions. There are two main mechanisms that may be used to achieve communication; the first picks up responses from planned external stimuli and in the second, the user is trained to perform predefined mental tasks to convey their wishes.

BCIs have four general components (Allison et al. 2013; see Fig. 2). First, a device must measure the brain's electrical activity[1] and extract selected brain signals. Typically, the electrical activity is measured using electrodes placed on the

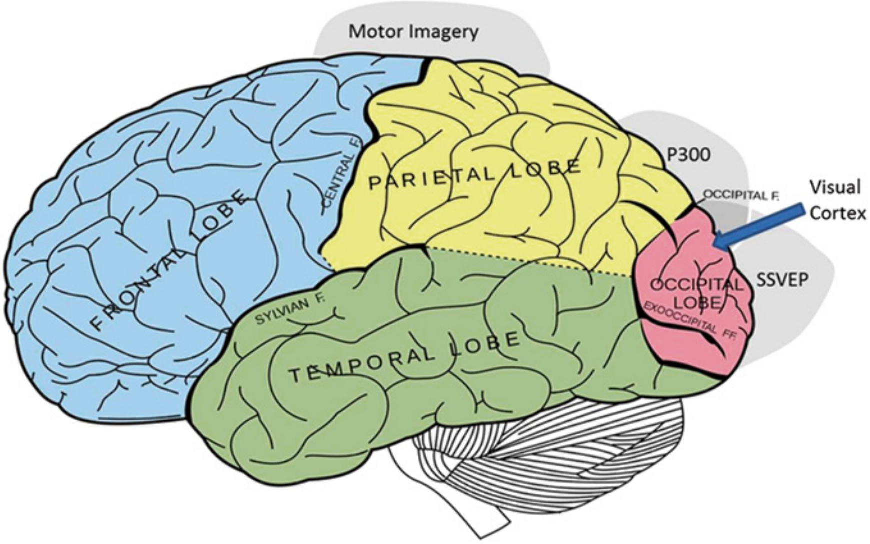

Fig. 1 Overview of the regions of the brain used for BCI. *SSVEP* BCIs rely on activity over the visual areas in the occipital lobe. P300 BCIs use these areas as well, along with parietal electrodes. Motor imagery BCIs rely largely on electrodes around the *left* and *right* central fissure, bridging the frontal and parietal lobes, which contain the brain's primary motor and sensory areas

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[1] BCIs can also use other physiological properties such as blood flow (Andersson et al. 2010), but these are less common and not considered in this chapter.

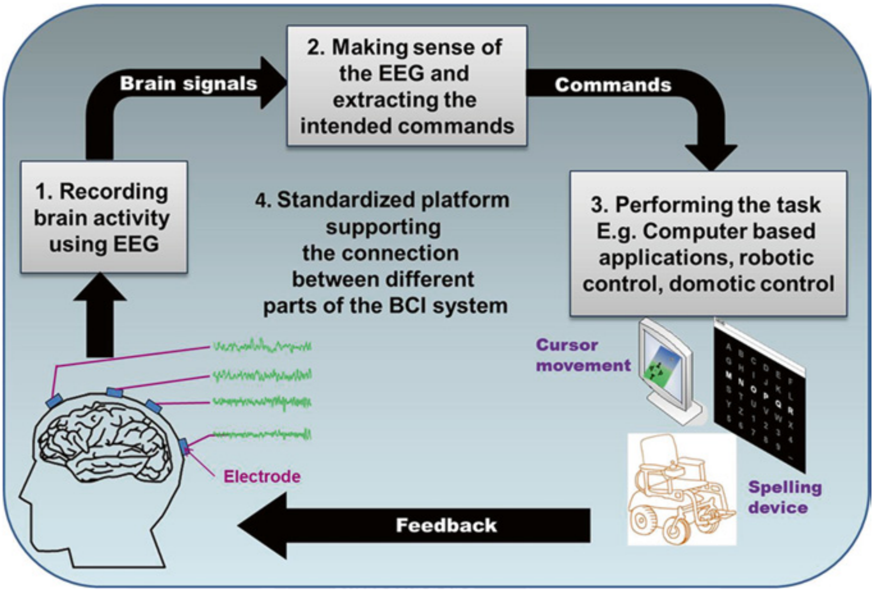


Fig. 2 Main components of a non-invasive EEG based BCI system (Adapted from Allison 2011; Wolpaw and Wolpaw 2012)

