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Spencer J Smith

Department of Educational Studies, The Ohio State University

Abstract

A survivor of a traumatic brain injury makes sense of his injury and reflects on the unique individuality of injury.

Beyond adjustment: Authoring a (re)learned reality

This story is about my brain; this story is not linear because my brain wasn't linear after the accident.[1]

When I was out driving on a school errand for my ninth grade students at a high school in Detroit, I was T-boned by another driver. The car accident left me with a very serious traumatic brain injury (TBI)[2] among many other serious injuries.

TBIs, especially ones that have so many related injuries, as one of my therapists said, are like snowflakes. Each one is unique. This uniqueness is/was maddening as I recover(ed). It's maddening because doctors who think they know how to treat me think that my TBI is just like everybody else's. And it may be. I don't know what it's like to experience any other TBI other than the one in my body. But that doesn't make this TBI any less frightening.

It's frightening because my story of personal experience always seems to be in tension with the story doctors told about me on my way to recovery. Medical humanist Rita Charon (1992) has described this tension:

> One must reconceptualize the domain of medicine as a series of singular realities rather than an ideal universe. Only then can the story of the patient and the story of the doctor approach each another and together add up to a deeper, more integrated truth that advances the work of healing. (p. 130)

In this essay, then, I place my authored narrative of my recovery beside the narrative the medical profession provided in its attempt to adjust me back to health.

Medical Draft

My parents are driving me to the university hospital where I went through in-patient rehabilitation. I am worried; I perceive that my parents are worried, too. My neurosurgeon has ordered another CT scan, my second in as many months. My neurosurgeon is surprised by the results of the first; I am confused at this surprise. He knew the extent of my injuries. It must be a bad sign that there is something he did not expect to see.

As we make our way to the waiting area, I muse on how universities scare me because they mean what is wrong with me is not understood. In an attempt to counteract this fear, I feign operating as an expert. When I am taken back for the CT scan, I try not to gawk at the futuristic-space-dome-looking device I am expected to lie under; I try to take the instructions for not moving very seriously, devising psychological tasks that will keep me from itching my head.

When the medical attendant walks me back to my parents, my father smiles. “You’re a pro at those now, aren’t you?” he jokes. I nod even though I do not remember most of my past CT scans.

The attendant leads us to a room where we wait for the neurosurgeon. We sit in silence. I wonder what my parents are thinking; I know that I am occupied on a nightmare in which the findings of this CT scan mean that I will never be able to live without my parents. I imagine my parents are trying to come to grips with the fact that their oldest son will never live a life of his own.

When the doctor comes in, he apologizes for making us come in again. “The scans look the same,” he says. Then he starts asking me questions: “Do you feel dizzy? Do you have trouble sleeping? Is there anything else you want to tell me?” I tense up. What does he think is wrong with me? But I shake my head at each inquiry; “No, I sleep fine.”

“Okay, this is exactly why I wanted to meet with you,” he responds. “We see this often with TBI-survivors. Your brain looks markedly different than the typical brain. You have enlarged ventricles, but if you are not presenting any physical symptoms, there is nothing to be worried about. You will have to be extra careful around alcohol or other drugs, though. But you should be fine.”

I nod. I drove into the city and was worried for this—an anti-drug lecture?!

A year later, I am thankful for the neurosurgeon who gave me the well-meaning mini-lecture. He understood me; I cannot say as much for the physician whose office my parents and I are currently in. Because my injuries are invisible and because I do not have any physical symptoms, the physician brushes away my concerns I have about anesthesia: “You’re walking and talking; your injury must not have been that bad.”

My mother bristles; “Spencer’s rehabilitation doctor says anesthesia will affect him differently since his ventricles are enlarged,” she says as my father nods. “Will we be able to talk to an anesthesiologist before the operation?”

“I’ll make sure the anesthesiologist is aware of the situation,” the physician says curtly as he leaves the room.

Beginning to Author

I began to regain self-awareness in my parents’ family room, over 200 miles from Detroit. My parents would talk to me, but I was confused. The room was exactly as I remembered it; I had been gone long enough to expect some change, hadn’t I?

The answer to that question was complicated. I had been in that room only months earlier before moving to Detroit, but my experience of my TBI left me feeling like I had lived an entire life. The months stretched into decades.

I could feel my mind frantically trying to work out the problem. For answers, it decided to skip over the time question. It fixated on why I wasn’t in Detroit. I had students to teach! *My parents tell me some of my first questions were about my students. Did the school supply them with an adequate substitute?*

I knew the time question and the questions about Detroit were related, but I couldn’t quite connect them, yet. I was in the semi-logical state you are when you dream. I didn’t yet know the rules of the reality I was in. This dream-like state meant that I did many things that were entirely logical to me but incredibly risky to my parents. Out of fear I would follow through with my dream-logic, my parents had to hide the car keys when I incessantly talked of returning to Detroit.

Then the memories started to come. There had been an accident in Detroit. I was a driver of one of the cars. I barely remembered. And now more questions. *I wasn’t driving any of my* *students at the time of my accident, was I?* “No,” my mother calmly assured me, “you were alone in the car.”

“What was I doing?” I asked, hoping to spark my memory.

“…. The school says you were out on an errand,” my father answered.

I grilled my parents about the details of the accident and my recovery because I worried the memory I had of the accident was only a dream. It involved an old man with a bushy beard helping me out of my car. I felt comfortable around him. Then, he said he needed to go.

