10-31-2016

Chasing Zebras: Rediscovering Identity After Illness

Erin Parke
University of South Florida, ehart@mail.usf.edu

Scholar Commons Citation

Parke, Erin, "Chasing Zebras: Rediscovering Identity After Illness" (2016). *USF Tampa Graduate Theses and Dissertations.*
https://digitalcommons.usf.edu/etd/6561

Chasing Zebras: Rediscovering Identity After Illness

by

Erin Parke

A dissertation submitted in partial fulfillment
of the requirement for the degree of
Doctor of Philosophy
in Curriculum and Instruction with an emphasis in
English Education
Department of Teaching and Learning
College of Education
University of South Florida

Major Professor: Pat Daniel Jones, Ph.D.
Danielle Dennis, Ph.D.
Jennifer Jacobs, Ph.D.
Jennifer Wolgemuth, Ph.D.

Date of Approval:
October 26, 2016

Keywords: autoethnography, qualitative methods, narrative, illness, identity, teacher identity

DEDICATION

This work is dedicated to my friends and family who supported me through each and every step – through the illness, through the recovery, through jobs and school, motherhood and marriage.

For my parents, who raised me to believe that I could do and be anything I want. My dad who told me to do what you love, even if the money isn’t that great, and who gets a little verklempt at literally everything. My mother, who taught me how to be a kind and loving mother, and who taught me a love of books and intellectual pursuits.

This is for my husband, for being every definition of the word “partner.” For firmly believing that soul mates exists, even when your soul mate doesn’t remember who you are.

And mostly, this is for my daughter, who can finally stop telling her friends that her mommy is “almost” a doctor.

ACKNOWLEDGEMENTS

This dissertation has been the work of many, not just myself. I consider myself truly blessed to have been a part of a program that is full of so many amazing people, not only in my own cohort, but also in the program as a whole. To my own cohort: Dr. Laura Sabella, Christiana Succar, and Renee O'Brien, you ladies have been so supportive and wonderful through everything, and I was proud to go through this journey with you.

To Dr. Maggie Saturley, you have had my back since my first day in the classroom. Fate (or a lack of funding) had us sharing a classroom back in 2007, and then we got to go on this doctoral adventure together. I would never have been able to do it without your constant support and encouragement.

I would also like to acknowledge my wonderful committee members. Dr. Danielle Dennis, thank you for your invaluable feedback, and for making me feel welcome in your class. Dr. Jenn Jacobs, you have always been a welcoming presence to me and I appreciate your support in my academic life (as well as your love of Disney). Dr. Jenni Wolgemuth, thank you for suggesting that I write this dissertation, for your wonderful sense of humor, and for giving such helpful (and thorough!) feedback.

Finally, Dr. Pat Jones, thank you for all the time you have given me. Your constant encouragement helped keep me focused. Your feedback has helped me become a better writer and scholar, and I truly appreciate the support you have shown me over the years.

TABLE OF CONTENTS

List of Tables iv

List of Figures v

Abstract vi

Chapter One: Introduction 1
    Background 1
    Purpose of the Study 2
    Research Questions 3
    Conceptual Framework 4
    Significance of the Study 6
    Definition of Terms 8

Chapter Two: Review of the Literature 11
    Encephalitis 12
        Identity 15
        Identity as a Teacher 15
        Identity as a Writer and a Reader 17
        Identity as a Patient 20
        Reconstructing Identity 21

Chapter Three: Research Design 23
    Autoethnography 23
    Data Collection 26
        Reflexive Interviews 28
    Constructing the Narrative: An Unreliable Narrator 31
    Data Analysis 32
    Verisimilitude and Trustworthiness 33
    Ethical Considerations 35

Chapter Four: The Narrative 38
    In the Beginning 38
        December, 2013 38
    Body in Revolt 40
        January 27th, 2014 40
        February 2nd, 2014 43
        February 4th, 2014 45

