Optimizing Opportunities for Brain Injury Survivors: Technology, Creativity and Soul Searching

Rohn Kessler, Sparks of Genius, USA
Paco, Sparks of Genius, USA

ABSTRACT

In this paper, the authors (a doctor and his patient) share their complex journey into cognitive rehabilitation and a relationship that propels healing in the face of complexity against all odds. The patient came to S.O.G. unable to walk, with unclear speech and cognitive deficits but nothing could stop the indomitable resolve that spearheaded his recovery after 2 months in a coma. The patient was to blossom as a writer, an artist and a patient volunteer. His insights and skills were gently mentored by the doctor as they traveled together on the road to success and healing. This is their story.

Keywords: Brain Training, Cognitive Training, Self-Awareness, Self-Regulation, Stroke, Traumatic Brain Injury (TBI), User-Driven Healthcare

WORDS FOR THE PATIENT

Your mother described the events that brought us together as follows:

“Our son at age 29 suffered a brain injury following a stroke and hypoxic episode while undergoing open heart surgery three and a half years ago. He became unresponsive and lapsed into a coma. A tracheostomy and feeding tube were inserted to facilitate breathing and feeding. After several weeks the parents were told that their son would remain in a vegetative state for the rest of his life. After two months he began responding and was transferred to a rehabilitation hospital and began to eat by mouth. During the next four months he was able to speak and sit up. Unable to walk without the assistance of his physical therapist, he was discharged in a wheelchair and began outpatient therapy. Over the course of a year he learned to walk on his own – first with a walker, then a cane and later on with an electrical stimulator.”

You came to Sparks of Genius to begin a cognitive training program in a wheel chair pushed by your mother about 30 months ago. You were depressed, weak and withdrawn but showed great effort and a quiet determination. We agreed that you would benefit from doing brain training exercises on the computer at home (Adams, 2006). I recommended “Captain’s Log” software from BrainTrain.
After some testing I met with you and your parents to decide how to proceed. We decided to begin with strengthening attention and immediate memory (Tang, 2009). As your attention stamina and cognitive reserve increased, we worked on improving processing speed efficiency, visual tracking and other perceptual skills. I reviewed your progress every two weeks and was impressed by your hard work. You truly understand “best effort.”

Soon, some gems of wisdom and understanding started coming from your mouth. Then one day, BOOM — everything changed. Suddenly you started “writing.” This is how it happened: One Wednesday morning you came in wearing an earring with a Jack and Ace of Spades on it. I asked “What’s that earring all about?” You became quiet and softly said something to me that sounded like “Jackass.” I asked “What did you say?” You repeated more clearly “I’m a jackass.” “You can’t be,” I replied, “there are absolutely no jackasses allowed in Sparks of Genius.”

Well, you started crying really hard, and as the tears subsided, began talking about going to all your doctors, therapists and specialists. There must have been at least seven of them. But none, you said, were talking to or asking about you. We spoke about your deep need to be recognized and treated as a person — a whole person — by the specialists, myself included. It was time for self-awareness (Leung, 2011).

You had so much to say that day. We just had to come up with a solution. Since you have difficulty using the computer keyboard, we agreed I would be your secretary and that you would dictate to me. I typed very fast, made lots of mistakes and had so much difficulty understanding your torrent of words that you had to repeat yourself over and over. Eventually, when you agreed not to fire me, we began working very well together.

You dictated that first story in less than an hour and called it Ambitions. Remember? It began

“Dear intermediate family Moskowitz. Hi. Please respect the space of people who are trying to think positive thoughts. I would like to be respected. Remember Inspector Jacques Clouseau in the “Pink Panther” TV from a long time ago? He said “When looking for clues, I was always looking in the wrong places.” To get back on track is sort of like picking up a picture upside down and turning it around to look at it from the right perspective.”

Here are some other selections from your first story.

“Before I was talking in metaphors, but not now. This involves my surgery. I am still like a larva in a cocoon, and with time and metamorphosis I will turn into a butterfly. But that is sometimes a slow process. Life is not like the movie “How to Become a Millionaire Overnight.” I used to be in a tent in the hospital. I had a lot of time to think there. I was in a coma. I thought the doctors were G-d. I kept hearing voices. “You’ll be all right. You’ll be all right. You have to find your way out with a strong will. Without Mom and Dad there would be no me.”

You ended Ambitions with:

“People take too much for granted. Like walking. People take that for granted. Like talking. People take that for granted.”

You followed up Ambitions with several other stories, including Living Life Through Cracks in the Wall, It’s Not Every Day That I Punch Drywall and a more recent one I call You Can’t Repeat Life.

In it you say

“You can’t go backwards. You get way off course and way out of time. Then you’re stuck with the regrets of yesterday. You’re stuck with them in your mind too. They are scars. You can’t take back the words and all the blah blah blahs…”
Related Content

Effect of Mobile Phone SMS on M-Health: An Analysis of Consumer Perceptions
www.igi-global.com/chapter/effect-of-mobile-phone-sms-on-m-health/192714?camid=4v1a

How Much does Post Discharge Follow-Up Matter?: Recommendations for the “Big Head” Case Study
www.igi-global.com/article/much-does-post-discharge-follow/76690?camid=4v1a

Transformation of a Reluctant Patient to a Proactive Health Advocate
www.igi-global.com/article/transformation-reluctant-patient-proactive-health/76680?camid=4v1a
Quality Based on a Spatial SERVQUAL Model in Healthcare
www.igi-global.com/chapter/quality-based-spatial-servqual-model/58735?camid=4v1a