surface of the scalp and connected to an amplifier. This process has been in clinical use for many years in the electrophysiology department and is referred to as the electroencephalogram (EEG). Particular electrode configurations are used for different types of BCI and there may be variations between users to achieve the best outcome. Second, a signal processing system must translate these measures of brain activity into a message or command. In turn, these meanings can be used to interact with external devices, offering a medium for communication, expression and control. Classic examples of BCI applications are spellers (Sugiarto et al. 2009; Guger et al. 2012a, b), robotic control (McFarland and Wolpaw 2008) and domotic control (Babiloni et al. 2009; McCullagh et al. 2011; Ware 2010). More recently BCI has found application in gaming (Nijholt 2009) and for self-expression (Miranda et al. 2011; Münßinger et al. 2010). Finally, a platform is necessary to manage the interactions between these different components and the user (Wolpaw et al. 2002; Pfurtscheller et al. 2008; Allison 2011; Brunner et al. 2013).

Recording the EEG

Most BCIs rely on the scalp recorded EEG to measure brain activity (Mason et al. 2007). However, some groups work with invasive BCIs that rely on subdural sensors implanted on or in the brain (Velliste et al. 2008; Hochberg et al. 2012). There has been substantial discussion about the practical and ethical issues involved in the decision to use invasive or noninvasive BCIs (Birbaumer 2006; Millán and Carmena 2010; Nijboer et al. 2011; Allison et al. 2013). Both directions merit further study, since different approaches may suit different individuals, based on their needs, preferences, spared abilities and other factors. Any potential BCI user, especially someone who might rely on the BCI as a primary means of communication, should be fully informed about the risks, challenges and potential limitations of any BCI they might use. The remaining sections of this chapter focus on noninvasive EEG based BCI, which is the modality that could have practical application outside the dedicated research laboratory.

It is not surprising that surveyed users repeatedly comment on the discomfort of gel electrodes and the length of time required for preparation and clean up (Blain-Moraes et al. 2012; Huggins et al. 2011). In a typical set up the electrodes may be placed on the user's scalp with the use of an electrode cap to guide the location of the electrodes, with gel needed to enhance the connection with the scalp and improve signal quality. These systems do not provide an aesthetic and user-friendly solution for home use but they are essential for research and development.

Conveying and Extracting the Information

While the exact definition of a "BCI" has become somewhat fuzzy in the last few years, amidst efforts to expand the term, most BCI research groups focus on real-time systems that allow people to send information via direct measures of brain activity (Allison 2011; Zander and Kothe 2011). BCI can be separated into two categories: one in which the user receives some visual or auditory stimulus which in turn invokes a response in their EEG; the other is based on intended actions of the user and requires no external stimulus. The following paragraphs provide a brief overview of the more typical BCI paradigms.

The visual cortex positioned within the occipital lobe receives and processes information from the eyes. This region can be stimulated to evoke a response distinctive enough to be captured within the subject's EEG recording and classified by a computer algorithm. Garcia-Molina provides details about how the responses can be harnessed into a useful application (Molina and Mihajlovic 2010). The brain's sensory components can be stimulated to give a response, referred to as an evoked potential. A well-known mechanism for evoking such a response in the subject's EEG is the Steady State Visual Evoked Potential (SSVEP) (Zhu et al. 2010). The subject views a visual stimulus that oscillates at a particular frequency. The resulting response in the EEG is detectable using electrodes placed over the occipital region (Fig. 1) and can be distinguished from the background electrical activity.

Stimulus mechanisms include Light Emitting Diodes (LEDs) (Fig. 3a) and reversible checkerboard icons (Fig. 3b). By using a variation of stimulus frequencies it can be possible to differentiate between the responses in the EEG and therefore between the LEDs being observed by the user. If each LED relates to some defined context, then the translated information from the EEG can be then used