The Great Escape 52
  February 6th, 2014 52
I've Lost My Mind 62
Violet Light… And a Hum 74
So, Now What 76
Out, and in Again 79
  February 25th, 2014 79
A Big Fish 86
Reboot the System 90
  March 12th, 2014 90
  April 3rd, 2014 94
Here Time Turns Into Space 99
  April 17th, 2014 99
  May 5th, 2014 101
A Methodologist 107
Break Out the Bagpipes 109
I'm an Idiot 114
An Unlocked Door 117
  August, 2014 117
Fatten the Arsenal 122
Who Put Me in Charge? 124
Zines 126
  May, 2015 126
But What About Now? 128

Chapter Five: Analysis, Findings, and Reflection 133
  Epilogue 133
  Analysis 134
    Research Question One 136
      Effect of Coworkers on Identity 136
      Finding Confidence 137
      Transitioning from Pedagogue to Facilitator 137
      Sharing My Identity 139
    Research Question Two 139
      Core Identity 140
      Struggles With Confidence 140
      Identity as Patient 141
      Identity as Reader and Writer 142
    Research Question Three 143
      Reading as a Method of Healing 143
      Writing the Narrative 144
  Findings 145
    Teacher Confidence and Identity 145
    Flat to Round Teaching 146
  Significance of the Study 146
  Implications for Future Research 147

        Implications for Teacher Research 147
        Implications for Other Areas of Research 147
    Reflection 148
        On Confidence 149
        The Impact of this Study on the Researcher 149

References 152

Appendix A: Informed Consent 160

Appendix B: Interview Protocol 164

Appendix C: IRB Approval Letter 165

LIST OF TABLES

Table A: Themes and how they lead to the findings 135

LIST OF FIGURES

Figure 1: A visual representation of my identities according to Gee (2000/2001)..........................5

Figure 2: Different data sources informed the narrative...26

Figure 3: Transition from pedagogue to facilitator..138

ABSTRACT

This autoethnographic study focuses on changing identity after experiencing a rare disease. The purpose of this study was to examine the ways in which identity shifts during an after a rare illness. Three research questions guided this study: How and in what ways has my identity as a teacher shifted as a result of my experience with major illness? How and in what ways have other aspects of my identity shifted as a result of my illness? How can the writing of my autoethnography influence the healing process and my understanding of identity?

The participant/researcher of this study was hospitalized with anti-NMDA receptor encephalitis, and subsequently lost her position as a high school teacher and was forced to find a position at a new school. Using Gee's (2000/2001) concept of identity as an analytic lens, the researcher developed a narrative of her journey from illness back into the classroom. After analysis, she identified a transition from a traditional, knowledge-giver teacher role to the role of teacher as a facilitator. Another finding was the role confidence played in the recovery process. The researcher then offers suggestions for further research regarding teachers who return to the classroom after illness.

CHAPTER ONE:

INTRODUCTION

> What used to be called a “zebra” (in doctor parlance, a very rare disease) is now increasingly recognized and swiftly treated…. Now many doctors test for it, and if it is found early and treated aggressively, 81 percent of patients recover fully, a staggeringly high figure considering how utterly devastating the disease appears at its height.
>
> (Cahalan, Afterword, 2012)

Background

It is strange to lose who you are, to not know your family, your friends, to lose your place in time. It is also odd to attempt to reconstruct this time, not only through foggy memories and half-dreamed realities, but through the stories others tell of your lived experience. With this work, I am attempting to piece together not only what happened to me through my perception, but from the perception of those around me, many of whom gave up their own lives to support mine: my husband of nine years, Mark, who spent whatever hours he had out of the hospital trying to keep our home life from falling apart, or my father who stayed in the hospital with me, even when I forgot who he was.

