## ORIGINAL PAPER

# Extending Our View on Using BCIs for Locked-in Syndrome

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Abstract Locked-in syndrome (LIS) is a severe neurological condition that typically leaves a patient unable to move, talk and, in many cases, initiate communication. Brain Computer Interfaces (or BCIs) promise to enable individuals with conditions like LIS to re-engage with their physical and social worlds. In this paper we will use extended mind theory to offer a way of seeing the potential of BCIs when attached to, or implanted in, individuals with LIS. In particular, we will contend that functionally integrated BCIs extend the minds of individuals with LIS beyond their bodies, allowing them greater autonomy than they can typically hope for in living with their condition. This raises important philosophical questions about the implications of BCI technology, particularly the potential to change selves, and ethical questions about whether society has a responsibility to aid these individuals in re-engaging with their physical and social worlds. It also raises some important questions about when these interventions

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should be offered to individuals with LIS and respecting the rights of these individuals to refuse intervention. By aiding willing individuals in re-engaging with their physical and social worlds, BCIs open up avenues of opportunity taken for granted by able individuals and introduce new ways in which these individuals can be harmed. These latter considerations serve to highlight our emergent social responsibilities to those individuals who will be suitable for, and receive, BCIs.

**Keywords** Brain–computer interfaces · Locked-in syndrome · Extended mind theory · Neuroethics · Autonomy

#### Introduction

Locked-in syndrome (LIS) is a severe neurological condition that typically leaves a patient unable to move, talk and, in many cases, initiate communication [1]. Though a rare syndrome, it has been recently receiving media attention, along with spinal cord injury and motor neuron diseases, due to some of the successes of neurotechnology companies like Cyber-kinetics in testing Brain Computer Interfaces (BCIs) that promise to enable individuals with conditions like LIS to re-engage with their physical and social worlds.<sup>1</sup> Examples of successes include the ability of a tetraplegic to use a BCI to read email, remotely

<sup>&</sup>lt;sup>1</sup> Available at: http://www.cyberkineticsinc.com/content/index. jsp. Accessed on 19 Dec 2007.

control a robotic hand, or even remotely control a wheelchair [2]. The term "locked-in syndrome" conveys something of the severity of the condition both from the point of view of individuals with the condition and their care givers. It implies that the relevant individuals are trapped, intact, within their bodies. This implication places a distance between the individual understood as the self and their body. The body is presented as a vessel in which the self is housed and through which the self must express itself, if it can at all.<sup>2</sup> Under such an understanding of this neurological condition, neurotechnology is held out as a hope of by-passing the body.<sup>3</sup>

Though this is a natural reading of the term, and an understandable metaphysical outlook on the condition, it is out of step with a more dominant and better evidenced view of the self as embodied. When the self is understood as embodied, the body is constitutive of the self. From such an embodied perspective, the implication of LIS, that individuals are trapped intact within their bodies, conveys a distinction that distorts what has taken place. Also, as we will indicate, it misconstrues the promise of BCIs in helping individuals with LIS re-engage with their physical and social worlds. In particular, BCIs have the potential to change the self who receives the intervention, even though the devices may do little for their body. In the course of our discussion to follow, we will offer another way of seeing the potential of BCIs when attached to, or implanted in, individuals with LIS. In the first section we will discuss some of what is now known of LIS with an eye to some of the cognitive dysfunctions that result from the relevant brain stem insult. Next, we will discuss the state of some of the current research on BCIs, indicating where researchers hope to make breakthroughs that may benefit individuals with LIS. In the third section we will introduce what has become known as the extended theory of mind and then show how this theory of mind can help us re-see the potential of BCIs, particularly in the lives of individuals with LIS. In particular, using an extended theory of mind as a lens through which to see individuals with LIS, we will contend that functionally integrated BCIs extend the minds of individuals with LIS beyond their bodies, allowing them greater autonomy than they can typically hope for in living with their condition. This raises important philosophical questions about the implications of BCI technology, particularly the potential to change selves, and ethical questions about whether society has a responsibility to aid these individuals in re-engaging with their physical and social worlds. It also raises some important questions about when these interventions should be offered to individuals with LIS and respecting the rights of these individuals to refuse intervention. As these are early days for BCI technology, we will be cautious in our conclusions. What seems reasonably clear is that BCI technology has the potential to change the lives of a certain sub-set of individuals with LIS in some fundamental ways. By aiding willing individuals in re-engaging with their physical and social worlds, BCIs open up avenues of opportunity taken for granted by able individuals and introduce new ways in which these individuals can be harmed. These latter considerations serve to highlight our emergent social responsibilities to those individuals who will be suitable for, and receive, BCIs.

# Locked-in Syndrome

LIS first entered the clinical literature in 1966. It is a rare condition frequently brought on by brain stem stroke (i.e., lesioning of the ventral pons), though it can also occur as a result of traumatic brain injury or late stage amyoptrophic lateral sclerosis (ALS). Three symptoms characterize the syndrome: quadriplegia (i. e., paralysis of all muscles with the occasional exception of those enabling blinking and vertical eye movement), anarthria (i.e., loss of the ability to speak) and preserved consciousness [5]. There now exists a taxonomy of LIS that highlights three expressions: classic, incomplete and total/complete. In classic LIS the patient is as described above, quadriplegic (with the capacity for vertical eye movement or to blink), anarthric, with preservation of consciousness. Patients with incomplete LIS have some voluntary muscle control other than their eyelids and eyes. Total or complete LIS leaves the patient with no voluntary muscle control whatsoever. Though their consciousness is preserved, the complete loss of voluntary muscle control prohibits them from communicating [5].