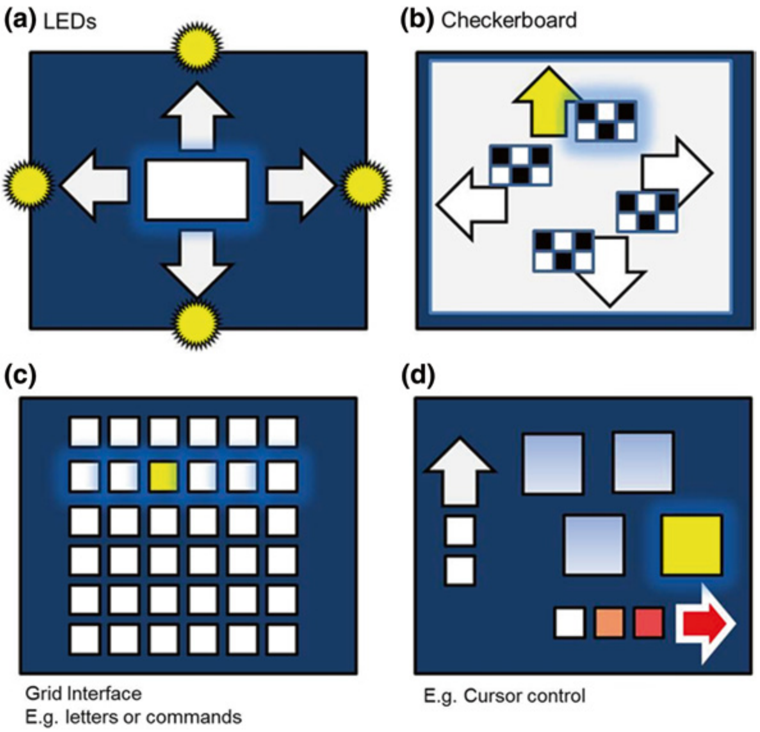


Fig. 3 Example BCI user interface and interactions. (**a–b**) In the SSVEP BCI, users would focus on one of the four LEDs or revisable icons, which would each oscillate at a different frequency. When the BCI detects this frequency over the occipital areas, it recognizes which is the user's target. (**c**) In the P300 BCI, users count each time the target item flashes. This will produce a P300 that does not occur when the other items flash. The BCI detects this P300 and thereby identifies which item is the target. (**d**) In the ERD/ERS BCI, users might imagine hand of foot movements to drive a cursor in two directions via EEG activity over the brain's primary movement and touch areas

to control a computer mediated application. Although in theory a broad range of frequencies can be used, ranging from about 5–45 Hz, as the number of frequencies increases, so does the difficulty in distinguishing between the desired outcomes. As such, a typical SSVEP based BCI system may rely on 4 flashing LEDs, enabling a four way navigation mechanism ideal for movement around a computer screen, as illustrated by Fig. 3a. With this mechanism a range of applications can be supported and examples of spellers and user interface control have been reported (Allison et al. 2010, 2012; Guger et al. 2012a; Wolpaw and Wolpaw 2012). The operation for the reversible checkerboard icons is similar. Zhu et al. (2010) provides an overview of SSVEP stimulus mechanisms.

A different type of response in reaction to an 'unexpected' visual or auditory cue may be elicited using the 'oddball paradigm', whereby a rare target event is interleaved with many non-target events (Fig. 3c). A resulting event within the

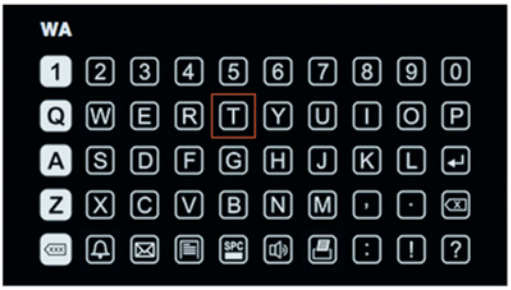
EEG gets the P300 label from the location of the evoked response wave appearing in the region of 300 ms post stimulus onset. It is most strongly captured using electrodes over the occipital and parietal areas (Fig. 1). P300 BCIs require very little training and are reliable in field settings for most users (Sellers et al. 2010; Guger et al. 2012b; Mak et al. 2012).

By imagining a movement it is possible to initiate activity within the sensorimotor cortex within the brain (Fig. 1). The process involves the modulation of a motor component of the EEG known as the ‘mu-rhythm’. The paradigm is often referred to as Event-Related Desynchronization (ERD) and Event-Related Synchronization (ERS). By extracting this intention from the EEG a user can use trained imagined activities as control mechanisms, without the need for external stimuli. Typical examples would be imagining left-hand, right-hand or foot movement although other paradigms do exist (relate to Fig. 3d). In all cases, sophisticated signal processing is required to extract these intended movement components and the software needs to be matched to the user. With non-invasive electrodes, fine dexterity is not feasible, and typically only a 2 or 3 way decision is possible. With suitable technology such as intelligent robotic wheelchairs or tailored user interfaces, control can be achieved (Graimann et al. 2010; Millán et al. 2010; de Laar et al. 2013).

