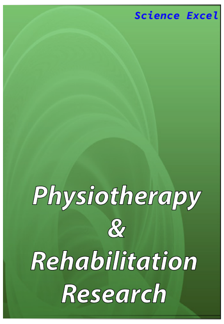
Physiotherapy and Rehabilitation Research

Opinion Article

Limitations in the Medical Treatment of Spinal Cord Injuries

Robert Sky Allen

Licensed Clinical Therapist, Chicago, Illinois, USA



*Correspondence
Robert Sky Allen, Ph.D.
10056 New Devon Street
Munster, IN 46321
E-mail: skyallen@comcast.net

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Psychologists say that people remember their failures more than their successes. I firmly believe this is true because I am a prime example. I have had many successes in life. But as I lie here in bed typically for twenty-two hours a day, I find myself ruminating over my many past failures. I have made many mistakes, but the circumstances that cause me to require a hospital bed and wheelchair are not of my own doing. Though some people may blame a diving accident or motorcycle crash for their disability, I have done nothing, and could have done nothing, to cause the spinal cord injury that prevents me from living a full and satisfying life. How did it happen? Why did it happen?

My mind is like a meandering stream in that every question seems to spark two or three new ones, leading me to follow the path of least resistance toward their exploration. This is my story as written by me and for me, the gospel according to me. Maybe in time I will find the answers. But for now, this is what is on my mind as I battle cancer, transverse myelitis, chronic inflammatory demyelinating polyneuropathy, and a host of other random maladies on this journey of life.

Though I almost choke on the words, I am a paraplegic. Nobody seems to know why. I have been to five hospitals and have seen at least seven neurologists, some supposedly among the best in the world. Yet all I have received is speculation and assumption, including four prominent theories. Paralysis is like a prison to me. Most of the time, I am confined to a small space approximately eight feet by six feet, about the same size as a cell. I eat my meals in bed. I enjoy recreation a couple of hours a day. I am transported in a van. Visits to the doctor require special arrangements. Instead of bars on the door, I have railings on the bed. Perhaps people who work in cubicles can relate (humor intended).

I have gone from knee braces to canes to crutches to walkers to rollators to standup walkers to manual wheelchairs to power wheelchairs. Sometimes I feel like Mr. Potter from the movie “It’s a Wonderful Life,” demanding to be pushed here or there. I have been to outpatient physical rehabilitation once and inpatient rehabilitation twice. I require a hospital bed to sit up and lie down, a Hoyer lift to get in and out of bed, a power wheelchair to move from room to room, a stairlift to go up and down steps, a BiPap to sleep, a wound vac to suction drainage, and even more equipment to scan and monitor my medical conditions. My wife has two herniated disks in her back, and frequently injures herself trying to position me for transport to destinations inside and outside the house. It is embarrassing to ask other people for help, especially when they notice the tubes and wires attached to me, and the atrophied legs. I used to help my neighbors. Now they are helping me with the most basic tasks. There is living and there is existing. Right now, I feel like I am barely surviving, suspended between living and dying, with my total reliance on medical devices and the beneficence of kind people.

For background, in 2012, a scan revealed a lesion on my left kidney, and I underwent a partial nephrectomy to remove it. The surgeon said he believed he had removed all the malignant tissue and that there was no indication the cancer had spread. The only recommended follow-up was an annual scan. In 2016, I was diagnosed with prostate cancer and underwent a prostatectomy, no known connection to the kidney issue. In 2019, a scan showed that my entire left kidney was diseased and I underwent a radical nephrectomy to remove it. Again, the surgeon was confident he had excised all malignant tissue. However, a routine scan at the end of 2020 indicated the cancer had spread to the bones, most notably shoulders, spine, and pelvis, and I was diagnosed with metastatic renal cell carcinoma to be treated with targeted therapy and radiation. After some troubling side effects, I met with the radiation oncologist who oversaw the treatments, and he said it would have been malpractice not to radiate as a lesion was within a quarter-inch of my spinal cord and, left untreated, likely would have invaded and compromised the nerves that control lower body movement, producing the same outcome.

