

# Ethical, psychological and social implications of brain-computer interface application in paralyzed patients

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## Abstract

We reflect upon ethical and psychological issues of groups of patient where verbal communication is not possible due to severe physical impairment. This group of chronically ill patients is capable of emotional and cognitive processing but the patients are locked in a paralyzed body. Thinking and feeling are intact but can no longer be expressed. Brain-computer interfaces (BCI) maintain and allow communication in severely paralyzed patients. The ethical, psychological and social implications of BCIs concern mainly hasten death decisions and euthanasia.

## Locked-in patients need communication

Imagine that you are bedridden, speechless and immobile, without any possibility to express your thoughts and feelings. Imagine furthermore that this imprisonment is not temporarily, but lasts for days, weeks, months and even years. This state is called *Locked-in state (LIS)*: a healthy brain is locked into a paralyzed body. There is no communication; patients are locked out from society.

The classical Locked-in syndrome is the consequence of infarcts of the anterior part of the pons cerebri. Eye movements and blinking are often, but not always, spared. The Locked-in state is often the consequence of other neurological or neurodegenerative diseases such as motoneuron disease (MND), polyneuritis, tumors, brain trauma, meningitis or infantile cerebral palsy. In advanced and end stages complete motor paralysis is present while sensory systems, emotional processing and cognitive abilities are usually unimpaired. Patients become trapped in their paralyzed bodies, unable to move or speak and thus with no possibility to communicate their needs, wishes and feelings.

Patients with amyotrophic lateral sclerosis (ALS) need artificial ventilation for survival. ALS frequently results in LIS. These patients are confronted with end-of-life decisions. They have to decide to accept or decline life-sustaining treatments such as artificial nutrition and artificial ventilation. These end-of-life decisions touch on ethical issues. A discussion on ethical problems should be based on empirical research and not on clinical folklore and personal opinions.

Studies show that more than 90 % of ALS patients do not receive artificial respiration and die from respiratory

insufficiency (Borasio 1996). However, it is unclear what determines the ultimate cause of death. No documentation on the circumstances of death and dying in these patients exists besides anecdotal evidence. Patient's attitudes towards life-sustaining treatment and towards artificial ventilation are influenced by the physician and family members' opinion (Moss et al. 1993). How physicians and relatives perceive patient's quality of life shapes their attitude toward life-sustaining treatment for the patients.

Unfortunately, most physicians, caregivers and family members (significant others) assume that quality of life of ALS patients is poor (McDonald, Hillel and Wiedenfeld 1996). Empirical data on quality of life in ALS patients show instead that quality of life does not necessarily depend on the physical situation and that it can be maintained despite physical decline (Kübler et al. 2006; Simmons et al. 2000; Robbins et al. 2001). These findings lead us to the main question of this paper: *do we have to accept ALS patients' decisions to die although we know that it is possible to substantially increase their quality of life?*

A BCI was developed to maintain or even to restore communication in severely paralyzed patients. Because patients report communication to be the most important determinant for quality of life (Bach 1993; Hecht et al. 2002), we assume that BCI should improve quality of life in these patients. Being able to communicate and to control the environment could influence not only their actual quality of life but also anticipated quality of life and thus their attitude toward end-of life decisions.

## Brain-Computer Interfaces may provide communication for Locked-in patients

A brain-computer interface (BCI) can be seen as a system with several functional components. The user, whose intent (communication, environmental control) is translated into neural activity (input). The output consists of the application (communication or environmental control program), controlled by the brain activity. Figure 1 schematically shows the components of a BCI.

