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On Being a Zebra: Negotiating a Professional Identity Whilst Coping With a Rare and Recurrent Illness

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Abstract

In this autoethnography I discuss some of the impacts of a chronic and long-term illness on my professional identity of a professor. I examine issues of lack of control throughout the discussion. I also discuss the contribution of phenomenological accounts in the form of autoethnography in serving to challenge society's view of disability. I suggest the individual intersection of disability and identity demand that the scholarly community listen more to the stories of people who have actual experience of long-term chronic illness. In doing this, we may develop nuanced understandings of the impact of chronic long-term illness on the development on professional identity.

Keywords

Autoethnography, Chronic Illness, Professional Identity, Acquired Disability, Disability Theory

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On Being a Zebra: Negotiating a Professional Identity Whilst Coping With a Rare and Recurrent Illness

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In this autoethnography I discuss some of the impacts of a chronic and long-term illness on my professional identity of a professor. I examine issues of lack of control throughout the discussion. I also discuss the contribution of phenomenological accounts in the form of autoethnography in serving to challenge society's view of disability. I suggest the individual intersection of disability and identity demand that the scholarly community listen more to the stories of people who have actual experience of long-term chronic illness. In doing this, we may develop nuanced understandings of the impact of chronic long-term illness on the development on professional identity. Keywords: Autoethnography, Chronic Illness, Professional Identity, Acquired Disability, Disability Theory

I am well and in control

I run everyday

I am well and in control

I dance in Zumba

I am well and in control

I go to the gym and I work out

I am well and in control

WHAT?

I am in pain

I can't move

Don't take me to the hospital

My head hurts, I can't move, I'm going to be sick, I can't drink anything

Take me to hospital

My head hurts, I can't move, I'm going to be sick, I can't drink anything

Listen to me...

My head hurts, I can't move, I'm going to be sick, I can't drink anything

I don't want another lumber puncture

It won't tell you anything

I don't want to argue

My head hurts, I can't move, I'm going to be sick, I can't drink anything

I'm very dehydrated and just need some IV fluids

This is okay... Please don't panic

I don't want to stay in hospital

I don't want another lumbar puncture
 I give up...do what you need to do
 I am not in control....

Introduction

I have Mollaret's Syndrome, a rare illness, which is basically recurrent viral meningitis but presents as Parkinson's or MS. The opening poem reflects my struggle with the onus of control and my developing identity as a professor in teacher education in the UK and the US. I attended a Dissertation Award presentation from the Qualitative Inquiry Congress, entitled "Chasing a Zebra: Identity as a Teacher" in 2016. I listened in fascination to the autoethnographic journey of a wonderful doctoral student, who had experienced a chronic illness whilst struggling to be a K-12 teacher and pursuing her doctorate in education. I was enthralled to listen to her story, which shared her experiences in an eloquent way that also wove in appropriate theoretical constructs. I was happy to see her well and strong having experienced such a debilitating event and appearing at this presentation vibrant, strong and well. In sharing her story, she discussed her evolving identity as wife, mother, teacher and scholar. I listened to the presentation with increasing levels of connectedness and awe. Connectedness through reflection of my own experience and the realization that I too moved through different identities as I navigated a thirty-year illness while being a wife, mother, teacher, assistant principal and professor. However, it took several more years, until 2019, before I felt ready to put "pen to paper," before I accepted that the illness I endure is an integral part of my professional life and that needs to be embraced.