<sup>&</sup>lt;sup>2</sup> See [3].

<sup>&</sup>lt;sup>3</sup> See, for example, [4].

Patients with LIS, in particular classic or total LIS, can superficially resemble individuals in comas or persistent vegetative states, particularly as patients emerge from comas but do not recover voluntary muscle control beyond the ability to vertically move their eyes or blink [6]. Prospects for recovery of nonminimal voluntary muscle control is sensitive to the speed of onset, the nature of the damage to the brain stem, whether it is transient or chronic, and how quickly the condition is diagnosed. For example, promising, though non-statistically significant, reports indicate some recovery of voluntary muscle control with minimal deficits after the occluded vertebrobasilar artery is surgically opened. Limitations of this surgical intervention include its significant risks (e.g., intracerebral haemorrhage), and its limited effectiveness when it is performed from a few to 12 days after occlusion. The current prognosis for recovery in longterm or chronic LIS is largely pessimistic (i.e., the patient's loss of voluntary muscle control is not expected to improve beyond what is described as minimal) [7, 8]. Importantly, many patients with LIS appear to enjoy a moderate or high degree of cognitive functionality [9, 10].

From the outset, we must be cautious in making claims about the degree of cognitive functionality enjoyed by individuals with LIS. The extreme difficulty in communicating with those with total or complete LIS significantly limits the available methods for convincingly demonstrating higher cognitive function. Though communication with individuals diagnosed with classic LIS is comparatively easier, their limited responsiveness restricts the complexity of the questions that can be answered and hence the degree of functionality that can be discerned.<sup>4</sup> Despite these caveats several studies provide potentially revealing data about the inner lives of individuals with LIS. In their 2002 report of 44 individuals diagnosed with LIS, León-Carrión and colleagues

claim that 86% (roughly 38 individuals) reported a good level of attention. Only 11.3% either tended to sleep or slept most of the time. Interestingly, though only 23.8% watched television regularly, 95.3% claimed to be able to watch, and follow, a film on television, or to pay attention to something of interest, for longer than 15 min; 76.7% (roughly 34 individuals) claimed the ability to read, while 97.6% (roughly 43 individuals) could say what day it was. Socially, 81% (roughly 36 individuals) met with friends at least twice a month, while 14.3% participated in what was described as social activities and 61.9% participated in other activities (e.g., family activities). Moreover, 30% (roughly 13 individuals) maintained sexual relations with their partner. Regarding cognitive deficits or dysfunctions, León-Carrión and colleagues claim that 14% reported visual deficits and 18.6% reported memory problems [13]. These deficits cohere with the experience of Smith and Delargy who also report that some individuals suffer from vertigo, insomnia and emotional instability [14].

In their case report of 2005, New and Thomas were concerned to introduce data that detailed cognitive impairment over a period of 24 months in one individual with LIS, beginning with the initial brain stem insult and indexed to neuroimaging that revealed brain damage limited to an infarction of the pontine area of the brain stem. The authors contend that this allows for some extrapolation from a common cause of LIS and a common lesion of the ventral pons. New and Thomas reported various cognitive impairments of this individual who was diagnosed with classic LIS due to "occlusion of the basilar artery above the anterior inferior cerebellar artery and acute infarction of the pons" [15]. This individual's cognitive deficits after the brain stem insult included lower than average verbal IQ, divided attention problems at levels substantially below pre-morbid estimates, poor performance on mental arithmetic tests, significant slowness of information processing, poor performance on the object assembly subtest of the WAIS-III, problems in verbal learning tasks, and deficits in certain executive functions (e.g., mental flexibility, impulse control) [16]. Though this report's findings require further study in other patients, it is New and Thomas's contention that his deficits suggest that other individuals with LIS with a similar profile share similar cognitive deficits [17].

<sup>&</sup>lt;sup>4</sup> These caveats should not be taken as concessions to Neo-Cartesian theories of mind. The assumption of Neo-Cartesians that mental states are essentially private is not required to make our point. Due to the anomalous circumstance of interacting with a largely or totally unresponsive individual, the evidence, including context of action, ordinarily used to justify cognitive vocabulary in explaining intentional behavior is unavailable. We can expect that this will sometimes place severe constraints on what can be reasonably ascribed to a patient with classic or total LIS. See [11, 12].

Though depression has been reported among LIS patients, reports conflict on its predominance in the relevant patient population. León-Carrión and colleagues aforementioned study indicates that 47.5% claimed to be feeling good, while only 12.5% described themselves as depressed and 5% as feeling bad. Of the medications prescribed for any of these individuals, only 10.8% were antidepressants [18]. Smith and Delargy, however, report a more pessimistic view of LIS patient mental health. Though, like José León-Carrión and colleagues' study, their study was not statistically significant, three of the five patients who completed their questionnaire (or 60%) reported being depressed. Smith and Delargy also claim that "a series of seven patients with locked-in syndrome had a worse quality of life on the Spitzer quality of life index than cancer patients but better than terminally ill patients" [19].

