

An American Pathos: Autoethnography of a Life with MS

Amy L. Pablo
University of Calgary

Abstract:

In this paper, I present the story of a woman afflicted with multiple sclerosis, describing the battles she fights, and her ultimate realization of a sense of success in her life as she endures the stages of epiphany, exploration, and transformation through her struggles. Thus, this tale is truly pathos in that it evokes an emotional response to persuade others that her narrative tells of an experience of life that is justly sad.

"When I sit down to make my stories I know very well that I want to take the reader by the throat, break her heart, and heal it again"

Quote from Ruth Behar (1996) the Vulnerable Observer

As I struggle to cope with, and make sense of, my own experience living with Multiple Sclerosis. I find myself trying to put into words what I'm personally experiencing, so that I can share it with others in my life. Hoping to lighten the loneliness of it, I guess; imagining there must be something therapeutic in actually articulating the grief I feel for my past self, (Pennebaker, 1997); harkening back to what one of my favorite academicians said in a book he wrote, "How can I know what I think until I see what I say" Weick(1985). About this chronic illness that I carry, and the infinite losses that have been inflicted on me through it (Jackson, 2014), I just have to keep moving on, which basically means for me at this point in time just writing about it. Keeps me busy and hopeful that someday, somebody will find it of enough value and interest, to actually publish it (the only metric of accomplishment, and or happiness, I actually operate by these days).

Introduction:

In 1994, three years after beginning my first professorial job, I was diagnosed with multiple sclerosis. Not only was I undertaking a new job in a new profession, but I was also living in a new city and a new country. This experience was like learning on steroids (i.e. incredibly intense). The research method used in this study is qualitative in nature and allows for a deep understanding of the focal individual in the social and historical context in which they work live and play (Merriam & Associates, 2002,p. xv).

This research perspective allows the researcher to focus on the "process meaning and understanding of the individual under investigation"(myself) in this case(Merriam & Associates,1998, p.8).In doing an auto ethnographic piece of research, I have the advantage of using first hand observations. I try to use analytic reflexivity to create theoretical understanding of how individual learning processes have had a transformative effect on the subject of study (i.e. myself).

This pathos is a narrative intended to persuade an audience of readers of the credibility of my case as a disabled author. I'm really trying to craft a farewell contribution to my self-identified community of academicians so they'll understand my lengthy absence from the "publish or world" of the typical professor.

MS Types of Multiple Sclerosis (hereafter noted as MS):

MS is an autoimmune disease that affects the central nervous system. The disease disrupts the flow of information within the brain and between the brain and the body (Witherspoon, J. F., 2017). There are five

types, or disease courses of MS. They are clinically isolated syndrome (CIS), relapsing-remitting (RRMS), primary-progressive (PPMS), secondary-progressive (SPMS), and progressive-relapsing (PRMS). The type I was diagnosed with was RRMS. This involves clear episodes of inflammatory activity and well defined attacks of new or recurrent neurologic symptoms. A person with RRMS will typically experience full or partial recovery. However, a person is never sure of when an attack (or exacerbation) will occur. Thus it is hard to plan your life around your disease.

Symptoms commonly associated with all types of MS include numbness and tingling, fatigue, weakness, vision problems, and dizziness or coordination problems. There is no clear way of absolutely diagnosing MS but it typically an individual presenting with the symptoms noted above frequently over some period of time, and when it is suspected MRIs can be used to look for lesions (scarring) in the brain and spine. Episodes of symptoms can last from 24 hours, two weeks, or continue for the rest of your life (Lewis, M.N., 2009).

But let me begin my story . . . :

In 1987, while in graduate school, I had the first symptoms of what turned out to be Multiple Sclerosis: What is *multiple sclerosis* it is an autoimmune disease that affects the central nervous system. The disease disrupts the flow of information within the brain and between the brain and body (Fletcher, J., 2017). I experienced numbness in my hands which made taking notes in class a real challenge. Along with that I had bands of numbness around my belly, and tingling in my feet. I did go to a doctor at the local hospital in Austin, Texas and they passingly mentioned it could be MS. They did nothing about it, so I guessed it was not that important. These symptoms passed over time, so I stopped thinking about it and did nothing to investigate further.

Well, time went on and I graduated from my PhD program, and took a job in Calgary, Alberta, Canada. In 1991, my first year there, my husband and I took a driving trip to Jasper, Alberta. During that trip I had excruciating pain in my eyes and could basically not stand to move them (later diagnosed as optical neuritis). Upon returning from that trip I decided I needed to see a doctor about what had happened. So, he sent me to get my first MRI to get more data to try to make a diagnosis. At that point, using the data and information about my earlier 1987 experience, he declared that I did indeed have multiple sclerosis, but made no prescription to treat it. He tried oral Prednisone on me (whacking huge doses to start then tapered down), but since it's a steroid didn't want me to stay on it long.