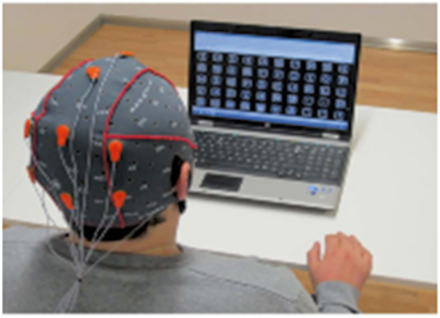
Example Applications

The last decade has seen the first commercialization of BCI based products (Allison et al. 2013). Unsurprisingly, much of the commercialization has been targeted towards the healthy user. In particular BCI is appealing in the areas of gaming and entertainment, facilitating another channel for communication between the user and the game. Often signals such as facial electromyography (EMG) are used in addition to the EEG. The resulting systems need fewer electrodes since only simple information needs to be conveyed. As a result the average price is lower, opening up a wider target consumer market. Some of these consumer devices retail for under \$100. MindWave Mobile from Neurosky (MindWave 2013) was developed for iOS and Android platforms. The system uses attention, meditation and eye blink, combined with raw EEG to gain the control. Applications that can be controlled using the system include MindPlay for controlling video. The Emotiv EPOC (about \$299) from Emotiv Systems (Emotiv 2013a) is a more advanced and complex device with a greater range of capabilities. It uses 14 electrodes with 2 reference electrodes and is targeted both to the consumer and research markets (Emotiv 2013b). It should be stressed that such devices listed above are not tailored as yet to the assistive technology market and most rely on some muscular movement (EMG). Nevertheless, this highlights the potential for such technology and the range of applications, and this will help fuel opportunities for further BCI research.

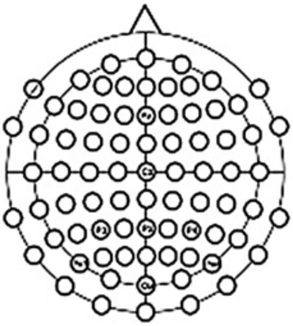
A pure BCI system which uses only brainwaves has been commercialized by g.tec Medical Engineering Company (IntendiX 2013) and has been on the market now for a couple of years. It is the first commercial BCI system for home use, and



(a) Shows the IntendiX Spelling Matrix at the beginning of a “copy-spelling” run.



(b) Presents a photograph of a subject using the system in free spelling mode



(c) Shows the electrode montage used for both dry and gel electrodes. The ground is the left mastoid and the reference is on the right mastoid

Fig. 4 The intendiX system, from Guger et al. 2012b

relies on the P300 paradigm. In the speller version of the system (see Fig. 4), the user sees 50 tiled letters and numbers on a grid with 5 rows and ten columns on a computer screen (Guger et al. 2009, 2012b). The rows and columns flash in a random sequence. The user is asked to focus on the letter of interest. As the row and column containing that letter flash, a P300 response is elicited in the user’s EEG. However, when other rows or columns flash, the P300 does not occur. IntendiX, like most P300 BCIs, requires averages of at least 3 flashes for adequate signal quality. In many respects, this is a BCI version of the system used by Bauby to write his memoirs. g.tec has developed new modules for IntendiX, providing new applications with new target items and corresponding commands, enabling control over domestic devices (Intendix 2013b), a platform for creative expression (Intendix 2013c) and a system for gaming (Indendix 2013d).

BCI opened up a communication channel using spelling applications to enable verbalization. Other examples of BCI application include control of devices within the home. From a central system the user’s commands can be sent through a central hub in the home onto devices which can then be controlled (McCullagh et al. 2011). It could be the switching on or off of a light, the opening of a door or possibly the control of a multimedia entertainment center and TV control. BCI has also been demonsted as an avenue for creative expression using music (Miranda et al.) and art (Münßinger et al. 2010).