As we have already stated, BCIs offer hope to at least some of those with LIS that they will be able to initiate and maintain communication, control television viewing, interact with others in cyberspace, manipulate objects in their environment using robotic arms or even control their movement in wheelchairs. It is anticipated that even achieving this level of autonomous capacity will positively affect their quality of life [19].

#### **Brain-Computer Interface Devices**

Clearly, an explanation of BCIs is needed at this juncture, in order to appreciate how they could allow people with LIS to develop a stronger sense (both literally and metaphorically) of independence. During this discussion, it will be important to bear in mind that some of the capabilities that BCIs may allow are not necessarily exclusive to these particular devices, although BCIs could broaden the scope of what LIS patients can accomplish for themselves.

In contrast to other assistive technologies, which rely on the brain's natural electrical pathways to effectuate actions or speech, BCIs create new output pathways for the brain (p. 613) [20]. Because the brain is "plastic" (i.e., it has the ability to adapt and change its organization through experience), a BCI:

attempts to assign to cortical neurons the role normally performed by spinal motoneurons. Thus, a BCI requires that the many CNS areas involved in producing normal motor actions change their roles so as to optimize the control of cortical neurons rather than spinal motoneurons. The disconcerting variability of BCI performance may stem in large part from the challenge presented by the need for this unnatural adaptation [20].

Brain-computer interface systems essentially translate signals from the brain into useful outcomes, without the use of muscles [21]. They are complex systems composed of a neural sensor to acquire the signals, a decoder or signal processor to perform the translation, and an actuator (the "thing" that is being acted upon). Working together, these devices may allow LIS patients to more easily communicate by manifesting the thoughts they have into some sort of communicated message (whether in writing, simulated voice, or perhaps by steering a wheelchair). With these devices, people with LIS have the possibility of acting on their environments, something that, absent the devices, they can do to only a very limited extent, if at all.

It is useful to describe the devices we are not discussing in this context. We are not including in our discussion devices such as cochlear implants or retinal implants (which are often termed "neuroprosthetics"). While some consider these to be BCIs (an argument not to be taken up here), they nonetheless are devices that do not provide the functionality of interest here. While improving/providing the ability to communicate is a fundamental goal that drives much of the research behind all these devices (including BCIs), sensory perception is of less importance for LIS patients than is the ability to engage others and make oneself understood.

There are principally two different types of BCIs that could be applicable for persons with LIS: implantable (invasive) BCIs and those based on electroencephalogram (EEG) technology, which are non-invasive.<sup>5</sup> Each has advantages and disadvantages, depending on the needs of the person involved and what the intended action outcome is (e.g.,

<sup>&</sup>lt;sup>5</sup> Note that there are other technologies being examined for use as BCIs (e.g., magnetoencephalography and functional magnetic resonance imaging), but their utility and practicality for patients with LIS is unknown.

communication, mobility, consistency of functionality, etc.). Each also has ethical implications. All these will be discussed later in the article.

It should be noted that much of the research that has been conducted to date on BCIs and LIS have focused on patients with ALS. Because ALS is a degenerative disease, we conjecture that this may have implications for ease of use or how long any BCI, and particularly non-invasive ones, may be shown to be efficacious.

# **Non-invasive BCIs**

Most of the non-invasive BCIs that have been tested or are in current use are based on EEG technology, in which the subject/patient wears a cap that has been outfitted with a series of electrodes. The wires connected to the electrodes bundle together, and connect to, a computer which records and interprets the brain signals into useful commands. Some of the devices are designed around detecting slow cortical potentials (SCP), while others detect P300 waves, or sensorimotor (*mu*) rhythms [22–24].

Much of the research using non-invasive BCIs has focused on persons with ALS or who have experienced brain stem strokes leaving them in a locked-in state, and has centered around enhancing their ability to communicate. For instance, researchers at the Wadsworth Center in Albany, NY, USA have been mostly working with EEG-based BCIs for ALS patients for nearly 20 years. With these EEG-cap systems, users learn to perform word processing, write emails, select computer icons or move a robotic arm [25]. For instance, to perform word processing,

the user's brain waves were translated into simulated keystrokes. Software developed at Wadsworth presented rows and columns of a 72-element,  $8"\times9"$  matrix that flashed in random order while the user paid attention to the element that he or she wanted to select. The software recognized that element and executed the appropriate keystroke. With this design, the patient could use the entire keyboard [26].

One version of the Wadsworth BCI relies on a laptop computer, and is simplified in order to be initialized and monitored by a caregiver [26]. The electrodes must be applied on the head using electrode gel, although dry electrodes are being developed.

Currently, there is a lot of variability in the functionality of this type of BCI for several reasons. First, because the electrodes sit on top of the skull (i. e., a fair distance and a skull away from the actual neuronal or synaptic activity), there is generally limited signal resolution that can be obtained from this type of BCI. Second, and partly because of the first point, the cap must be fitted fairly precisely each time, which can be difficult to do. Third, using EEGbased BCIs requires a lot of training with an attending high error rate until the person wearing it acquires the necessary skill to use it as intended. Sometimes this process can take several months. The Wadsworth BCI is being designed to minimize this third issue by allowing users to find and choose the brain signals with which they are most comfortable (from an "ease of use" perspective), and program the software to rely on those brain signals to accomplish the desired action [27, 28].