Listening to the story of this doctoral student gave me permission, after almost thirty years, to think of my own chronic illness in a different light. In this conference room, celebrating an amazing achievement, I began to think of the years that I struggled to keep my illness separate from my work. I became a successful professor and scholar despite this incredibly inconvenient "illness thing" that is always lurking in the shadows. I saw in the room and through the award that people were actually interested in such stories. I heard that integrated meanings can be made of incredibly complex, and, on the face of it, totally unrelated phenomena. Indeed, more authentic meanings come as a result of this integration. The medium of autoethnography enabled this to happen. A medium that garnered scholarly respect. I left the presentation knowing that I needed to write my own story. Easier said than done. I spent the summer of 2016 getting the sequence of my own story down on paper and creating the poem. It was hard. It felt very self-indulgent and alarmingly I felt very vulnerable. Did I really want to shed light on an aspect of my life that for many years I had managed quietly and distinctly separate from my professional existence? Perhaps that is why I shelved it for another three years. In the summer of 2019, I returned to it.

Literature Review

I was intrigued by a term the doctoral student had shared back in 2016, that of "Chasing a Zebra". This term, used in the medical profession, is adopted when a patient presents with a complex and rare medical condition. She shared that, in her experience, the medics pursued a pathway to diagnosis through a maze of known and familiar illnesses. This pathway did not apply to her and she experienced the reluctance of the medical profession to navigate a rare and unfamiliar illness. The process is termed in the medical field as "chasing an unfamiliar and unique zebra," while the profession, for the most part, is organized to chase more familiar and known phenomena. Consequently, they only have the ways and means to "chase the more

familiar.” The process of diagnosing an illness that presents as different, unusual and unique poses real challenges to the capacity of the medical profession.

I, too, may have presented the medical profession with an illness that may be referred to as a “zebra.” However, in my case, in England and America, doctors went to extraordinary lengths to arrive at a diagnosis, (which, indeed, took thirty years). I listened in awe at this presentation by the doctoral student as I came to the realization that through autoethnography I could construct new understandings of an ongoing and recurrent illness (Richards & Haberlin, 2017). Should I rewrite that sentence and say “**my** ongoing and recurrent illness”? No, I don't need to be defined by this dark cloud of chronic sickness, however intrusive it is. I choose to keep it away from personal ownership... I chose to keep it at a distance until its disabling features could not be hidden anymore.

In processing my understandings of identity, as they relate to my personal and professional story, the early work of Jenkins (1996) is helpful when he suggests identity can best be understood on a dialectical model that acknowledges the crucial role of boundaries and tensions. I appreciate Bakehurst and Sypnowich's (1995) theory of the potential for the individual to exert influence on identity, “We are participants in our own construction and exercise some autonomy in the face of the forces of socialization,” (p. 5). I appreciate my mobility is impacted, that I experience a level of disability, but this does not impact who I am, a professor, a writer and a teacher. However, I do accept the role of Social Identity Theory (Stets & Burke, 2000), how identity is impacted by the people who form your community. I realize the intricacies and complexities involved and the volume of work connected with identity is extremely large and can be overwhelming. The early work of Park (1950) frames my understandings of such intricacies and complexities:

It is probably no mere historical accident that the word person in its first meaning, is a mask. It is rather a recognition of the fact that everyone is always and everywhere, more or less consciously, playing a role...it is in these roles that we know each other; it is in these roles that we know ourselves. (p. 259)

Methods

As a form of writing. I had not considered autoethnography. To be honest, I thought it a little too self-indulgent for my comfort level. The autoethnography I read impressed me with its dance between the personal and academic (Denshire, 2014), but that only added to my assumption that I could not successfully write my story in such an eloquent way. Also, this nature of scholarship was personally threatening. Did I really want to inhabit this scholarship space? However, the qualitative award dissertation presentation showed me, not only that such a personal narrative could be a respected academic venture, but also be valued by an academic community. People may even want to read it. Autoethnography involves inquiry that is both highly personal and scholarly to offer a unique perspective on an issue. It is linked to identity politics and personal narrative inquiry (Adams, Holman Jones, & Ellis, 2014). Both are particularly fitting to my current story; issues of identity are central to my scholarship.