The doctors had plenty of diagnoses: bi-polar disorder, a psychotic break, stress, sundowning syndrome, and even multiple sclerosis. It was almost a year after my release from the hospital that I received an official and final diagnosis of anti-NMDA receptor autoimmune encephalitis. The continuing uncertainty of my illness terrifies me, but in the writing of this dissertation, I hope to find some solace as I attempt to explore my journey from perfectly healthy mother/wife/student/daughter/sister/woman to bed-ridden “basket case” and back again.

What I remember from this time period comes in flashes and blurred images. I open the washing machine to see the pair of green treaded hospital socks that my husband insisted on keeping for himself, and I see them on my feet as they stumble across the cold linoleum floor of the hospital, as I struggle to put them back on when I forget how to dress myself, how I rejoice when I am allowed to wear my own socks and wear real shoes. I bring out my knitting while Mark and I watch a movie and remember my mother hauling bags of yarn into the hospital in the hopes that it will bring me back, and later Mark’s crestfallen expression as my hands fumble with the needles and I declare nonchalantly “I don’t remember how.”

Even still, I question every word that I say, every decision I make. I use the wrong word, notice a headache has lasted two days, lose a point on an assignment, and I wonder if these things would have happened two years ago. I found myself trailing off when speaking in graduate classes after my hospitalization, wondering while I talk if my opinion is valid or even welcome, or if everyone around me is wondering what is wrong with me.

Purpose of the Study

The purpose of this study is to examine my own experience with a life-threatening illness and prolonged hospitalization. I am a 34-year old mother of one beautiful 4 year old girl, and until this experience the closest I had come to a hospital stay was the recovery of her birth. I examined, through a first-person narrative, how my sudden illness disrupted my life and changed my views of myself as a teacher, student, and person; my family; and the world around me. I see the writing of this autoethnography as a way to "reclaim" my story and find a "place of healing" (Liggens, Kearns, & Adams, 2013).

Ardovini (2015) discusses the idea of "consciousness raising" and offers this as a tool for feminist praxis. Consciousness-raising relies on the idea of the researcher working with the research subject to emancipate and liberate her from the "realities" of her situation. In my case, I am both researcher and subject, and it has been my role to emancipate myself and take charge of my identity. Consciousness-raising also extends outside the text of my autoethnography to those who may be in similar situations; perhaps they can learn from and connect to my experiences.

Finally, I believe that this illness caused me to completely reconstruct my identity as a teacher. When I examine my practice now, I see myself as an entirely different teacher than the woman who came home every day drained, angry, and bitter about the school day. I complained about everything from the students to the administration, to the way that the A/C blew too hot or too cold. After I left the hospital and started a new position at a new school, I found myself working to be the teacher I always thought I would be when I began eight years before: the one who takes time for every student, and is genuinely interested in what students think and how they feel.

Research Questions

1. How and in what ways has my identity as a teacher shifted as a result of my experience with major illness?
2. How and in what ways have other aspects of my identity shifted as a result of my illness?

3. How can the writing of my autoethnography influence the healing process and my understanding of identity?

Conceptual Framework

Finding an identity framework that worked within my unique situation proved problematic. I identified with disability identity theories but I was reluctant to take on that mantel, as I do not have a permanent disability. Teacher identity frameworks also fit, but only told a portion of the story.

I was excited when I came across Gee’s (2000) perspectives on identity as a way to frame my own view of identity and shifting identity. Gee notes four ways to view identity: the Nature, or N-identity, is something that is inherent; for example, being a tall person is an N-identity. The Institutional, or I-identity, are identities that are placed upon us by others through a position or earned role, such as the role of teacher or mentor. An Affinity identity, or A-identity, is an identity we choose for ourselves based on preference, such as identifying as a fan of punk rock music. The Discourse or d-identity are identities that are shaped through our interactions with the people around us – the roles we perform and are assumed to be by others. These identities are varied, malleable, and interwoven.