More recently, research has been done using functional magnetic resonance imaging and magnetoencephalography, and near-infrared spectroscopy technologies, which has shown some efficacy as non-invasive techniques for communication. For now, however, these technologies are not practical for use, given their size, complexity, and high cost. Additionally, some research has been done using minimally invasive BCIs which rely on electrocorticographic (ECoG) technology. These BCIs have so far been tested mostly in epileptics [29], and use a subdural grid of recording electrodes; hence they are invasive, although less so than the BCIs discussed below.

Researchers at the Wadsworth Center, along with a group from the University of Tübingen in Germany have developed a general-purpose BCI platform that can be used for many different applications [30], and used with any brain signal. The researchers have made their software available for free for educational and research purposes. In addition, Wolpaw and his team hope to establish a self-sustaining nonprofit organization to distribute its BCI systems to those who would benefit from them [31]. Neils Birbaumer (of Tübingen) has also developed an EEG-controlled web browsing system called Descartes, operated by SCP self-regulation [32]. As the group describes the system, it can "help motor-impaired patients to regain autonomy in the interaction with the outside world and thereby enhance their quality of life" (p. 513) [32].

# **Invasive BCIs**

Invasive BCIs are surgically implanted directly into the brain's grey matter and so come into much closer contact with neurons and neuronal activity than the BCIs above. Because of this and the need for surgical implantation, they are also much higher risk devices. The only invasive BCIs currently in use are those in clinical trials, mostly in the United States. Their functionalities are focused on either movement or communication [33].

Cyberkinetics, a private company based in Massachusetts, is one of the few companies that has been conducting clinical trials using implantable BCIs. The sensor used in their trials is a  $4\times$ 4 mm chip containing 100 insulated microelectrode silicon spikes that are 1.0 or 1.5 mm long, which is embedded into the primary motor cortex. Each of the chip's active 96 spikes is attached to its own fine wire that forms an electrical connection to a pedestal "plug" device anchored to the skull. From there, a cable connects the plug to a computer that interprets the signals sent from the brain and translates them into the desired action. There are currently two clinical trials being conducted by Cyberkinetics: one for spinal cord injury, muscular dystrophy, stroke, and LIS; and one for motor neuron disease, including ALS [34]. The goal of the first trial is to test the reliability of recording neural activity and translating it into a computer control signal [35]. For instance, in one of the first trials of the device, the tetraplegic research subject, after very little training, was able to move a cursor on a computer screen to carry out commands (e.g., reading email and changing channels on a television) while carrying on a conversation. He accomplished this by thinking about moving his right hand (note that the chip was implanted into his primary motor cortex). The goal of the second trial is to use a thought-controlled computer signal to operate communication software [36]. As of late 2006, the system has been successfully demonstrated in 4 research subjects (a tetraplegic, a person with late stage ALS, a person who had a brain stem stroke, and a person with a spinal cord injury) [37–39]. The trials are still ongoing.

Neural Signals is a private company, based in Georgia, which in 1998 implanted a different type of BCI into a patient with ALS-induced LIS [40]. This

BCI is a "neurotrophic electrode"<sup>6</sup>—a cone shaped device consisting of two gold electrode wires in a glass enclosure-that also contains neurotrophic factors that induce adjacent neurons to "grow into the glass tip where they become myelinated. Growth and myelination are complete at about 3 months and henceforth produce stable recordings" (p. 1707) [40]. The second patient was implanted in March 1998. Although his training took several months, the second patient was eventually able to spell by moving a cursor across a computer screen containing letters. Two of the glass and gold wire electrodes were placed next to his primary motor cortex (i.e., by the part of his brain that controlled his right hand), and he initially imagined moving his hand in order to move the cursor. Eventually, he did not need to imagine moving his hand for the cursor to move-i.e., his brain had been "re-wired" to directly control the cursor's movement [41]. Neural Signals has continued to work with LIS patients (with and without ALS), refining its BCI, but retaining the essential elements from the 1998 version. The newer versions of this BCI are designed to restore natural speech to those with ALS, stroke, and other locked-in conditions. The first subject under this protocol was implanted in December 2004 [42]. Indeed, in February 2008, Neural Signals scientists and engineers succeeded in providing this subject with "real-time feedback of synthetic speech (created using a formant synthesizer) decoded from the neural firing patterns of cells in the speech motor cortex while he imagined speaking" [43].

These devices have the potential to change the daily lives of the individuals who use them. From a perspective rooted in embodied theories of cognition, these devices also have the potential to change the individual users themselves. To see how this is so we turn to a brief discussion of extended mind theory.