I first encountered narrative research through the lens of disability studies and the work of Goodley (2000, 2001) who worked with young people with disabilities to document their lives and contribute to fundamental understandings of critical disability studies. The power of story and the theoretical contribution were impressive and helped to shape my academic life. The contribution of Bochner showed me that scholarly work could focus on very personal issues (Bochner, 2016). It makes sense that both understandings of identity and personal narratives can contribute to my own meaning making as a scholar and someone who experiences a sustained “zebra” like illness.

Results

We now understand that it may have begun when I was eight years old with an attack of shingles. I had had chicken pox as a toddler and the fact that I had succumbed to shingles was a very strange phenomenon. I lived in the North East of England at the time and was the youngest of six children. My dad was a laborer in the local steel works and mum stayed home. We lived on a council estate, called Dormanstown named after the steel worker Dorman Long, where my Dad worked. It was a close-knit community and my having shingles at the young age was worthy local news - something slightly out of the ordinary. Lots of fuss was made and jokes from my older siblings about getting an “old fogey” illness. More significantly, the shingles virus then laid dormant on my meninges. Little did I know that this three week encounter with shingles would define my adult life in such a definite and pronounced way.

Move the clock eighteen years on. I was the first in my family to attend college and I travelled fifty miles north to attend university to prepare to be a teacher of children with severe disabilities. I had my first attack of viral meningitis at the end of my first year at college. This first bout lasted about a month. I presented as someone with bacterial meningitis. The ambulance was called, and I was admitted to hospital. I was given a lumbar puncture and it was ascertained I did not have bacterial meningitis but the less dangerous form of viral meningitis. We celebrated this news, even though I experienced a significant and debilitating illness. I stayed in hospital for a week and then I was sent home to Dormanstown to recuperate. Over the following month, I recovered and returned to college not missing anytime as the illness occurred during the summer. Phew, a brush with serious illness that I seemed to have overcome. This first episode was explained as my immune system reacting to the unfamiliar viruses the children brought to the classroom—not an unusual phenomenon for new teachers. Eighteen months later another attack occurred. Again, there was a similar panic that it may be bacterial and hence the need for a lumbar puncture. Another attack eighteen months after, and another eighteen months after that. Sometimes it was nine months between attacks. I lost count of the number of times lumbar punctures were administered, sometimes they were able to culture a virus and sometimes not.

After numerous lumbar punctures, (nine or ten, I think), I called it a day with them. They left me flat on my back for days and prolonged the time I was “out of action” and the need to confirm viral meningitis as opposed to bacterial was not so marked. However, the doctors in the emergency rooms did not see it this way, and each time saw the presentation of bacterial infection. My notes never seemed to follow me, so it is understandable that they felt the need for a lumbar puncture. After the third attack, the doctors told me that I presented with a very rare medical case that was inexplicable at that time. However, they did not give up, even though I moved from doctor to doctor. It took thirty years for the doctors and myself to disentangle the mystery of why I kept succumbing to recurrent bouts of viral meningitis.

This journey to diagnosis has definitely been interesting. I was one of the first people in England to have an MRI (difficult to imagine now). I was sent to London to have the MRI in a private hospital. One time, I was hung upside down to see if there was a leak in my skull. Another time, I was given a lumbar puncture when I was well, which showed the spinal fluid did present differently in a viral meningitis attack. Yet another time, a doctor from Finland came to see me in hospital as my illness was considered so rare. In the eighties, I was under the care of the auto immune disorders (AIDS) doctor as it was believed I had an immunity issue.

It is now the prevailing explanation that the shingles I had when I was eight years old left a dormant virus on my meninges. Every so often, for no apparent reason, this dormant virus would become active and present as aseptic meningitis. The journey to this realization has been

long and arduous. These bouts of meningitis are very frightening and particularly alarming to my family, doctors and medical staff.