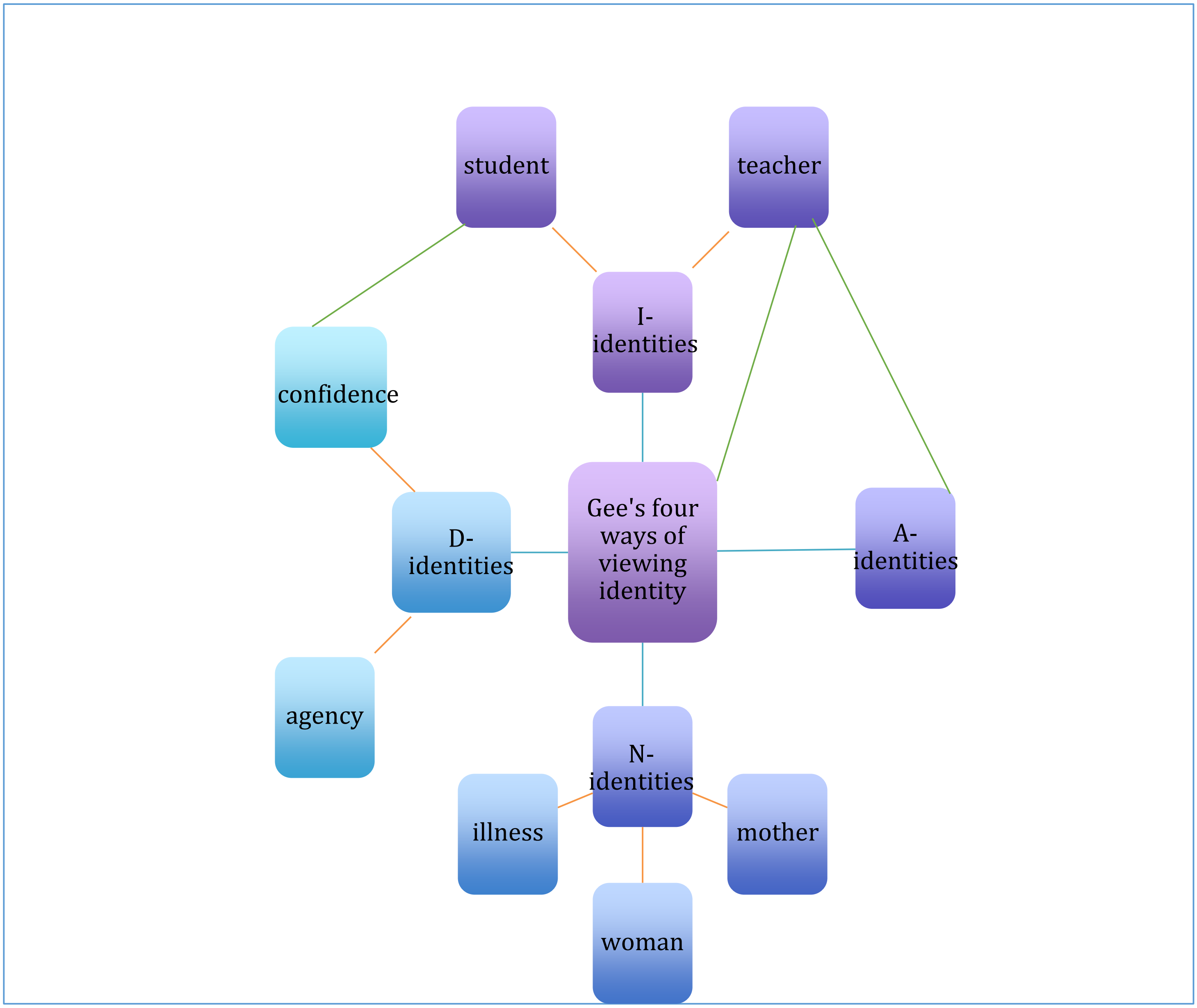

Figure 1: A visual representation of my identities according to Gee (2000/2001)

What is important to note about Gee's views on identity is that our identities are co-constructed by ourselves and through our discourse with others. The varying identities that we ascribe to ourselves are also recognized and interpreted by others. Gee also recognizes the rapid changing of identities; an identity that was once part of the self can disappear, change, or be replaced when certain events, like a trauma, happen. Gee also notes that the modern world enables us to identify more readily with others, as we have more access to others; people “can come to feel that they share more with people far from them than they do with people closer by” (p. 114). In the confines of this study, this statement is relevant in that it brings in the factor of the extended network: online communities and friends of friends that were indispensable to my recovery.