#### **Extended Minds, Extended Selves**

In the span of the last 100 years or so, theories of mind and behavior have taken a number of turns in ways relevant to our present discussion. Though we

<sup>&</sup>lt;sup>6</sup> "Neurotrophic electrode is a tiny device implanted onto a target area on outer layer of brain to detect neural activity there." http://www.neuralsignals.com/movementrestoration. htm. Accessed 21 Dec 2007.

cannot do justice to this history, we offer the following highlights. Perhaps one of the more significant explanatory approaches to intentional behavior that rose to dominance in the mid-twentieth century was behaviorism. Characterized by a search for empirically tractable general principles of learning, behaviorism rejected any appeal to "unobservables" (e.g., mental states) to explain animal (including human) cognition. Underlying the insights on learning yielded by behaviorism is the view that learning consists of conditioning processes that arise out of perceived connections between responses to various stimuli and rewards. Importantly, behaviorist explanations of learning do not require positing causally efficacious phenomenal conscious states, nor do they fall prey to over-intellectualized treatments of intentional behavior [44]. Treating the intentional agent as a black box was rejected as inadequate by succeeding cognitivist theories of mind, however. Their shared insight on nonhuman and human cognition concerned the importance of information processing in the animal brain. What and how information is processed in an individual's brain, including which environmental contingencies are salient when deciding how to act in the world, effects her subsequent behavior [45]. Interestingly, from our perspective, the "what and how" of human information processing must take into account various physical, physiological and psychological characteristics of the human animal (e.g., the nature of our sensory organs, how we move in physical space, how we interact with conspecifics) and its evolutionary history [46]. Evolutionary analyses of the cognitive capacities or sensitivities of various cognitive animals (including humans) have illuminated learning biases (e.g., "rats are easily taught to jump to avoid shock, but jumping to obtain food is almost impossible to teach") [47]. Though not cognitivist, ethological perspectives offer evolutionary and physiological analyses of intentional animal behavior that have historically off-set the a-biological tendencies of traditional behaviorism. Contemporary cognitive ethology combines this strength of ethology with more cognitivist interpretations of the proximate causes of intentional behavior [48]. Importantly, the story of human cognition does not end with what goes on in the skull. As we have just suggested, various physiological processes are implicated in human cognition. Additionally, the social contexts in which

an individual matures can also profoundly affect how she cognitively develops and responds to her environment [49]. This has lead to the emergence of embodied and embedded views of human cognition, respectively.

In the preceding short history of relatively recent theories of mind and behavior extended mind theory is a new arrival. It is probably best regarded as an extension of embodied and embedded views of human cognition in that it incorporates the insights of these views while also including certain events or processes outside of an individual's body as constitutive elements in the physical substrate that underlies an individual's cognitive processes. In other words, human mental states like beliefs, desires, intentions, and feelings are not physically implemented solely as brain states, or as states of our nervous system (i.e., central and peripheral nervous systems), but can also include (e.g., supervene over) bodily movements or non-biological structures (e.g., language) [50]. Think of human memory, particularly explicit memory. In defending their views of extended mind Andy Clark and Neil Levy have suggested that notebooks or personal digital assistants (PDAs) are not merely tools useful to those of us with too much going on in our lives, but can become integral elements in our memory processes, extending the relevant cognitive mechanisms beyond areas of the brain implicated in memory (e.g., the hippocampus, entorhinal cortex) to include the notebook or PDA [50:14-16, 51].

The basic argument motivating this re-seeing of traditional memory aids (and cognition more generally) plays on intuitions that readily re-see implantable or wearable technology to replace or augment naturally occurring neurocognitive structures as constitutive of the underlying substrate of the relevant individual's cognitive processes. The argument can be understood to contain four premises. First, it is possible, or at least conceivable, to restore or enhance certain cognitive faculties by attaching or implanting machines that can detect, store or transmit information hitherto unavailable to the relevant cognizer. Second, once these machines are functionally integrated, they are reasonably regarded as constitutive elements of the underlying substrate over which supervenes the relevant cognitive processes of the individual to whom they are attached or in whom they are implanted. Third, it is possible, or at least conceivable, that nonattached, external devices can play relevantly similar functional roles to the aforementioned implantable devices. Fourth, it is mere prejudice (read irrational) to regard attached or implanted, functionally integrated machines as extensions of the relevant cognitive machinery underlying an individual's cognitive faculties but not functionally integrated unattached, external devices that may even play very similar roles. From these premises it is concluded that functionally integrated unattached, external devices are reasonably regarded as constitutive elements of the underlying substrate over which supervenes the relevant cognitive processes of the individual.<sup>7</sup>

Importantly for extended mind theorists, it is inconsequential whether the cognitive 'aid' is a physically discrete machine or a cultural artifact such as language or pen and paper. Think here of using a pen and paper to calculate a particularly lengthy division. We can accomplish each discrete stage of division handily, with certain calculations taking place 'in our heads', but a lengthy calculation cannot be accomplished, or even conceived, by most of us without the aid of paper. Though our ability to think of this feat of calculation without the aid of what is written down is limited in its detail, there can be little doubt that what is written down and recorded on that paper is no less a 'cognitive product' than what we can concurrently 'hold in our head.' What is more, as a repository of our thought, the used paper seems to be relevantly similar to the neural repositories of other thoughts (i.e., memories) constitutive of the relevant calculation. The paper, that is, is an analogue to the neural sites implicated in explicit memory.<sup>8</sup> This motivates the extended mind theorist to suggest that our cognitive processes responsible for this lengthy division are not restricted to that which supervenes neural states. In cases such as this, the paper is an integral material substrate of cognition [53].