Case Study: BCI as an Assistive Technology for ALS

Javier has always enjoyed sitting on his patio, enjoying the warm Catalan sun. Some2011times, he would invite friends and family and play music well into the night. Shortly after he was diagnosed with ALS, Javier learned to use assistive technologies based on eye, finger, and tongue activity. These provided him with decent control over various activities of daily living

DLs), including a music player and smart home controls to open the door to his patio and control the lights. As his control declined, Javier found these systems increasingly fatiguing. His doctor recommended a BCI being developed through The Guttmann Institute, a local rehabilitation hospital. A local graduate student in engineering set him up with a BCI that could control all of the same functions as other assistive technologies. The "hybrid" BCI system could also let him use other assistive technologies when he is not tired.

Javier is impressed with the technology and with the efforts of the local student. He has strong support whenever problems arise, and his BCI can control a wide range of customized applications. Javier appreciates that his experience is not typical—most people do not have such technical support. However, Javier also has major problems with the electrode cap. He prefers to feel independent and dislikes asking a nurse or his wife to help. He finds the gel messy and uncomfortable, and does not enjoy having his hair washed afterward. He is also concerned about ongoing support—will this student be available forever?

Elke has come to accept that her career as a painter is over. Her ALS has made it impossible to paint and over the course of a few years, has left her with only limited control of facial muscles. She learns of a BrainPainting system designed to allow people to paint using a P300 BCI. She tries it, and after several hours, produces an original painting. She is moved to tears, stating (via a P300 BCI speller) that she "feels like an artist again" and recognizes her own style.

Over time, she produces many more BrainPaintings, gaining some attention from local and national media. Since she is very close to a local university, she has help from a local graduate student for technical issues. She can also afford an extra 2,000 Euros for a dry electrode cap, and she does not especially mind wearing it. Her main concern is the speed. She can spell and paint, but much more slowly than before. The system is not perfectly accurate and mistakes are frustrating. She also dislikes the appearance. She feels that it makes her look odd and highlights her dependence on an assistive technology. The cables are especially annoying to her. She would prefer a system with electrodes embedded in a hair beret or earrings. The manufacturer has replied that they are working on it.

Are We There Yet?

Today's BCIs systems still have many limitations (Babiloni et al. 2009; Sellers et al. 2010; Allison et al. 2013). BCI technology is at the point of migration from the laboratory setting to the domestic environment, which entails many challenges and limitations. But the technology has been at this point for some time. What is stopping BCI being deployed widespread? Over five years ago there was a significant impetus within the research community and funding bodies such as the European Union Framework Programme financed large projects (Brain 2013; Brainable 2013; TOBI 2013; Future BNCI 2013) to enhance BCI technology, with the vision of moving it out of the laboratory and into the domestic setting. At that time some of the key scientific advances noted to help achieve this were:

- A convenient setup: The objective was to develop an inexpensive and straightforward EEG acquisition system that can be easily mounted on the head without expert supervision. The importance of aesthetics is highlighted.
- Individualized BCI: The creation of a flexible, reliable BCI system that can automatically identify and optimize important BCI parameters with minimal hassle to the user.
- Application suite: The creation of a straightforward, easy to use link between the BCI system and exemplar applications. Broadening the availability of applications and enabling a modular system consistent with use for a diverse group of applications from multimedia to domotic control.
- Evaluation: To involve target users to inform the development and provide valuable evaluation results for comparison with healthy user trials.

There have been significant movements forwards in these areas but the problems are complex and many goals are still relevant. The key aspects are summarized below.

A Convenient Setup

Several recent reports on users' opinions of BCI have reported negativity towards gel EEG caps and electrodes (Blain-Moraes et al. 2012; Ekandem et al. 2012; Huggins et al. 2011). This is not a surprise and research to develop dry (Gargiulo et al. 2010) and water based electrodes (Mihajlovic et al. 2012) has been undertaken. Volosyak et al. (2010) reported similar results when comparing gel based electrodes with water based electrodes, which rely on simple tap water to moisturize the electrodes. Sufficiently high quality EEGs were achieved even after 4 h of continuous usage. Guger et al. (2012b) found that a dry electrode system was effective for nearly all users, who attained accuracy comparable to state of the art gel-based electrode systems. The ability for non-technical application of electrodes with no clean up time will open up BCI as a more practical day to day technology. It also offers the promise of an easily made customizable cap tailored to the user, creating greater comfort and aesthetics.