I processed this memory and formed the theory that I was in a kind of purgatory (wouldn’t it make sense that purgatory engender the same level of comfort as being surrounded by family?). I had been in an accident; I had seen God (the bushy-bearded man); and now I was in limbo until He decided what to do with my soul. I thought I knew where I was then: I was in a purgatory.

One day, I walked out the front door of my childhood home, expecting God to come take me away. I didn’t have to be in purgatory anymore. My parents tell me they have no memory of such an event, but it’s part of the story I tell myself about my recovery. *Walking to wait for God to take me away seemed like a perfectly natural end to this story.* In attempting to author my relation to reality, bizarre drafts materialized.

Tension between Authoring and Adjustment

Nearly six months after my accident, I sit across from a therapist and patiently answer her questions about my daily habits. I’m quickly losing focus, though, because I need to relieve myself. For several weeks now, *this* is one of the many daily problems that I want to talk about. But, instead, I am talking about how much I sleep at night, my plans for returning to work (I want to teach!), and what I spend my time doing (reading, writing, *do you nap during the day?* no, I read!).

Adjustment therapy. This is what my doctors think will help make me feel normal. A therapy that would seek normalcy for me should help me conceptualize and integrate the bizarre thoughts/memories/ideas I am having; it should give me space to (re)author my narrative. And more importantly, it should help me begin to (re)learn the roles I had in my life before the accident. But I'm starting to worry that doctors don't know what I mean by normal. I mean normal *me*.

I think this woman wants to help me be the average twenty-three-year-old TBI-survivor. I think she believes that my memory is lapsing (that's a symptom of my condition, after all) and that I'm not remembering adequately what I do during the day.

"Buy a daily planner. Write down everything you do so that when you come here next time, you can tell me what you do during the day," she tells me. I nod and write down her instructions. She tells me to bring in my parents. I really need to go to the restroom. My father recognizes it on my face as soon as I walk out to get him and my mother. In walking out to get my parents, I finally make a trip to the men's room.

Adjustment as (Re)Learning

I know now that my therapist would certainly have let me go to the bathroom earlier had I asked. I didn't know that then. In my mind, that's precisely why I needed adjustment therapy. How do I (re)learn how to be socially appropriate? I know a symptom of my condition is saying inappropriate things. Is asking to go to the restroom inappropriate?

Another common occurrence of a TBI accompanied by other serious internal injuries is experienced as an oversensitive bladder, my rehab doctor tells me months later. My bladder and brain needed to learn how to communicate with each other again. My primary care physician referred me to a urologist.

An understanding urologist prescribed me pills that seemed to help. At my follow-up meeting with him, I asked how long I would need to take the pills before my bladder and brain started communicating again. He shook his head solemnly at me. “Some people are on many pills their entire lives,” he answered. “Feel lucky you are only on one,” seemed to be the end of that thought. After my prescription ran out, I didn’t get a refill. My bladder and brain communicate fine. This urologist, I thought, read me like a typical TBI-patient and not an individual 23-year-old.

(Re)Adjustment

The next time I see my adjustment therapist, I come with a day planner, where I have dutifully recorded all of my actions throughout a day, sometimes including things like making my bed and taking a shower. My thoroughness is out of a belief that this level of detail will allow my therapist and me to recompose my life into something recognizable as my own.

As I leave this second session, my therapist gives me pointers for living with a TBI and a new session-date. She also recommends that I stay active for 8 hours a day. This recommendation is confusing to me. I spend most of my days reading. I could give my therapist a report on Foucault’s *The Politics of Truth*, for instance; I read it in one day. Was I supposed to do hard labor for 8 hours a day? I tried to help out around the house as much as I could. Since my last appointment, I had made dinner. Was I supposed to teach for 8 hours a day? How do I get back to that?

Failure to Adjust?

I never returned to my therapist. I had trouble connecting with her; I had agreed to go to adjustment therapy because of what I recognize now as a very human impulse—a desire to try to figure out how to live. It was difficult to achieve that desire when I felt like only the injured part of me was important; I am so much more than my TBI and I wanted to be in a space where that was recognized. I freed myself to see that I had mostly already recovered; I do not need a special kind of TBI-related therapy to figure out how to live. Like everyone else, I am becoming a particular kind of human. Still, adjustment therapy could have been useful if it had helped me recognize this individual humanity sooner.

Recognizing this individuality, my “singular reality,” was a vital part of my recovery. I am currently attempting to communicate this important recognition to healthcare professionals. I have co-founded a nonprofit, Smith Brain Connections, in order to advocate for TBI-patients who I know are not just textbook examples of TBIs. I want medical professionals to build upon Charon’s (1992) integrated truth that incorporates both that textbook story as well as narratives like mine. It seems like narrated integrated truths might be the key to a healthy kind of adjustment therapy, medical professionals adjusting to the “singular realities” of their patients and patients adjusting to their medical histories; maybe these adjustments can do “the work of healing” for TBI-patients.

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Endnotes

[1] I want to thank my family, Dr. Joseph Bianco, Dr. Laura Ellingson, and two anonymous reviewers for helping me control this story's lack of linearity.

[2] The Brain Injury Association of America (2011) has defined a TBI "as an alteration in brain function, or other evidence of brain pathology, caused by an external force." It has been estimated that 1.7 million people suffer a TBI in the United States annually, 275,000 of whom are hospitalized (Faul, Xu, Wald, & Coronado, 2010).