This approach to human cognition is not without its critics and we do not need to endorse it as a general theory to profitably use it in our discussion.<sup>9</sup> As with other embodied or embedded theories of cognition, extended mind theory can be regarded as a lens through which we learn to re-see particular aspects of human cognitive engagement with the relevant physical or social environment.<sup>10</sup> Its relevance to discussions on LIS arises out of some of the expected changes to the patient who receives successful treatment through BCIs. In such circumstances, the relevant BCI will not be merely acting as a doorway through which a person, intact but hitherto hidden or concealed, can "walk". It is a matter of Western tradition to think of the self as encased in a body that facilitates engagement with the physical or social world. From the standpoint of contemporary psychology, this view of the self is untenable. Micro changes in the underlying neural substrate that subvenes various cognitive events reflects not just changes in the maturing biological system of which our brains are a part, but the learning that occurs as we cognitively engage with our physical or social environments. Many of these changes, particularly as they relate to learning, translate into changes in those cognitive events constituting our inner lives [56]. From our meager beginnings as infants, our selves develop from, or

<sup>&</sup>lt;sup>7</sup> See [50].

<sup>&</sup>lt;sup>8</sup> Arguably, extended mind theory falls under the broad rubric of functionalism, where mental state terms are functional terms and any given mental state is identified, and individuated, by its respective functional roles in ordering an individual's behavior or interacting with other mental states [52]. Extended mind theory contends that the physical substrate over which human mentality supervenes is not limited to either the central nervous system or the organic body. This will come as a surprise to brain centrists (e.g., mind-brain identity theorists) and dualists, but perhaps not to many functionalists.

<sup>&</sup>lt;sup>9</sup> There are, for instance, attendant worries about the boundaries of the extended mind that emerge out of accounts like this one. Put succinctly, where does the material substrate of the extended mind stop? We suspect that any answer to such a question must be contextualized to the particular instance of cognition we are discussing. This allows for, or places no a priori conditions on, a change in physical substrates (e.g., a PDA instead of paper and pencil) over which an individual's cognitive processes supervene as she cognitively engages with her environment. Substantive, a priori means of setting the boundary of an extended mind are limited to such conditions as have already been mentioned (e.g., functional integration). Rather than rehearse emerging discussions in the literature responding to this, and other, kinds of worries or criticisms, we direct interested readers to Neil Levy's helpful discussion. See [54].

<sup>&</sup>lt;sup>10</sup> Here we follow the work of such feminists as Sue Sherwin in using various theories or frameworks as lenses through which to re-see a certain domain of action or discourse. See [55]. Instead of becoming embroiled in metaphysical debates about the nature, or extention, of mind that might threaten to undo any possible philosophical advance arising from a re-seeing of mind as extended, we use extended mind theory heuristically.

emerge out of, interactions with our physical and social worlds. Our physically embodied and socially embedded nature shapes who we are [57]. With these observations in mind, we can reasonably anticipate that the relevant BCI will change who these patients are. Functionally integrated BCIs will change, as well as facilitate, cognitive expression. A level of physical or social feedback, hitherto missing from a patient's life, will now effect changes in how they act, the desires they will consider or to which they will respond, or even how they conceptualize their world. It is reasonable to think that such functionally integrated devices will extend a patient's cognitive as well as physical capacities [58, 59]. At least seeing it this way opens up news ways of understanding and describing the lives and subjectivity of individuals who received successful interventions using BCIs.

# BCIs, Extended Autonomy and Equalizing Opportunities

Before eagerly embracing the use of the aforementioned neurotechnology, it is important to acknowledge that many persons with LIS have been able to communicate, absent any sort of BCI. For instance many communicate through eye movements or blinking. Jean-Dominique Bauby,<sup>11</sup> perhaps one of the more renowned LIS patients, retained the ability to blink his left eye—his only means of communicating with the outside world. In March 1997, shortly before his death, his book *The Diving Bell and the Butterfly* was published, which chronicled some of his experiences and impressions of life before and after LIS. Indeed, Bauby's ability to articulate his experiences and impressions helped physicians better understand the condition, and how to deal with LIS patients.

Physicians have learned from Bauby and other locked-in patients that the inability to communicate is far more frightening and debilitating than the inability to move. As a result, rehabilitation strategies for patients with LIS have focused on finding ways to facilitate communication using whatever means are available to a particular patient-whether blinking an eye, twitching a thumb, or even focusing one's thoughts to control a computer cursor with the help of a brain-computer interface (BCI). Clinicians believe that in the majority of cases, improved communication drastically improves patients' quality of life and allows them to be more actively involved with family and community. But some patients with LIS also have communicated feelings of frustration, depression, and even suicidality-thus sparking debate about what the quality of life for a locked-in patient really is and about the relative value of artificial ventilation and other expensive technologies used in

Clearly, Bauby (and many other persons with LIS) learn to communicate absent BCI systems, implantable or otherwise. These "low tech" methods can include:

- a simple yes/no, based on eye position or blinking,
- Morse code (relying on blinking),

sustaining their lives [60].

- the "vowel/consonant" method (where letters are divided into four groups: vowels, and consonant groups 1, 2, and 3),
- groupings of letters into columns and rows designated with coordinate numbers in which the LIS patient indicates the letter by blinking the number of times that corresponds to the coordinate numbers, and finally,
- a heavily used method (and the one used by Bauby) that arranges letters of the alphabet in a line, according to the frequency with which they appear in the English (or French for Bauby) language. An interpreter reads off the list of letters, while the patient blinks as the desired letter is read [61].