The complexity and set up is a major hindrance in the widespread adoption of BCI technology. Blain-Moraes et al. (2012) evaluated the opinions of group of target users with ALS. They found that those with technical knowledge expressed confidence in "their ability to learn to autonomously use and operate BCI". However, those uncomfortable with technology found the complexity of the BCI systems overwhelming, with one user stating, "how can this be made accessible to the computer illiterate or technology illiterate…?" Without existing technology competence the naïve user felt that the BCI operation was beyond their capacity for independent use.

The shrinking of the technology is an absolute must for enhancing battery life and system portability. Brunner et al. (2011b) provide some insight in the current status of software and hardware development for BCI.

Individualized BCI

There is significant complexity involved in providing successful BCI for the individual. Some key issues recur in the literature, namely, technical complexity, the need for strong carer and family support, the need for training, on-going technical support and the BCI accuracy disparity between users. The latter is also highlighted by Allison (Allison et al. 2010a), stating that there is no "universal BCI".

One of the main disparities in BCI technology is the difference in user efficacy between individual users and groups of users. The concept of a generalized BCI setup that can be deployed to the masses actually only has potential impact on certain groups of users. For those in greatest need of a method of non-muscular communication and control the resulting system is not readily available. Commercial BCI technology (Intendix 2013a; Emotiv 2013a) demonstrates potential success for non-disabled users (Guger et al. 2009, 2012b) but whether it will be suitable for the broad spectrum of users remains to be seen. The general BCI literature discusses the measures and support needed for long term domestic BCI use and highlights many challenges (Sellers et al. 2010). Nevertheless, for those who could operate such easily available and refined BCI systems, the technology could prove to be beneficial. Different users with or without brain injury may have a broad spectrum of BCI capabilities, referred to as BCI literacy (Allison et al. 2010). In reality the development of any assistive technology requires a combination of both clinical and technical expertise, tailoring the technology and applications to the user. The Brain Communication Foundation (Brain Communication 2013) is a non-profit organization with the aim of developing BCI for users in which there is a need for such a tailored approach, unsuitable for a more commercial product.

Automated Configuration

How do we determine a personalized BCI for the user? There are a range of potential solutions but matching the person and their needs to a possible solution is a multifaceted task. It relies on the ability to enhance the BCI system from the best position of the electrodes, to tailoring the algorithms, and providing the applications, services and support needed.

How do we determine without long trials with a user what form of BCI will be best suited to their needs and characteristics? Mak et al. (2012) are looking for key parameters that might show a user's feasibility for use with the P300-BCI. If they can determine the EEG features that best correlate with P300 performance they can use this to not only determine suitable candidates for long-term P300 BCI operation, but they can also monitor performance online, an important aspect for remote technical support.

A realistic overview of what the near future could achieve is considered with some suggestions of what such a system would entail and with what caveats it would operate under. FutureBNCI (2013) was established within a cluster of thirteen European funded BCI projects with the joint aim to promote and guide BCI research, development and application. They provided an insight into the future perspectives (Allison 2011; Allison et al. 2013) with a clear overview of combining BCI modalities resulting in hybrid systems. Such technology could combine different BCI mechanisms (Allison et al. 2012; Brunner et al. 2011a; Pfurtscheller et al. 2010) or combine BCI with other input modalities such as eye-trackers. A fluid approach to what is best for the user which steps across the technical boundaries is now the goal. Millán et al. (2010) discussed the need for increasing the level of automation within the system to compensate for low accuracies and creating more context-aware systems that improve with use (Allison et al. 2012; Wolpaw and Wolpaw 2012).

Application Suite

There remains a strong need for tools that can tailor each BCI to each user and there are many aspects of a BCI that could be customized: the sensor system (such as different electrode types and montages); many details of pattern classification (such as which electrodes and frequencies are used for control); the type of brain activity used for control (such as P300 or SSVEP); the application being controlled (such as a speller or internet browser); the interface (such as different displays and feedback methods); and other details. A reliable "BCI Wizard" is needed, a software platform that would walk each user through a series of tests and questions to help identify which options would be best for that user. There has been substantial progress toward such a goal, with many improved open-source software platforms that require less expert help than previous versions (Brunner et al. 2013). The first home commercial BCI platform, called intendiX (IntendiX 2012), also uses software that is aimed at non-expert users. These software tools have reduced the burden on users and their carers, but a practical BCI that can provide a wide range of assistive technology solutions for end users requires further research and development.