Bartlett (2007) adds another key aspect of identity, which is the need to convince ourselves of our identities. Whether or not others think of us as good teachers is not as important as viewing ourselves as such. It is not enough for a person to perform an identity – they themselves must believe it as well. This is a concept that I recognized as I tried to return to the identity of doctoral student – I could perform the identity, but I did not believe it, and recovering that belief became part of the healing process.

Discussing identity also requires talking about how identity is enacted. This idea that our performance of identity is not entirely in our own control (such as in Gee’s discourse identity) leads me to interview other people in my life about my experience and specifically my identities before and after my illness. Danielewicz (2001) discusses how the construction of the self does not happen in a vacuum: “Others are active too. Institutions, situations, actors, all features of the social world are involved and affect not only what selves get presented, but also how they are interpreted, taken up, or transformed by our social partners” (p. 61).

Significance of the Study

Illness is a recurring theme in ethnographic research (Ellis 1995, 2004) and many researchers use autoethnography to explore their own personal experiences with illness.

However, in autoethnography, every single person's experience is new and different, with something to be learned from each moment. There are no academic studies written from the perspective of a patient with Anti-NMDAR encephalitis, and there are few autoethnographies written by a teacher who experienced a personal trauma and returned to the classroom, which I have referenced in my review of the literature.

The nature of encephalitis means that the sick do not get to tell their story. Patients are often so disoriented that they are sedated, which then delays diagnosis and treatment (Asztely, 2012). Many of the symptoms of the disease are similar to other illnesses; when I originally began to research some of the symptoms, the most common result in the literature was schizophrenia. Many patients with anti-NMDAR encephalitis are first thought to have some type of psychiatric problem – even one of my neurologists, when I told him my diagnosis, said "they thought you were crazy at first, right?"

My goal with this study was to explore my experience and its effect on my identity, and the emphasis on my experience is important because of the nature of my illness. Before the illness, my intelligence was a major facet of my identity, but that would be challenged by this illness. The swelling of my brain caused me to have delusional thoughts, hallucinations, complete lapses in judgment and memory – all aspects to my story that would not come out from, say, my husband's version, or my doctor's. By exploring my version of the story at the forefront of this study, I have tried to open a window to the mind when it is on overdrive, to what happens when we, as intelligent beings, lose control of our cognitive skills.

I also explored how this illness affected my life as a student in a doctoral program. After two years of coursework I found myself faced with the possibility that I would not ever go back to the classroom, let alone go on to finish my Ph.D. Like others who have written of their illnesses while on their graduate journeys (Lewis, 2007; Schneider, 2010; Martinez, 2015; Tarantino, 2016), I hope that my story can resonate with someone who may be going through a similar trauma.

This study addresses gaps in the literature about how teachers change when they experience illness and are out of the classroom for an extended period of time (Bevilacqua, 2005). In the same vein, I add to the body of work on doctoral students who encounter life-threatening illness during their studies (Fabris, 2014; Liggens, Kearns, & Adams, 2013; Weil, 2001).

I hope that this work can help others who find themselves in my position, help them to advocate for their own health, and to realize that even in our darkest moments, we are still in control of our bodies and are the best experts of those bodies. This work is also for those like my husband, who found himself a caretaker for a young wife and discovered that "for better or for worse, in sickness or in health" sometimes comes sooner than expected.

