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ABSTRACT

At a time when the medical field is dominated by the pressures of private insurance demands and government regulations, many people discover they need to be self advocates in order to battle illness and regain their health. Moreover, these issues are not constant, as many countries (like the USA) face changing demographics and continuing radical changes in healthcare funding. These conditions require that patients seeking healthcare re-examine constantly their assumptions on several levels including, but not limited to medical professionals’ motivations, training and accuracy, healthcare philosophies, and recommended treatments. Within this context, patients’ self-advocacy becomes essential. Yet such positive independence regarding the medical professions contradicts traditional American cultural mores. A critical question for this situation springs from adult learning and development: what are the relationships among discovering self-agency in personal healthcare, wellness, and transformative learning? This article uses the frame of an autoethnography to explore the relationship among these domains. The writer’s eight-year journey through debilitating illness includes growing understandings of and connections among transformative learning, mind-body-spirit connections, self-agency, self-advocacy, and cultural concepts of wellness.

Keywords: Autoethnographic Method, Body, Cultural Concepts, Mind and Spirit, Radical Change, Self-Agency, Wellness

INTRODUCTION

Sitting at my desk at the university it started again. The fireworks shot up the back of my neck, building to a crackling crescendo of electrical pain.

It was 2006 and I was nearing my wits’ end. I had been battling chronic, excruciating pain through the back of my neck up into my head for about a year. This intermittent pain-
ful phenomenon was only one dimension of the constant pain which crippled my activity, concentration and life-energy. I constantly had hard, sharp pains shooting through my feet and lower legs. My lower, mid and upper back all hurt with sharp pain; I could no longer flex my feet to press the car gas pedal; and my feet felt like painful rocks when I tried to walk on them. I used a cane to help me navigate walking, but even with that assistance I dragged my tortuous left leg.

Due to a hereditary condition which first surfaced in 2004, the cause of my debilitating condition was not a few herniated discs, but eight of them scattered throughout the cervical, lumbar and sacral regions of my spinal cord. Two of the three offenders in the cervical region had been replaced with cadaver disc transplants and a metal plate in 2004, after I had suddenly become mostly paralyzed on the left side of my body. However, more spinal discs continued to “pop” and their angry roar of pain racked my entire body.

My spine and joints also had arthritis which was magnified by the other conditions, and the offending herniated and ruptured discs waged relentless and violent physical, emotional and psychological war on me… physical agony and depression were constant companions. My description of the pain was “head banging,” because “It feels better to bang my head on a concrete wall than go through this.”

By 2010, I had consulted 45 doctors to address the health issues, but many of these consultations had been insulting, demeaning and discouraging. Looking back, from 2004 to 2006 multiple doctors pushed me to file for disability or enter early retirement; they said there was no way to address my many medical complications. In addition, others administered scores of injections and outpatient procedures to effectively dash my hopes of a rapid recovery. Within this discouraging record of healthcare “assistance,” I connected with two Indian pain management doctors who scaffolded multiple strategies to manage my pain and debility.

Yet the physical deterioration and pain progressed, and by 2007 I needed to use a mobility scooter/wheelchair and had a pain medicine pump surgically implanted in my body. This device reduced the relentless “head banging” pain to a low roar, but walking and sleeping were still impossible tasks.

In the midst of this physical trauma, the critical issue for me was that I had to learn to refuse short-sighted and misguided recommendations of many doctors. And even this approach was unrewarded until I found two helpful medical professionals. Two helpful professionals, among 45; that is a poor commentary on the healthcare support we currently have.

During and since this urgent quest for quality healthcare, I contemplate how I arrived at the point of dismissing medical professionals’ advice, grasping self-advocacy in a system which denies it, and charting a path towards wellness.

The epilogue of this account is especially pertinent to the questions posed. In 2009, I determined that it was time to move to a warmer climate in order to seek relief from the joint based arthritis, achieve year round activity in a warm pool, and perhaps seek different and more successful medical care. I was fortunate to encounter a job posting at a prime program for my discipline in Florida, and was offered the position after successful interviews.

I moved to Florida in June 2010 in order to begin treatments with a pain specialist recommended to me. By September 2010, I proudly and permanently stored my mobility scooter in the garage, as the pain had been “turned off” for the first time in 8 years, and I had rebuilt my feet and legs by daily swimming in my backyard pool. Furthermore, by January 2012, I was able to play golf two times a week. If I had believed the doctors, I would be on disability and still be in a wheelchair.

BACKGROUND

Even before President Clinton’s attempt at healthcare reform in the 1990s (Kooijman, 1999), private insurance companies dominated the medical field with demands and govern-
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