BCI in Use: Beyond Evaluation

Nam et al. (2010) report that BCI's lack of acceptance could be a consequence of a lack of understanding of the usability of BCI systems. Finding the right opportunities to make BCI usable and accessible offer the potential to turn BCIs into practical assistive technologies that can help users interact with their family and carers, as well as home-based technologies including assistive devices, home appliances, or computer and internet technologies, A key challenge to this is to minimize the work in deploying BCI systems successfully for users and their supporters.

There is a growing need for a "BCI service provider", referring to people or companies that can provide expert support. These service providers should ideally be certified through an entity consisting of appropriately qualified and experienced experts to avoid misrepresentations of providers' capabilities. The providers may often need to travel to users' homes as well as provide remote support and should be familiar with the challenges unique to any patient populations they might encounter. But what needs to be done to achieve this vision and at a feasible cost?

Discussion: Can BCI Provide a Solution for OD:LIS?

At the beginning of the chapter we asked the questions:

> Can BCI offer the mechanism to enhance social inclusion and empowerment through communication and control? And if so, what hindrances are there in making it readily available for those that would benefit most?

There are many obstacles to the uptake of a BCI system. One of the major issues when collecting the EEG is artefacts caused by movements such as eye blinks, facial twitching and jaw clenches. BCI systems require the user to suppress such movements which may be involuntary due to their underlying condition. Ourand (2004) gives an informative overview of BCI for the ALS Association. She makes a key point that "when the individual is 'concentrating' so fiercely on regulating brain activity and limiting muscle movements, it can severely impact non-verbal pragmatic language and interactions with those in the immediate environment". She also highlights the commitment in time and energy that users may need to invest in training for BCI use before a usable system is achieved. There is certainly a disparity in efficacy between users and indeed user groups. Studies involving target users systematically report lower accuracies than healthy users (Mulvenna et al. 2012).

Kübler et al. (2005) investigated a number of variations of BCI systems working with healthy users and 7 users with ALS (pre locked in state). They comment on the disparity between the user groups, highlighting the need for longer training sessions for the patients with ALS. Healthy users were able to achieve a level of control over a small number of sessions but the patients needed 20 sessions to achieve a 70 % accuracy using BCI with imagined movement (ERD/ERS).

Such disparity can be expected for many varied reasons such as the underlying neurological condition of the user (brain injury for example), the difficulty in controlling involuntary movement, the ability to maintain visual focus on the objects of interest on a screen or maintaining concentration on the imagined movement. Ourand (2004) adds that BCI solutions using visual stimuli such as P300 and SSVEP can be "very fatiguing, and are often not useful in the presence of certain visual impairments, since some approaches require visual prompts from the screen. Because some people who are locked-in have limited vision, research in auditory interfaces is an important focus for the BCI community." Much more investigation needs to be done with target users, to determine how best to tailor BCI for their diverse needs.

All this said, can BCI provide a feasible assistive technological solution for people with ALS? There have been some long term studies with users but the numbers are limited. Sellers et al. (2010) report on their involvement with a user with ALS in which the user had two and a half years of independent use of a P300 based BCI. There were issues, common to most BCI systems, such as difficulty of use, high technical complexity, functionality and lack of user personalization. These factors made it difficult for long term support but the research team has endeavored to make some improvements. Neuper et al. (2003) provide an example of a BCI system for spelling (using imagined movement (ERD/ERS BCI)) established within the patient's home (clinical) setting and training was performed over several months. Technical assistance was also provided on-line. An average spelling accuracy of 70 % was achieved.

So there are some examples of successful BCI use out of the laboratory and with target users. But it is a complex task to achieve and is dependent on many factors. Potential users need to be screened to determine their feasibility for BCI use, as highlighted by Vaughan et al. (2006). As already discussed, there are many forms of BCI and within each of these types, a range of characteristics can be tailored for the specific user. BCI literacy varies from person to person for even those without any underlying neurological condition (Allison et al. 2010). For example, some people may not demonstrate a strong response in their EEG in response to a flashing light (for SSVEP-BCI), yet they may be able to use the Intendix Speller (Intendix 2013a) which uses a different type of visual stimulus (P300 BCI). Others may find it difficult using visual stimuli of any form due to sight issues and may need to use imagined movement (ERD/ERS BCI) or even auditory BCI (Nijboer et al. 2008; Birbaumer et al. 2012).