While all these methods can work (and have done so over the years), they also require a tremendous amount of time and patience, both for the person with LIS and their interpreter. The people who are most likely to spend that much time with an LIS patient to communicate in this way will be family members.

The advantage to using BCIs for communication is that, after some period of training, persons with LIS

<sup>&</sup>lt;sup>11</sup> Bauby, editor-in-chief of Elle magazine, suffered a brain stem stroke at the age of 43 in 1995. He had classic LIS, retaining the ability to blink his left eye, through which he communicated with others

can communicate much more proficiently than is possible without. As to issues of mobility, including steering a wheelchair or moving a prosthetic limb, there is no possibility of this type of activity absent the use of a BCI.

There is an important caution here in the literature. Research by Neils Birbaumer has found that unless patients are trained in how to use the ECoG or EEGbased BCI while they are in either incomplete or classic LIS, they will not be able to use the device once they reach complete LIS [62]. This is particularly true for persons who have LIS as a result of the progression of ALS, which is a neurodegenerative disease. It is less clear whether this applies to persons who have LIS as a result of suffering a brain stem stroke or other insult to the ventral pons. In other words, for persons who have LIS as a result of a brain lesion, it is not clear whether there is degradation of condition from, say, classic LIS to complete LIS. In any event, there has yet to be a documented case in the literature of a person in complete LIS acquiring skill at using a BCI when they were not first trained in its use while in less severe types of LIS (p. 481) [62].

Notwithstanding this significant caveat, it is important to consider the dramatic affect on autonomous capacity that may result from using BCIs. "Autonomy" is a difficult term to define in an inclusive enough way that it is acceptable to both traditionalists (e.g., liberal theorists) and non-traditionalists (e.g., relational theorists) alike. Difficult as it may be, the concept of autonomy has clear connections to BCIs and their anticipated utility to those who have limited or no mobility and little if any control over their torso or extremities (e.g., individuals with LIS, quadriplegics) [63]. In this discussion we retain the connotation of autonomy as "self-legislation" or "self-rule" but we do not take sides on the relational versus more traditional, non-relational interpretations of the term. It is enough for our discussion that "autonomy" connotes the capacity of an individual to freely acquire or develop values or interests and then act in accordance with them in contexts that are minimally coercive.<sup>12</sup>

It is anticipated that BCIs will affect the autonomy of individuals with LIS in at least two ways: it is anticipated that (1) their capacity to act autonomously will be enhanced beyond their pre-intervention capacity and (2) the functional integration of BCIs into the lives of these individuals will affect a change in not only their self-perception but also their self-nature (at least as viewed through an extended-mind-lens).<sup>13</sup>

As to the first affect, there is little doubt that many individuals with LIS experience a loss of autonomy, or autonomous capacity, [64] which can be readily seen as such through an extended-mind-lens. Our rather ordinary ability to express ourselves through action upon or interaction with our environments, or to think through or about various other aspects of our environments using non-biological structures or artifacts (e.g., using memory aids/enhancers such as PDAs), is lost to those suffering an insult to the ventral pontine area of their brain stem. As mentioned earlier, some describe this as being trapped or imprisoned within the body. In early phase trials of BCIs research subjects with LIS have described a change in this experience of loss [65]. This is to a great extent expected. Consider BCIs that either allow limited locomotion (e.g., control of a wheelchair) or the initiation and sustenance of communication (e.g., through either the detection of eye or eye-lid movement or the control of a cursor on a computer screen). In either case, individuals with LIS regain an albeit limited capacity to express themselves, either their desires in the case of locomotion or thoughts in the case of communication.

The second affect (described in (2) above) can be explained in a similar fashion. Individuals with LIS experience a loss of aspects of themselves. Their sense of themselves as individuals with a particular place in society or their community, living out various roles (e.g., from parent to lawyer), or perceived by others in ways that have been negotiated through time and over contexts of action (or interaction)—i.e., the narrative self—is profoundly and negatively affected with the onset of LIS [66]. Again, this sense of loss of self or essential aspects of self can be readily seen through an extended-mind-lens. According to extended mind theory, individuals are not merely embodied

<sup>&</sup>lt;sup>12</sup> Our thanks to Jocelyn Downie for this analysis of autonomy.

<sup>&</sup>lt;sup>13</sup> This is not intended as a claim that rules out other ways of seeing functionally integrated BCIs as self-changing. What an extended mind theory makes clear is that changes in the body, including changes in what counts as the boundary of the body, have ontic, rather than merely psychological or subjective, implications for self-identity.

but extend into a shared action space. If this extension is impaired or eliminated the relevant self suffers reduction (i.e., the self is in some sense importantly different than the self before LIS onset). This change to self-nature is tracked, or finds expression in, the sense of loss experienced by individuals with LIS. Consider, again, BCIs that either permit limited locomotion or the initiation and sustenance of communication. Because, in either case, individuals with LIS regain an albeit limited capacity to express themselves they can begin to re-extend themselves into a shared action space.