Definition of Terms

Seizures: Patients with Anti-NMDAR encephalitis almost always present with seizures by the peak of their illness. However, recent research suggests that men are more likely to present with seizures early, whereas women are more likely to first show symptoms of psychosis (Titulaer & Dalmau, 2014). Seizures can be either grand mal (convulsing) seizures, or petit mal (silent) seizures. One of the difficulties with my diagnosis was that I first presented with petit mal seizures that were undetected. It was not until I was first released from the hospital that I experienced my first grand mal seizure, with my mother, in a grocery store of all places.

Pulmonary Embolism: Blood clots in my lungs would cause me to throw two pulmonary emboli, an event caused by the blood clots traveling into my arteries and blocking them. The cause of my emboli are still up for debate; they could either be an anomaly, a side effect of the encephalitis, or a side effect of my birth control.

Flat affect: A flat effect is usually associated with schizophrenia; in fact, when I tried to search journal databases for "flat affect" without the word "schizophrenic" or "schizophrenia," my choices were limited. As my friends, coworkers, and family members have described to me, a flat affect is when someone suddenly appears to be disengaged in all that is going on around them. Our faces are blank, our gestures are minimal, and we are unresponsive and apathetic (Evensen, 2012). Many of my friends, including my husband, Mark, thought I was mad at them because I answered every question with yes, no, or maybe, if I spoke to them at all.

Anti-N-methyl-D-aspartate encephalitis: Also known as anti-NMDA receptor autoimmune encephalitis, a subset of limbic encephalitis, a rare form of encephalitis that, contrary to its name, does not necessarily relegate itself only to the limbic system. The disease was first recognized in 2007, and between 2007 and 2015, there were only 600 identified cases (Ziaeian & Shamsa, 2015). The disease is an autoimmune problem, and teachers are more likely than those in other occupations to die of an autoimmune disease (though the cause is unknown) (Young, 2001). The disease is notoriously hard to diagnose due to the fact that the symptoms are also symptomatic of several other illness, and the sick person is often not in a position to describe what is going on. People with this disease "have a subacute onset of disease with memory impairment, confusion, disorientation, agitation and sleep disturbances" (Asztely, 2012, p. 367).

For me, the onset of the disease was a slow build, starting with small missteps here and there, judgment calls that had friends and family questioning my sanity, and eventually an attack on my body from the inside. In an attempt to fight off something inside of it, my body failed me and shut down.

This type of encephalitis is often associated with ovarian teratomas (Tsutsui, K. et. al., 2012) and while none were found in my various CT-scans, there is always that lingering, nagging notion of “what if”; what if they never found the tumors, what if they are growing in me now, stealthily making a home that will only rip out my world once more? The disease occurs when the limbic system is trying to fight off something else in the body. But what else was there?

CHAPTER TWO:

REVIEW OF THE LITERATURE

In reviewing the literature, I looked at four specific areas. First, I looked into more recent information on limbic encephalitis and anti-NMDA receptor autoimmune encephalitis. I searched for both terms, and looked for articles that focused on newer developments and/or patients who were younger, as in the past the disease was associated with older people, and younger people were misdiagnosed. I chose to include this information in my review of the literature as I plan to explore the medical specificities of my disease. Additionally, the ever-changing nature of the diagnosis and treatment of anti-NMDA receptor autoimmune encephalitis also affects my own recovery from the disease.

I also looked at literature surrounding identity, specifically the framework presented by Gee (2000/2001), which posits four ways to view identity, and how those identities are interwoven and reconstructed, mostly focusing on my identity as a teacher, but also on my identity as a writer and patient. I explored the research on how those specific identities are formed and how those identities can change and shift. I initially set out to explore certain identities, but as the writing of the narrative in Chapter Four took shape, I noticed some emerging identities that I had not considered, such as that of a reader in addition to a writer.

Finally, I looked at the reconstruction of identity after illness, and the research regarding how illness can lead to a change in identity, or on the other hand, how certain identities can endure throughout an illness or trauma.