The electrical activity of the brain is measured by one or more electrodes at the scalp (electroencephalogram, EEG), or by the magnetoencephalogram (MEG), or by functional

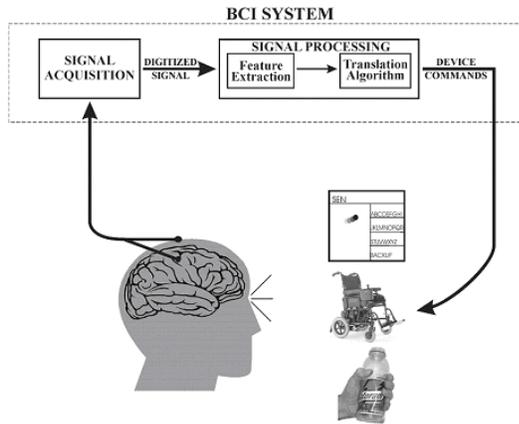


Figure 1 Basic design and operation of any BCI system. Signals from the brain are acquired by electrodes on the scalp or in the head and processes to extract specific signal features (e.g. amplitudes of evoked potentials or Sensorimotor cortex rhythms, firing rates of cortical neurons) that reflect the user's intent. These features are translated into commands that operate a device (e.g. a simple word processing program, a wheelchair, or a neuroprosthesis). Success depends on the interaction of two adaptive controllers, user and system. The user must develop and maintain good correlation between his or her intent and the signal features employed by the BCI; and the BCI must select and extract features that the user can control and must translate those features into device commands correctly and efficiently (with kind permission from Jonathan Wolpaw; Wolpaw et al. 2000).

magnetic resonance imaging (fMRI), or by electrodes directly at the cortex (electrocorticogram, ECoG), or intracortically.

The electrodes are connected to an amplifier, which amplifies the weak electrical currents and extracts certain frequencies of the EEG. Different patterns of brain activity can be extracted and used as input signals for a BCI. These patterns can be either self-regulated or they are externally evoked by visual or auditory stimuli. The self-regulation, the voluntary control over one's brain activity, can be learned: users are observing a graphic representation (for example a ball or a cursor) on a computer screen which moves according to their brain activity or they are listening to tones that change according to their brain activity. The BCI computer gives instructions to move the cursor or the tone in a certain direction. For example, a ball starts moving from left to right on a screen and the user's task is to move the cursor up or down to hit one out of two possible targets. Or the user has to regulate his brain activity in such a manner that the intensity of the sound of one of two possible music instruments changes.

The user achieves this by putting his/her brain in two different states, i.e. with two different thoughts. For example, the user can think about moving his right hand for moving the cursor down and think about nothing (relaxation) for moving the cursor up. If the user accomplishes the desired direction of brain activity, a smiley or a pleasant tone gives positive feedback, thus making it more likely that the user will learn the brain control (operant conditioning, positive reinforcement of desired behavior).

For the next step, a specific algorithm translates the input signals from the brain into commands that control applications such as a communication program, environmental control (light, television) or a robotic arm (Kübler and Neumann 2005).

Although state-of-the-art BCI research (Sellers and Donchin 2006; Piccione et al. forthcoming; Nijboer et al. in preparation; Birbaumer 2006) support the notion that BCIs can offer a realistic perspective for communication in paralyzed patients, they are not used in daily life (see Kübler et al. forthcoming; Birbaumer 2006). Data on patients progressing from Locked-in state into complete locked-in state do not exist, our lab is following patients on the verge of such a condition.

## Psychological, Ethical and Social implications of Brain-Computer Interfaces

Burchardi (2004) found that ALS patients estimate their actual and anticipated quality of life as the most important criteria for their prospective decision regarding life-sustaining treatments. They refuse life-sustaining treatments if the quality of life is low.

To maintain and improve quality of life of chronically ill patients is the major task for all health related professions. Since BCI can maintain or even restore communication, it is critical to inform patients about this possibility and to continue research on optimising BCI and implementing it in daily life.

Unfortunately, patients are not sufficiently informed about the course of the disease and the treatment options (for example against pain), particularly in the end-stage of the illness (Bascom and Tolle 2002; Erbguth 2003) to such an extent that in Germany for example only about 1/3 of neurological centres offer invasive ventilation for patients with motoneuron disease (Erbguth 2003). Not to inform patients about all palliative measures, including artificial ventilation and BCI-use is a violation of fundamental ethical rules and a lack of respect for autonomy.

Most people, whose lives are defined not worth to live by a 'healthy' society, if asked do *not* wish to die (Kübler, Weber and Birbaumer 2006). Liberal legislation of euthanasia usually does not promote the improvement of care for severely paralyzed patients who choose to live.

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