

The impact of a BCI for creative expression on the quality of life of two artists in the locked-in state

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Introduction: Brain Painting is an ERP based BCI application that allows for creative expression. Two artists (pseudonyms: HP and JT), diagnosed with amyotrophic lateral sclerosis (ALS) and in the locked-in state, have been using Brain Painting since 2012 (HP) and 2013 (JT) independently of BCI experts in their home environment [1-2], see **figure 1**. They have been using it in several hundred sessions and for several hundred hours duration. In this long-term study it was shown that use of Brain Painting improved quality of life (QoL) of these artists, in particular their self-esteem, self-confidence, well-being, feeling of usefulness, ability to participate and productivity [1-2].

Material, Methods and Results: To obtain a broader and deeper insight *how* Brain Painting influences the life and QoL, qualitative measures (interview) were applied. Interview questions were based on the quantitative results of the psychosocial impact of assistive devices scale [3], for instance, artists were asked *how* Brain Painting impacts the indicated dimensions (e.g., well-being) that were rated as “strongly impacted”. Interview took place after 3,5 (HP) and 2 (JT) years of usage of the BCI. Communication was enabled with help of assistive devices (HP) or by translation of an assistant by reading movements of the lips (JT).



Figure 1. JT in his art studio while painting with the BCI (left). The created painting has the title “Metropolis” (right).

Regarding *well-being* JT stated „If I couldn’t use Brain Painting, I would feel alone“. He stated further “I painted before and now I can still create paintings, this contributes to my self-esteem” (*self-esteem*), “Everything that I can do creatively, makes me happy” (*happiness*). “Other artists visit me - they are astonished what is possible with Brain Painting” (*ability to participate*). HP summarized: „I have a stable *self-esteem* and *self-confidence* and I feel mostly well, but of course Brain Painting contributes to my self-confidence and self-esteem by having new challenges. *Well-being* results from success. I feel very good while painting and with colours anyhow, quite the same as I love colours in nature. With Brain Painting *happiness* is higher, because I am *productive* and thus maybe also *useful*, in the way that I can make other people happy with my paintings. For me, being useful means being productive for others. Because I am unintentionally this no longer, Brain Painting is a welcome opportunity for me.” Regarding *ability to participate* HP stated: “This is very good for me, I have more contact to my external environment through exhibitions and requests by potential art buyers or people who simply wish to contact me. I mean others than patients”.

Discussion: Brain Painting unequivocally contributes to the QoL of the artists in the locked-in state, even after 3,5 and 2 years of use.

Significance: BCI-controlled Brain Painting allows for maintenance of QoL and emotional well-being in patients with ALS, even in the locked-in state.

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References

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