Encephalitis

In the medical field, research about encephalitis, specifically anti-NMDAR encephalitis, has become more prominent in recent years. As I previously mentioned, the diagnosis of this disease has gone up exponentially as information about it enters the arena of public knowledge. Susannah Cahalan's 2012 memoir, *Brain on fire: My month of madness* helped push the disease to the forefront of the literary world and also seems to have instigated a surge in medical research.

Researching the disease has been an interesting experience for me in and of itself. It has left me questioning many things, specifically why so many of my doctors had not read this research and were not willing to believe that this was a possible diagnosis. My husband, whose research and resilience annoyed many doctors, one of whom would tell us "there's no use chasing zebras," a phrase that became infamous in my family. I would later read in Cahalan's book:

> What used to be called a "zebra" (in doctor parlance, a very rare disease) is now increasingly recognized and swiftly treated… Now many doctors test for it, and if it is found early and treated aggressively, 81 percent of patients recover fully, a staggeringly high figure considering how utterly devastating the disease appears at its height. (Afterword, 2012)

In the years since my release from the hospital, I have struggled with the things I remember from my stay. I have memories that are so vivid and real, yet I know there is no way they could have happened: I remember shopping for a petticoat with my mother for a wedding. The experience did not exist, but I remember the details clearly: the color of the paint on the walls, even the prices of the petticoats. The differences between what I dreamed, I imagined, and I experienced became nonexistent and I began to wonder if I really had gone crazy. Then, I began my research, and discovered that hallucinations are not uncommon among young women with anti-NMDAR encephalitis. Tsutsui and colleagues (2012) wrote about a case in which a 27-year-old woman much like myself presented symptoms of psychosis including auditory and visual hallucinations. The researchers posit that they "have to consider the possibility of anti-NMDAR encephalitis, especially when relatively young women are suffering acutely from psychotic symptoms" (p. 2-4). This sentence gave me pause, and made me intensely angry. Why did these doctors immediately come to the conclusion that their patient may have an underlying issue, while mine refused to even consider that I was anything other than crazy?

This disease occurs disproportionately in young women. Eighty-one percent of recognized cases are found in women under the age of 30 (Huan-Quan, Hong-Yan, & Ling, 2015). Women who are ultimately diagnosed with anti-NMDAR encephalitis are often, like the woman mentioned previously and myself, considered to be having psychotic episodes (Aszetly & Kumlien, 2012; Tsutsui, 2012; Titulaer & Dalmau, 2014; Wagner, 2013; Sansing, 2007). The explosion of research over the last couple years in the disease is telling. The first sign of the illness in women is typically a flat affect, confusion, or psychosis, and until recently, these women were usually treated with anti-psychotics (as I was) or even induced comas (which was a threat for me).

The diagnosis of anti-NMDA receptor encephalitis can be difficult, as it does present itself like a psychological issue at first, though this is relegated to women. When men present symptoms of the disease, the first symptoms they show are seizures, a clear sign that something is physiologically wrong (Titulaer & Dalmau, 2014). Rui-Jin, Bu-Dong, and Dong (2015) describe an initial MRI of a patient with anti-NMDA encephalitis as showing white matter lesions. This is the first instance of lesions being associated with the disease. A thorough diagnosis is made after a lumber puncture, when the spinal fluid is checked for anti-NMDA antibodies (Sansing, 2007).

In one mixed-methods study by Atkin, Stapley, and Easton (2010), patients with a non-specified strain of encephalitis reported a feeling of relief when they received a diagnosis of encephalitis. Participants in the study were initially diagnosed with a psychiatric disorder, a disorder that they felt "had a particularly profound impact on how individuals saw themselves and how they felt they were seen by family members" (p. 389). When the diagnosis came through that it was really encephalitis, the patients reported that they were then able to make sense of events that had seemed entirely foreign before.

The cause of the disease is unknown. One study by Ioannidis & colleagues (2015) found a possible link to the measles virus. Cats may also catch the disease (Pakoszdy et al, 2007), and my husband and I batted around the idea that I had possibly gotten it from our sick cat, Miles.