This potential of BCIs in the lives of individuals with LIS raises some issues or questions regarding BCIs and their availability. Interventions that profoundly affect the ability of individuals to re-extend themselves into a shared action space (a) are restorative, however limited in outcome, and (b) contribute to the accessibility of persons and services that are, at the very least, implicated in those negative rights enshrined in law or constitution/charter in liberal democratic societies (e.g., freedom of association, freedom of speech, freedom of movement). The restorative aspect of BCI technology speaks to its importance and the need for continued funding or social support in the pursuit of further advances in the enhancement of the autonomous capacity of individuals with LIS (though we do not claim that this is unique to individuals with LIS). Breakthroughs to date, including the control of wheelchairs and computers to write or correspond in email, are encouraging, but limited in their benefit to those who receive the relevant interventions.

Though we wish to avoid taking a side in the debate on the intelligibility of negative versus positive rights, those who defend the continued use of negative rights discourse would do well to recognize that certain putative negative rights require certain provisions to be substantive. Freedom of speech is a paltry right when the individuals concerned lack the capacity to initiate or engage in socially significant discourse. Arguably, such basic freedoms or liberties are best conceived as predicated on certain provisions of the state, be it healthcare, basic wages or education.<sup>14</sup> In the case of those as disadvantaged as individuals with LIS, the provisioning should be more substantive where possible. Arguably, this principle is

reflected in the current provisioning of prosthetics or wheelchairs for amputees or paraplegics, respectively. In the case of LIS, such a provisioning principle lends support to measures that make BCI technology more accessible. It may also support a call for greater and continuing social support in seeking further technological advances. Interestingly, the anticipated benefits of BCI technology for those with such conditions as LIS has motivated the availability of some BCI hard-and software for interested laboratories worldwide [67]. This is one way in which the cost of this research and development can be mitigated so as to avoid downloading it onto the consumer, and may allow for the kinds of measures that make neurotechnology accessible to those in need without incurring a great deal of social cost.

However, we must be cautious here. As Dobkin reminds us, many of the LIS patients who would be candidates for BCIs are "fed by stomach tubes and require mechanical ventilation, frequent turning in bed or wheelchair to prevent skin ulcers," and more, all of which can interfere with concentration, attention, and learning (p. 638) [68]. That said, facilitating communication is among the most fulfilling immediate uses of BCIs for individuals with LIS, [69] to a sufficient extent to make the effort to learn to use a BCI system worthwhile for some individuals. It is not certain, however, that the benefits will outweigh the physical, emotional and financial burdens of the strain put on patients and their families.

Though it may be inconceivable to many who are able-bodied, intervention to connect an individual with LIS with a BCI may be unwanted. Consent should not be assumed, even by family members, and efforts should be made to communicate with the patient when considering intervention. Even where consent is impossible to obtain from the patient, it is not enough to show due care in what is considered desirable when those making the decision to intervene are able-bodied. Long-term quality of life issues should also inform intervention decisions. Among the "quality of life" factors to consider with respect to the possible use of BCIs in individuals with LIS are physical, mental, and social well-being, general health, and the caregiver's quality of life [70]. As Dobkin notes, "at present, most people who become locked-in choose not to be sustained by respirators and other invasive or painful medical procedures" [70]. He warns that the potential benefits of using a

<sup>&</sup>lt;sup>14</sup> Our thanks to Chris Kaposy for this point.

BCI may push families and physicians to encourage their use, equating them with increased quality of life for the individual with LIS. Dobkin recommends (once BCIs are much more highly functional than they currently are) waiting until the individual has decided to accept mechanical support before offering a BCI [70]. As noted recently by Phillips, albeit focused solely on ALS patients, patients who face entering a locked-in state also face future complications should their lives be extended. Increasing abnormalities in executive functions or even dementia are among them. Such complications will likely result in the individual losing their acquired ability to communicate through the relevant neurotechnology, should they acquire it, and so only add to the distress of their deteriorating psychological condition. Also those facing an extended life in a locked-in state may not enjoy a positive quality of life, even if they enjoy an ability to communicate as a result of intervention [71]. Though not as pessimistic as Phillips, Hemsley, in a paper discussing LIS more generally, also raises concern about the long-term quality of life of individuals with LIS and their care-givers should these individuals survive their first year in a locked-in state [72].

We must be cautious here not to again merely project attitudes or values intelligible from an ablebodied standpoint. Birbaumer and Cohen note that many physicians and family members believe "that the quality of life in total paralysis is poor and continuation of life constitutes a burden for the patient" [73]. In light of some of the work cited earlier on perceptions of quality of life among those with LIS, such a pervasive belief should not escape critical appraisal. Birbaumer and Cohen seem to concur [74].

### Conclusion

We have shown how looking through the lens of extended mind theory aids us in re-seeing how BCIs can affect the lives and self-nature of those with LIS. This, as we have also shown, has implications for the autonomous capacity of these individuals. Should advances in technology make possible interventions of the kind discussed above, this should not, however, obscure the responsibility of clinicians to ensure that individuals with LIS desire the intervention in question. If it is impossible to ensure consent from the individual concerned, a decision to seek consent from family members should be modified by the anticipation of further deterioration in the psychological condition of the patient. That said, the default view on long-term quality of life of individuals with LIS should not be that it is unbearable. Some studies do suggest that individuals with LIS, even over the long-term, enjoy a quality of life that makes life worth living. In this light, interventions using BCIs may not be merely desirable on the part of some of those with LIS, it may be the responsibility of greater society to ensure that access to such neurotechnology reflects the degree of accessibility currently enjoyed by those who are paralyzed or amputees.

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