Time passed, and I found myself having problems walking down the corridors at work , so I tried to talk again to the neurologist who had diagnosed the MS in the first place but at this point was passed on to another doctor who decided to try to do something to treat it. After a long time of waiting to get government approval for a drug that was considered experimental in Canada at the time, I was allowed to use Copaxone to get it under control. I used that drug requiring daily injections from 1994 to 2014. In the meantime, this being real life, I lost my first husband to colon cancer; a tragedy, of course, but as a result I met (and married) the love of my life, the most kind-hearted man and MS tolerant person I've met. After all, they say, "You married me, you married MS" what a great start to a new life!

During that time, I moved from Canada to California (part of which was to get more vitamin D, which is supposed to be beneficial for MS), and found yet another neurologist. She decided I was not getting much benefit from Copaxone anymore. This was fine with me because I hated those injections. [I remember one time on a business trip to Southeast Asia sitting in my hotel room for hours trying to get up the nerve to actually take my injection]. Anyway, my new doctor eventually decided to prescribe oral medication, and I

went through the usual trial and error with those pills until I found one I could tolerate. [One was so bad it made me feel suicidal].

Again time passed, and my neurologist retired and passed me on to yet another doctor. This new doctor has not quite got my medication routine down to a smooth transparent routine yet, and I, as a result am having to play tag with the drug companies to get the meds when I need them, and advocate for myself to be allowed to have them at all, even though they are prescribed by my doctor. As MS is an “orphan disease” (i.e. one that doesn’t have a lot of interest due to its incurability and the greater visibility of diseases like cancer and relatively small percentage of people who have it), the drugs used to treat it are classified as specialty drugs which aren’t readily available at just every drug store. You can’t just take your prescription to any drug store and expect to get them. You have to order them well in advance of when you need them and expect them to be hand delivered to your home in time. Getting that done requires a lot of one on one interaction with the multitude of players involved, all with their own interests at heart. (See Figure 1).

Side Comment on the American Health Care system:

When my husband and I moved to California and tried to get insurance for me, the agent compared me to a broken car, saying “You wouldn’t insure a broken car, would you?” All I can say is how happy I was when President Barack Obama was elected and he made it a law for insurance companies to have to insure pre-existing conditions, because that is what was being used to deny me coverage. Not that I’m a big Obama fan, but without insurance I wouldn’t be able to afford the costly drugs and treatments my condition dictates. (Insurance alone is costing me \$9,000/yr. and even with that the medications are around \$12,000/yr., talk about breaking your back).