Ten years ago I was diagnosed with stage 2b breast cancer, which required surgery. Fortunately, my surgeon was familiar with the Onco DX test, which checked the DNA of my tumor and possible treatments and found that my tumor would not respond to chemotherapy. Rather, a sustained dose of hormone therapy would reduce the odds of reoccurrence from 70% to 13%. This was a no-brainer for me, but not for my oncologists. Throughout the five years of treatment for breast cancer, my viral meningitis did not rear its ugly head. It was as if it knew my body had enough on its plate with the cancer. Throughout this period, I explicitly fought against any identity related to cancer "victim," any community assigned identity usually applied to cancer sufferers. I made the decision that I was going to create my own identity, that of a successful working mother. I was fortunate to be teaching online and recall a neighbor working the computer for me while I taught due to my restricted movement because of surgery. I also began to walk and run and completed two half marathons during the bout of cancer. I was able to do this because I escaped chemotherapy.

Unfortunately, after I had recovered from my dance with cancer, the bouts of viral meningitis returned. The first one occurred two years after my "recovery." It struck out of the blue and I was totally unprepared. I did not have any medication (anti-viral, anti-nausea and pain relief). My son was home from college and became distressed when I quickly fell into a state of dehydration. We rang our doctor's surgery to try to get anti-nausea medication, but to no avail. The advice we were given was to go to ER, which I reluctantly did, bearing in mind my son's distress. Of course, I was presenting as if I had bacterial meningitis and the ER panicked. I tried to explain about my condition but there were no notes and my family doctor was away. No talking or arguing on my part convinced the doctors. They wanted to give a lumbar puncture. I was getting considerably weaker by the hour, so, I unhappily succumbed and had my ninth or tenth lumbar puncture. Lumbar punctures are quite an invasive procedure. I was ill and was acutely aware I had to accept the doctor's power over me. Once the lumbar puncture came back supporting what I had said all along, I got my fluids and anti-nausea meds and began to feel considerably better. I stayed in hospital for twelve more hours and was then discharged, with the instructions to go to my family doctor the next day. This was a challenge. Every time I sat up, I was sick, and this aggravated the incapacitating headache. Getting home from the hospital was an ordeal in itself. Back in England, my family GP would make a home visit and I could remain flat on my back. Now, in America, I had to get dressed, get in the car, go to the doctor's surgery and wait in the waiting room. The doctor's surgery is a busy and bustling family practice, and it is not uncommon to wait for up to an hour to be seen by the doctor. I stayed in the car, in a semi reclining position, while my husband checked me in and waited for my name to be called. I eventually hobbled into the office and my doctor could see my predicament, gave me a small number of meds and asked me to return in several days. I felt as if, during the experience of the illness, I was powerless and at the mercy of the medical profession, no matter how they thought they were working in my best interest. I wanted to regain some level of power and control over the treatment of my illness. In this quest, I asked my doctor for a pack of medication that I would begin at home when I first experienced the onset of the meningitis. This involved anti-nausea, anti-inflammatory, anti-viral and pain medication. This proved to be problematic for my doctor, not that he did not want to be proactive, but that the health care system would not allow him to. How could he prescribe for an illness that he was not actually presented with? What if it was bacterial meningitis? He was not allowed to prescribe pain medication. I understood his predicament, but still wanted to take control and exercise some power over this illness.

In the summer of the 2019, I returned to the document that had remained on my desktop, glaring out at me and reminding me I needed to try to process and make sense of what was

happening to me. My illness had taken a turn downhill and I was preoccupied managing that. At this time, I was not driving, since the virus had seemingly migrated to my vestibular system causing double vision and major imbalance. When the doctor told me about the possible migration I responded with a question, "Does this virus have agency then?". The doctor looked puzzled and did not reply. But perhaps this virus really had "agency" and chose to exert its power over me because I had consistently managed it in a minimally disruptive way. I became aware of a Facebook support network of people with similar stories to mine. Rather than the virus having "agency" it appeared as a natural progression of the illness that balance was impacted and that people had been initially diagnosed with Parkinson's or MS by their neurologists, but the tests had come back negative although the symptoms were similar. The illness was taking its toll. As well as not driving I developed a limp and needed a stick to help with walking. Gone were the days where the illness was invisible for the majority of time. Folks asked why I was limping and sympathy oozed out of them. I have never reacted well to sympathy and felt folk were questioning my intellect. "Bless her," was the term that came to mind. Currently, I take each day without meningitis as a gift. I have my "bag of medicine" to take if I ever come into contact with shingles, or I feel an attack coming on. In addition to seeing the neurologist every three months, I am currently following a nutritionist advised supplement protocol to rid my body of the dormant virus along with a homeopathic course of medicine to build up my constitution.