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He predicted that some day I would be in a wheelchair, but I didn't believe him. I thought that, with time and treatment, the inflammation would resolve and I would be completely mobile. Since then, I have undergone nine therapies, including conventional treatments and some off-label treatments. Yet I still cannot stand or take a step. Radiation induced transverse myelitis is the first theory, and it seems to be the preferred one by most of my specialists.

Or my spinal cord may have been damaged by immunotherapy (Opdivo). After eight months of targeted therapy in the form of a pill (Cabometyx), the cancer was continuing to advance. After four months of immunotherapy, the cancer was deemed stable, but after just two months I noticed that the soles of my feet were numb. I did not think much about it as my mother often complained of neuropathy in her feet, and I presumed I had inherited the same malady from her. However, after mentioning said symptoms to my oncologist, she replied that she had seen immunotherapy "do crazy things" such as damaging internal organs, and that it was possible my own immune system was attacking the myelin surrounding the nerves. That's the second theory.

Or it could be that a combination of vaccines caused the damage. I was working in a hospital at the time the pandemic exploded, and all employees were required to receive the COVID-19 vaccine. The Pfizer vaccine I received was delivered in two doses with minimal side effects (a sore arm each time). However, shortly before beginning immunotherapy, the government was promoting the COVID booster, and I thought to myself that with all my other physical ailments, I did not want to contract COVID. Therefore, I volunteered to receive the booster. And while I was driving home from getting the vaccination, I reasoned that while I was thinking about it, I might as well get the flu shot. The nurse practitioner at the medical clinic was reluctant to give me the shot after learning that I had received the COVID shot earlier that day. But she called my oncologist who assured her that if I had no reaction to the COVID vaccine, I likely would not have a negative response to the flu shot. One medical professional speculated that it is possible the three vaccines supercharged my immune system to the point that it began destroying healthy tissue. And that is the third theory.

Or here's the fourth theory. It could be that the COVID booster alone caused my paralysis. As I write this, Robert F. Kennedy Jr. is running for president. He has taken some controversial positions on vaccinations, which led to him being labeled "anti-vaccine" with little chance of winning the election. However, he has clarified that he is not anti-vaccine, but rather opposed to vaccines that have not been thoroughly tested, such as the COVID vaccines that were rushed into the public sphere in less a year, leaving no time for studying the long-term side effects. There are reports of other people developing transverse myelitis after receiving a COVID injection, but apparently the cases are so few and far between that only individual case studies have appeared in the literature, which the government seems willing to accept as collateral damage for the greater good. I may be one of those rare cases, thus I used the Vaccine Adverse Event Reporting System (VAERS) to file a statement. But to date I have received no guidance from the government.

Okay, maybe there is one more. Doctors have said that all this could have been the result of an autoimmune disease or simply "bad luck." In the end, one neurologist stated that, and I paraphrase, "the only way we could know for certain is to perform an autopsy, cut into your spine, send a sample of your spinal cord to the lab for analysis, but you probably don't want that right now, do you?" I think they might call that "gallows humor." My mistake was getting the COVID booster, which was not required, and especially getting it the same day as the flu shot. Though this may not have caused my paralysis, I certainly wish I had not added one more option to the list.

I have always been a self-starter and go-getter, but now I feel trapped in my own body. I am writing this article in the hope that perhaps some specialist may read it and offer a few insights. Being an advocate for others as a licensed addiction therapist has helped me advocate for myself. There are more things I want from this life. I am not exaggerating when I say that an answer may save my life and the life of others. Sometimes, asking for help is when the miracle happens.

Author Robert Sky Allen is a licensed clinical therapist living in suburban Chicago, Illinois. He has a Ph.D. in Community Psychology; has published several articles on addiction in academic, peer-reviewed journals; and has written three children's books entitled, "I Am Not A Foot," "Why Is Mommy Acting Funny?" and "Why Doesn't Grandpa Remember Me?" Dr. Allen was a speaker presenting on the validity of assessment instruments at the Total Clinical Outcomes Management conference in Chicago. In addition, he is a proud husband, father, and grandfather.