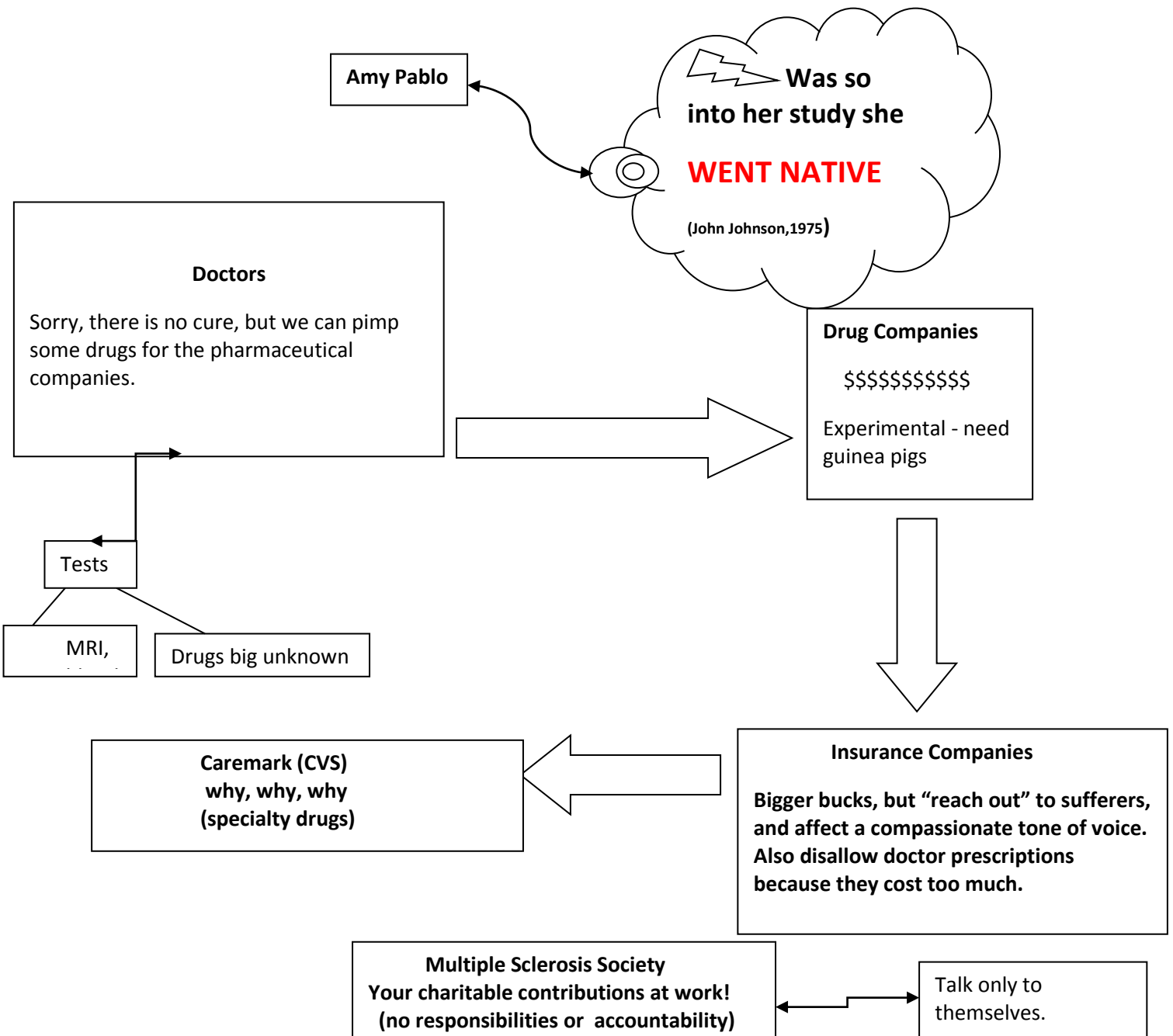
Management of this system is pitiful and it is really an oxymoron to use those terms together at all. At this point in my experience of trying to write and survive my own MS story, I have to say not only do I feel powerless over the disease itself, but in dealing with the system that’s supposed to be helping me.

All I really feel about it is that it’s like adding insult to injury. When my husband tried to get health insurance for me, he was sneered at by the agent with the comment “You wouldn’t try to get insurance for a broken car, would you?” Even the federal government is in on the act in terms of what they demand for Social Security disability coverage (Social Security Resource Center, 2017). I should note here that there is a sense of ‘othernesses for a person diagnosed with what is commonly considered to be a disability. That person begins to hold a marginalized status in any community of non-MSers. The toll exacted by MS, or any chronic illness is that it has a significant impact on the physical, social, psychological, and even political events in a person's life. The MS patient begins to think of themselves as an 'other' because of the cultural connotations, symbols and significations surrounding their 'special different' status.

Figure 1.

Amy Pablo Field Study on Multiple Sclerosis

Method: Participant Observation (no informed consent)



All the major players in my story (as denoted by the rectangular boxes on Figure 1) are too powerless and multilayered to really have any beneficial impact on the outcome of this story. The doctor who diagnoses what's wrong and writes a prescription for the drugs he/she thinks are appropriate can be overruled by the doctors employed by the insurance company if they deem the benefits of the drugs are not adequate to justify the expense (See Exhibit 1). One drug and pharmaceutical company to control the disease and one to manage the symptoms. And besides the prescription, the doctor has to complete prior authorization forms for every drug you have been prescribed.

Not only does all this have to happen before you can get access to any medication, the drug companies dispense their product only 30 days at a time so you have to get back on the merry go round to get a necessary refill on a timely basis. Every month is an uncertainty, and every year it starts all over again. And if you go on vacation, you have to apply for a "vacation override" to get access to more than your monthly allotment of 30 days worth of pills. And you dare not stop taking the medications because it could cause seizures. And not only are there the medications to take care of, the treatments (blood tests and MRI's) to monitor what's going on in your body have to be arranged and carried out and paid for (either self-pay or co-pay).

This charade affects the whole family and makes you hyper-aware of MS every single day. It's hard to count the endless hours and days being wasted in this process. Almost makes you feel like giving up on taking the outrageously expensive medications you've spent so much time and effort getting. MS alone is bad enough, but the treatment is insane.

In addition to physical impairment (not being able to walk or travel alone (i.e., loss of all independence), loss of proprioception (i.e., awareness of your surroundings and how you relate to them), concomitant cognitive and emotional symptoms exist which add to the burden. This is like concocting a study in how to create a condition of learned helplessness, and as Seligman (1975) found, ultimately depression, and Weiss followed with the notion of "stress-induced debilitation" (1975). This state result in further cognitive attributions specifically, awareness of uncontrollable factors in your environments which are viewed as unchangeable.

