

Chapter 9

My BCI Vision

Sonja Balmer

9.1 About Me

My name is Sonja Balmer. I am a 40-year-old business graduate employee, artist, and author and in December 2010 earned a degree in animal psychology. I have been ill since childhood and for many years lived diagnosed with multisystem disorder, and between 2000 and 2012 with the diagnoses PLS (primary lateral sclerosis) and ALS (amyotrophic lateral sclerosis) – the latter ultimately a fatal disease. As however the progress of the deterioration process sometimes showed regressions and due to the many years of the manifestation, the form of muscle weakness, and the fact that other organs were also involved, in 2012 the explanatory model of mitochondrial disease was declared. Neither the diagnosis of multisystem disorder nor of ALS can be considered incorrect, especially as the electrophysiological tests that led to the ALS diagnosis confirmed that both the primary and the secondary motor neurons of the diaphragm are affected. With ALS one has no explanation at all (yet); in my case through certain additional laboratory findings the mentioned explanatory model mitochondrial cytopathy arose. I suffer from paralysis and muscle weakness with pain throughout my entire body and am artificially (invasively) ventilated by tracheostomy. Many organs are affected by the illness, which is associated with gene mutation: eyes, ears, ingestion, intestines, autonomic nervous system, central nervous system, kidneys, bladder, muscles, glands. I have often been on my deathbed, but always recovered and survived thanks to medicine and *joie de vivre*.

Between the ages of 14 and 31, I painted impressionist paintings and from 1998 to 2005 organized painting exhibitions and book readings throughout Switzerland. In my three books (Balmer 2002, 2006; Jenzer and Balmer 2008) I dealt intensively with key ethical questions in medicine, psychology, and care, as far as possible

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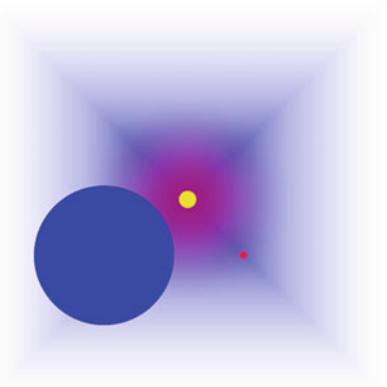
from a philosophical perspective. I plan to start a degree in psychology in 2014 and am currently teaching myself English and Latin.

9.2 My Path to BCI

The first time I heard of Brain Painting (see Kübler et al. 2008), I was in a dying phase, as I had given up on myself and everything around me. Afflicted by severe pneumonia, I was at a physical and psychological low point in my life. I hadn't only experienced pleasant encounters in the many years of my dependency. I had no energy left to enthuse myself for a life that was in no way "Sonja's". The inventor of brain painting, Adi Hoesle (cf. Hoesle 2008) had no chance of convincing me to live – not even his visit and not even his enthusiasm for brain painting. My grief over the lost impressionist painting was that profound. The disease progressed, although not as first thought. ALS generally leads to death within a few years, but I survived every dying phase that came, while everyone else around me died. I stood in public under enormous pressure to do what was expected of me: The toll of the fatal disease ALS – to die. The Sonja Balmer once full of *joie de vivre* despite the serious illness surrendered herself to her fate and wanted nothing more than simply to die. This fundamentally contradicted my philosophy. I was again reanimated, which triggered the turning point. Adi Hoesle stuck to his guns; from then on he supported me and gave me the courage to face life, visited me, wrote me e-mails. He showed me that I still have a mission and callings in life. He managed to make me grateful again for the gift of life. Shortly afterwards, Adi Hoesle visited me again. It was about a TV appearance on Swiss television, where I brain painted in front of the camera for the first time in my life. While as representative and spokesperson for other ALS patients I was a very public person, this was my first TV appearance for many years after the long withdrawal from the public sphere. Nobody can imagine the feelings that flooded over me after years ago giving up impressionist painting as a result of the paralysis: Butterflies in the stomach like previously in front of an oil painting, similar to love. Life is a miracle and I am someone who can kneel down in front of the miracle and marvel like a child seeing this wonder for the first time. That's how I felt (Figs. 9.1 and 9.2).

9.3 My World and My Art

Humans are highly communicative creatures and in the course of evolution will become ever more so. Today we are connected through Twitter, Facebook, e-mail, FaceTime, and so on and believe that we are so integrated that we are no longer lonely. Many people have 200–400 connections to so-called "friends" in their smartphones and view them as friends. Far from it! Communication is not only speech and writing but can be found in pictures, colors, photographs, and drawings.



Figs. 9.1 and 9.2 My first brain painting in front of running cameras

Art and painting is a form of communication for me, a way to voice myself externally. Wanting to create art comes from the more inner essence of mankind. It is a real, deep need to communicate something, to show something, to leave something behind, or make something visible. A creative urge that every artist understands, translates, realizes, and expresses in their own specific way. Art in all its forms gives us the unrestricted freedom to give utterance to our thoughts and feelings. The way in which one translates one's own creativity is something that needs to be sought.

Brain Painting allows me to communicate externally again via painting. Brain Painting shouldn't only be enjoyed by physically impaired people. So-called "healthy" people will also be inspired by the painting of a picture through nothing more than the concentrated power of thought from the depths of the brain.