Discussion

Through the bouts of illness, I have sought to retain a separate professional identity: first, in England, as a teacher of children with very complex needs, then as a professor at a new university in England and then at a Research One university in America. Through my account, I hope to contribute to understandings of the nuances of the development of professional and personal identity and affirm the work of some scholars in the areas of the development of identity and critical disability studies. I appreciate the limits of my scholarly contribution. I offer a personalized and individual account of my developing identity as I navigate a chronic illness, and it is not intended to represent the perspectives of others.

During the bouts of viral meningitis, I did not think of the illness defining me. I was promoted from classroom teacher to the school senior management team and then became an assistant principal. Clearly, the illness was not impacting my seemingly bright professional career. But as the years have passed, my mobility has been impacted, which, in turn, has impacted how I present physically. I accept that I am in transition, processing my new identity as a disabled person. Clearly, I am different. I was acutely experiencing the tension of Jenkins (1996) as I was hovering on the boundary of disability. My balance is weak, and my gait is awkward, I cannot climb stairs without help, I experience sympathetic looks and questions about what is wrong, to which I do not respond positively. On the inside, I do not feel any different but the assigned identity, that of disability needing pity does not sit well with me. The role of Social Identity Theory (Stets & Burke, 2000), how identity is impacted by the people who form your community has an influence on me. This creates a tension. I have spent my life advocating for people with disabilities and now, experiencing a small physical disability, I am challenged by the identity others assign to me. I agree with Bolt (2015) who posits that disability is something that impacts all of us as some point, and the one identity that we will all eventually share. The problem, I think, is the loss of control over who says what is assigned as my identity and what I choose my identity to be at this phase of my life (late fifties in age). I am the youngest in my pain relief Tai Chi class, something a fellow participant commented upon sympathetically. I tried hard not to cry. In my scholarly and teaching career, I have been influenced by scholars in the critical disability studies field (Goodley, 2013) and have worked

and advocated for students (and their teachers) with complex disabilities. Relatively, my small physical disability is miniscule in comparison. My struggles with identity seem somehow a little self-indulgent. However, it is what it is. I continue to be influenced by Goodley (2013) and colleagues in that I accept disability as being a social construction of society (Zheng et al., 2016). I am a warrior for the students and teachers, but struggle with my own identity. A tension that is confusing and complex. I accept that the discourse relating to identity is about continua, tensions and boundaries (Hills, Elward, & Lewis, 2010) and I am experiencing this tension as I process the repercussions of my illness. However, society's response to disability may be difficult, as it is influenced by social norms, which themselves can be viewed as problematic. How far have we moved beyond the critique of Synder and Mitchell a decade ago? "[The] experience of disabled embodiment in order to disassociate disability from its mooring in medical cultures and institutions. Although recently disability criticism has been calling for a return to a phenomenology of the disabled body" (Synder & Mitchell, 2001, p. 368).

Conclusion

I suggest that we (scholars/society) pay more attention to the individual phenomenological stories of acquired disability, and through this listening, we (scholars/society) may learn something new about the subtle continua of identity and appreciate what some of the tensions may be. Autoethnography makes a great contribution to the gathering of these phenomenological accounts. For me, once I left the feelings of self-indulgence behind, the writing of this piece has been very beneficial. Not only for me personally, but as a contribution to the knowledge base of the impact on professional and personal identity of someone coping with a rare and recurrent illness.

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