And so it goes, a person who once thought of themselves as capable and competent in almost every aspect of their lives is now reduced to groveling to the powers that be for some relief even while knowing (or at least believing) that they are more powerful and unconcerned. After all, they have their own agendas and no discretion in their own decision making realm to do anything that does not contribute to the profit making goals of their masters.

Thus, the outcome for the subject in this cruel experiment is that you are robbed of any enjoyment in life (positive reinforcement in dealing with your situation). The situational factors of not knowing how the system in which you find yourself works and the constant worry about finding the route to a positive outcome are truly debilitating and more harmful than the disease you are trying to manage. And you are engaged in a battle with a much more powerful actor which you will never be match (the corporate world that controls the playing field you are in, adding to the frustration and knowledge that you will never beat them, again piling on to the awareness that you will never beat what this disease is doing to your life). And finally, the destruction to the safety shell you have by good fortune and love from others had bestowed upon you.

Ultimately you feel like you are set asail on a ship without a captain that is headed straight for the reefs and you have no capability of changing the course even though you can see disaster coming. And all the while, the one organization you thought was your life raft (the national MS Society) is smiling and laughing in the wings with no concern for your plight.

When I first started writing this paper I thought I was going to frame my role in it as being the ultimate participant observer in a field study. However, in order to present my narrative as appropriately as possible I decided to term it an Autoethnography because I am a participant observer who is completely integrated in the population of study beforehand, or personal sociology, participant observation to the max. Thus my recorded observations are never going to be the full description. This researcher' personal beliefs of what is relevant and important influence data collected and how it is analyzed. Researcher (myself) is completely integrated in population of study beforehand. It is therefore possible that data collection loses all level of objectivity, thus risking what is analyzed and presented to the reader.

In this my own Autoethnography, however, I am presenting a personal narrative by way of which readers can connect with my personal experiences on this journey. Here, they will witness and the epiphany, exploration, transformation of a person knowing that things will never again be as they were before this crucible of life with multiple sclerosis.

To me, this writing has been therapeutic in that it communicates to others the chronic nature of the isolation that has been mine since being diagnosed with MS, a disorder which is cloaked in secrecy reflecting the taboo nature of even talking about it in my world it's the elephant on the table.

Conclusion:

At this point in time, I have learned as of my latest MRI, that not only do I have multiple sclerosis, but I also have been gifted with arthritis of the spine, another autoimmune disease. I have felt for some time (approximately last 6 months), that my whole body was being twisted at the spine causing me to be unable to stand up straight and further diminishing my walking capabilities. I thought initially that my MS had morphed into some type of scoliosis, but learned that my MS signals (the lesions in my brain and spine) had not changed, but rather were joined by another autoimmune disease (spinal arthritis). Again, there is no cure, but a coterie of remedies for symptoms that have to be accessed to get some relief.

And so for now ends my tale of woe. Currently, I am happily engaging in some physiotherapy that at least makes me feel like I am trying to take some control over this body that I no longer know.

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Exhibit I - Denial Letter

Blue shield of California

10/19/2015 8:56 AM

RE: **AMY PABLO**

Date of Birth: **07/25/1952**

Drug: **AMPYRA 10 MG TAB ER 12H ORAL**

Member ID#: **900678024**

Case ID#: **1HJ3U4C5HZ**

Provider: **Dr. RICHARD ALEXAN**

Dear AMY PABLO:

Blue Shield of California received a request for authorization of the above-noted medication. The request cannot be approved under your pharmacy benefit at this time. The rationale for this decision is:

The clinical information submitted for coverage of the above medication does not meet the AMPYRA coverage criteria for medical necessity established by the Blue Shield of California Pharmacy and Therapeutics Committee. Your request for coverage has been denied due to the following.

- Ampyra is covered for patients who achieved at least a 20% improvement in the timed 25-foot walking test compared to baseline. From the information provided it does not appear that you achieved at least a 20% improvement in the timed 25-foot walking test compared to baseline.

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If you would like a copy of the guidelines used to review this request, please contact Blue Shield by calling the Member/Customer Service 800 number on your identification card. If you or your representative wishes to appeal this decision or have additional information which you wish us to consider please see the enclosed appeal procedure.

Diagnosis and treatment code (g35) submitted with this request for coverage, and their meanings, can be requested by contacting Customer Service.

Sincerely,



Tony J. Van Goor, MD, MMM Senior Director,
Medical Affairs Blue Shield of California
Enclosure: Information Regarding DMHC
BlueShield of California
P.O. Box 7168 San Francisco, Ca 94120-7168
(Last Modified 07/09/2009) - Mbr HMO/PPO Denial)