Neurotechnology-mediated communication: a new tool for personal rights of patients with disorders of consciousness?

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Contemporary neurotechnology

Real time observation of brain’s activity
Case of Disorders of Consciousness (DOCs): Vegetative States (VS)/Unresponsive Wakefulness Syndrome (UWS) – Minimally Conscious States (MCS) – Locked-in Syndrome
New possibilities of communication with patients with DOCs in the absence of overt external behavior or speech
Brain Computer Interfaces (BCI): direct connection between living neuronal tissue and artificial devices

non-muscular communication pathway between a computer and a brain
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- Detection of changes in brain activity in response to stimuli

- Training of the user to use these changes to select items, words or letters in communication software or for neuroprosthesis control
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BCI: functional and physical hybridization

New personal identity?
The case of DOCs: prospective use of EEG-BCI or fMRI-BCI at the bedside to detect volition
Cerebral communication

BCI

cerebral communication without motor response?
Cerebral communication

Conditions for communication

Patients should:
- Properly understand verbal commands
- Be able to react to external stimulation
- Be able to express her/his answers
  (e.g., yes/no communication)
Cerebral communication

- Retain the ability to attend to stimuli
- Retain the ability to selectively process the salient ones
- Retain the ability to store and process information in working memory
Necessity to clear possible long-term capabilities retained in patients with DOCs for implementing communication
Possibilities:
- Neurotechnology = new forms of communication
- Neurotechnology = new tool for promoting personal rights
Risks

- Patients with DOCs could retain a limited capacity to understand instruction: at what level of accuracy the communication can be considered effective?
Cerebral communication

Risks
- Questions too difficult to answer
- Questions asked when the patients were sleeping
- Movement, ocular and respiration artifact can cause false positive results
Cerebral communication

Risks
- Inadequate assessment of BCI and inappropriate clinical decisions
- General difficulty to map intended responses to motor imagination
Emerging issues

Relationship between brain activity, which is the specific object of the neuroimaging investigation, and awareness: how to judge when the first implies the second;
Emerging issues

- kind of consciousness that patients with DOCs retain (e.g., can they perceive the same emotional meaning of the provided information?)

- how to assess the capacity of patients with DOCs to make an appropriate informed decision.
Emerging issues

- how to assess residual capacity of self-determination

- whether and how much a prospective 'cerebral communication' may be considered as valid for an informed consent
- whether a prospective direct communication with patients with DOCs through neurotechnology implies the necessity to rethink their clinical management, particularly the role of legal guardians
Fig. 1. We observed supplementary motor area (SMA) activity during tennis imagery in the patient and a group of 12 healthy volunteers (controls). We detected parahippocampal gyrus (PPA), posterior parietal-lobe (PPC), and lateral premotor cortex (PMC) activity while the patient and the same group of volunteers imagined moving around a house. All results are thresholded at $P < 0.05$ corrected for multiple comparisons. $X$ values refer to distance in mm from the midline in stereotaxic space (SOM text).
Similar results were obtained in the follow-up study jointly conducted in Liege and Cambridge: 54 patients with severe acquired brain injuries were scanned through fMRI: in response to the request to perform imagery tasks, 5 of them were able to modulate their brain activity by generating blood-oxygenation-level-dependent (BOLD) responses which were judged by the researchers as voluntary, reliable and repeatable.
Sample Question Scans

Imagine **Tennis** to answer 'YES'
Imagine **Navigating** to answer 'NO'

a)  *Is your father's name Alexander?*
   - Patient
   - Control
b)  *Do you have any brothers?*
   - Patient
   - Control
c)  *Is your father's name Thomas?*
   - Patient
   - Control
d)  *Do you have any sisters?*
   - Patient
   - Control
Additional tests in one of the 5 responsive subjects revealed his ability to correctly answer yes-no questions through imagery tasks, showing the feasibility of communication.
The activation of a brain area as such is not enough to conclude that the patient is aware (passive stimulation reaction or implicit learning)
Time-related condition: the activation of the cerebral area in response to a specific task has to last at least 30 seconds
To date, all these attempts are still at the stage of proofs of concept rather than being practical means to really ensure long-term communication.
Main problem: given the plasticity of the brain, the anatomy and functional neuroanatomy could have undergone a functional remapping in patient with DOCs, so that a specific cerebral area could have been functionally replaced by another one.
Open questions

DOCs $\rightarrow$ new consciousness and new personal identity?
Informed consent

Could a reliable and effective “cerebral” communication justify an assumption of a right to self-determination of these patients? Could it, for example, be justified to ask them for an informed consent to treatment?
Giving an informed consent is not yet realistic for these patients
The formal condition to have self-determination through informed consent in a medical context is the existence of a relationship between the clinician and the patient.
A cerebrally communicating patient with DOC is formally able to be in relationship with the clinician, which means that the 'formal condition' for an informed consent could be satisfied.
Yet there is also what could be named a 'substantial condition' for informed consent: the patients have to retain the capacity properly to understand the information provided and to make a choice on this basis between options and the related consequences.