The Wadsworth Centre for Brain Computer Interfaces (Wadsworth 2013) are at the stage of development whereby they can offer a research version of the system for home use for specified users who have undergone initial suitability investigations. They report that they have used domestic BCI within their homes for several months or more. "One has now been using the system up to eight hours per day for two and a half years." They provide guidelines as to who might be eligible to be involved in their BCI trials:

- Severely paralyzed by any of a variety of neuromuscular disorders such as ALS, cerebral palsy, muscular dystrophy, multiple sclerosis, and high-level spinal cord injury.
- Too disabled to use conventional assistive communication technology such as systems that use muscle activity or eye movements.
- In adequately stable physical condition, with stable physical and social environments, and with caregiver(s) who have basic computer skills.
- Able to see and to understand instructions.
- Able to use the BCI system as determined in a screening evaluation.
- In a geographical location and an environment that allows the Wadsworth BCI group to provide ongoing technical support.

They report a common set of problems for the widespread deployment of BCI, namely, the substantial level of technical support required. The cost the system hardware is reported to be in the region of 5,000 dollars. However, it is expected that this financial value is not the true cost, due to the large support overhead. The goal of the Wadsworth center is to reduce this overhead by means of simplification of the BCI system. They also plan to develop more applications and deploy the system on a Windows platform. FDA approval is to be sought to enable widespread dissemination of the system beyond the research capacity. They point to the Brain Communication Foundation as a possible source for funding.

Positive stories have reached the media. The BrainGate (2012, 2013) neural interface was reported recently in the news, depicting a video of one of the two end users involved in their trials. The woman, who is paralysed, had implanted electrodes and through the BCI paradigm that uses imagined movement she was able to control a robotic arm. Although positive, the researchers made the important point that the user had trained long and hard to be able to gain the control.

Conclusions

BCIs offer a possible mechanism for communication and interaction with external devices using solely non-muscular interaction. Since BCIs do not require movement, they may provide a potential medium for interaction for the most severely paralyzed people, who have little or no reliable control of voluntary movements. They offer a potential assistive technology for people with neuromuscular disorders which, when the conditions are severe can lead to a locked in state for the patient. At this point mainstream assistive communication devices may not be helpful as they rely on residual motor movements. BCI could provide a feasible technology to reinstate a level of interaction and control to the user.

Until recently, most BCI research efforts focused on helping such users, with relatively little focus on other user demographics. This has begun to change, as various improvements to BCIs and underlying technologies have drawn attention to other user groups who might also benefit, leading to a potential diverse user group. For example, people who have lost an arm or the ability to control an arm, might use BCIs to control a device to restore function (Velliste et al. 2008; Hochberg et al. 2012; Mattia et al. 2013). It has sparked interest within gaming (Allison 2007; Nijholt 2009; Tangermann et al. 2009), and may offer an avenue for bio-feedback rehabilitation for conditions such as autism (Zhu et al. 2011). BCIs might also help facilitate stroke recovery (Gomez-Rodriguez et al. 2011; Ortner et al. 2012; Mattia et al. 2013).

In terms of an assistive technology, the opportunity to gain control and express oneself without movement is at one end of the diverse spectrum of the user characteristics, with the gaming community at the other extreme. Between these two extremes, BCI could act as an alternative assistive device that alleviates the stress on the user by switching technology when one becomes tiresome or ineffective. People with mild to moderate disabilities might use a BCI as a supplementary or complementary communication system when other assistive technologies are unavailable or impractical. Indeed, one of the most active BCI research areas involves hybrid BCIs, which combine BCIs with other communication devices to provide users with a suite of communication options (Pfurtscheller et al. 2010; Brunner et al. 2011a; Allison et al. 2012a; Müller-Putz et al. 2012).

"The solutions have the potential to improve productivity and extend communication for education, vocation, recreation and leisure activities. It is indisputable that when BCI technology becomes a routine, everyday symptom management device, individuals will likely experience increased independence and improved quality of life." (Ourand 2004)

"Despite the wealth of interest and solid work in this field, it has to be said that overall the field is still in the research and development phase. Although clinical trials of devices are on the near horizon, the field has more work to accomplish before the technology is readily available and is a proven intervention for people with ALS. With the generosity, dedication and involvement of people with ALS and their families, the clinical studies to test the practicality and effectiveness of services will help immeasurably to move the field forward." (Ourand 2004)

All this is only possible with the unwavering support network of carers, family and friends.

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