Although brain painting lacks for example the smell of oil paints and turpentine or the feel of the brushstroke on the canvas, it achieves a direct connection to our creative thoughts. The path to painting is shortened and not disrupted by motor problems or blockades. BCI allows an undistorted reality. At the current time it is however not yet possible to paint in the precision that a painter of the impressionist style seemingly does or did. If however one looks very closely at a painting from Claude Monet, it is barely any different from the realization of an impressionist picture with brain painting. This confirms that (1) it is not only the result that is essential, but also the path to it, and (2) the viewing of a picture is always dependent on the perspective. Do I see that picture as a bird? As a bug? This consideration is essential not only in brain painting (Fig. 9.3).



Fig. 9.3 My second brain painting picture. As an impressionist painter I tried to depict a sunset at the horizon of a sea with a flying bird in the twilight. However, during the painting a memory of my near-death experience came up, the being between life and death, and I tried to depict what I felt

9.4 My Future and the Future of BCI

As long as I can communicate with my surroundings in the conventional manner, I want to mobilize all my energy to supporting the development of BCI. I am currently still able to use my multifunctional electric wheelchair including ventilator to travel outside into nature, where I gather many ideas. However I have found myself multiple times in the bad situation of the locked-in syndrome, from which I then recovered again. I know that the time may come when I do not recover from a locked-in state. I am friends with locked-in patients and their relatives.

It is today possible to use eye-tracking to control doors, windows, curtains, lights, and the computer, to write, or to activate the nurse call function. I have a device that contains all infrared codes: from the TV channels to the light and nurse call function. I imagine what it would be like to control my environment via BCI in order to acquire as much independence and self-responsibility as possible. If it is today possible to control this small, multiple-infrared device via eye-tracking and thus open a door, it must also be possible to do it via BCI.

In a few months I would like to leave the care home and move into my own apartment with 24-h care. I hope I can achieve this. I can look back on many years of experience of nursing management and medical care of my artificial ventilation as an outpatient. I imagine in my apartment, or in apartments generally, an “art room” in which I brain paint, write my books, communicate, tweet, e-mail, listen to music, relax, etc. All controlled by BCI. A videoconferencing link connects me to the outside world. But not only me. My visitors take part as well. We could even

play games. As a more or less bedridden patient this would be the only opportunity for me to connect with the outside world. It would allow me to be autonomous and independent.

Bedridden patients can generally no longer go outside into nature. In this “art room” I picture 3D nature images and films that the patient can move via BCI controls. He travels with his bed along for example a virtual and acoustical farm track, perhaps even sensing the smell of the field. Via acoustic signals he hears the rustling of the trees and the chirping of the birds. This vision is not only pleasant, but provides spiritual and physical stimulation. Through the contact with the outside world and the artistic involvement and relaxation, hormones are distributed and the mental wellbeing is improved, and the immune response improved. For people no longer able to move themselves (for example can’t breathe by themselves), the defense against infection (for example pneumonia) is strengthened. By recovering the psychological balance through BCI in the “art room”, an equilibrium of the immune response can be achieved.

Working with BCI or even just imagining working with it (1) reduces my fear of at some point no longer being able to communicate externally and (2) excites me that I can participate in what is happening around me.

At the moment that the computer selects *the brush, the stroke, the letter, the color, the door, the window, the piece that I ordered* through the pure power of thought, I detect wonder and godly reverence. I feel as though I have gone back to the creation of the human brain. I feel as though I am part of evolution. The technology allows me to go on an evolutionary journey through time. The connection to our most primal cultural needs is unavoidable. With BCI one doesn’t only advance to the future, but also engages with the past of human existence, thought, science, and progress. We should always take an example from nature, to which humans also belong. The differentiation between nature and technological development only exists at the surface. If we look deeper, we can see a pulsation in everything that we encounter in life: space pulses, a heart pulses, a plant pulses, and an EEG lead from a BCI also pulses. Everything comes and goes, grows and recedes, which seen from the outside always looks like pulsations. In a certain sense, nature communicates no differently than via a brain–computer interface. It is beneficial and we can profit from it without removing from it. We should handle nature as well as our own mental faculties with great reverence and always remember that mankind did *not* create the world but that we can learn from it to use constellations that are good for us. BCI is such a constellation. We should look after nature because we benefit from it daily. We should use it without abusing it. Humans belong to nature, and we should look after it, and we should look after ourselves. BCI is a technical opportunity to satisfy natural needs and so we should gratefully protect the nature that belongs to our age, such as plants, animals, people, cells, etc., as living beings. We would lose so much if we could only travel through space and time with BCI because we buried everything living that we could find in nature. Nature will always continue developing, and we haven’t experienced or cherished anywhere near all of its facets. Evolution-related developments, technical developments like BCI, should therefore always be harmonized with our living

existence. In the same way that body, spirit, and soul belong to mankind, so science, belief, technology, philosophy, a blade of grass, an animal, a person, bacteria, etc. are a part of nature.

If BCI can be seen as part of our nature, doors will open. However, BCI should always be subordinate to the will of the respective user. It would harm the meaning and purpose of BCI if it turns away from this and begins to try to read people's thoughts, to manipulate them. Until a few years ago seen only in science fiction movies, this form of exploitation and misuse of the technology and thus also of nature is no longer that far-fetched.

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