The treatment for anti-NMDA receptor encephalitis varies depending on the cause. In some cases, the disease is associated with a tumor in the ovaries, though research also shows that many cases (like mine) do not involve a tumor (Huan-Quan, Hong-Yan, & Ling, 2015; Titlar & Dalmau, 2014). The typical treatment for the disease is an aggressive course of steroids (Hong-Yan, & Ling, 2015; Sansing, 2007). Bach (2014) argues that treatment must be individualized; it is not enough to treat only the physiological symptoms, as the psychological effects of the illness can be long lasting.

Identity

Throughout this experience, I have noticed a stark change in my various identities. Because of my illness, and because my teaching position was cut while I was in the hospital and I was forced to find a new job, I was given the opportunity to reinvent myself as a teacher: a new school, new students, and new co-workers. As such, I was invited to restructure my identity as a teacher, which also led me to examine the other facets of my identity. For this section of the chapter, I will focus on what the research says about identity and how certain identities are formed and change over time. In the analysis of my narrative, I looked for aspects of these various identities and how they emerged and metamorphosed through my experience.

Part of understanding identity is understanding the basis of identity. Some psychiatrists believe that at the neurological level, all our "base" selves are the same (Kihlstrom, 2012). However, according to Klein (2001), this is our base identity, which works in union with the ontological identity – our first-person view of ourselves which shapes the way we view and interpret the world. Beyond this base identity, we then construct and form other identities. Gee (2000-2001) recognized four categories for these formed identities: the Affinity identity, the Discourse identity, the Nature identity, and the Institutional identity.

Identity as a Teacher

Teacher identity is holistic (Alsup, 2006), and while we perform as teachers, aspects of our everyday lives creep in to our practice. The multiple identities that make up the teacher identity are not restricted to the classroom. While the teacher is conditioned to perform, the teacher must also negotiate that performing identity in her home life. Danielewicz (2001) compares this performance to acting, but notes that identities "require the commitment of self to the enterprise in a way that acting out a role does not" (p. 10). In Danielewicz's view, becoming a teacher requires the construction of that person's identity.

Coia and Taylor (2013) argue that teachers must bring their viewpoints and identities into the classroom, and women who identify as feminist must therefore perform feminist pedagogy. As an English teacher who identified as a feminist, I was originally reluctant to enact this identity in the classroom. Likewise, Danielewicz (2001) says that "In our students and in our teaching, we are obligated to value openness" (p. 183). Doecke, Locke, & Petrosky (2004) view the collective identity of the English teacher as shifting in recent years from pedagogue of literature to critics of Western ideologies. They describe a divide between English teachers who still maintain that they are protectors of culture and literature, and those that see the job of the English teacher as a teacher of critical thinking.

In the same way that the teacher's home identity creeps into her practice, identity of the teacher also extends outside the classroom. Alsup (2006) sees the life of a teacher as "constructed, in part, through and because of the material realities of a teaching life" (p. 90), inextricable from the personal life of a teacher. She also found in her own narrative research that teachers who cannot find a communion in their ideologies or identities do not find a "satisfying professional identity or a sense of fulfillment as a teacher" (p. 55).

As I have worked on this study, the central idea has seemed to gravitate around my identity as a teacher: how I have changed in my professional life and what was the catalyst for this change. Kempe and Reed (2014) found that teachers who are involved in pedagogical conversations with their peers are more likely to identify as innovative and effective teachers, as well as have a positive attitude towards their job and performance. In a mixed-methods study, Davies (2013) found that English teachers who were supported by mentors and given the opportunity to develop creative and interesting curriculum identified themselves as more confident and better teachers. This is the kind of environment I have seen at my new school, with teachers who look to each other for ideas and are sincere when they want to collaborate. What impact has this change of venue had on my teacher identity?

The intertwined nature of a teacher's life becomes thoroughly complicated when that teacher becomes ill. The teacher is expected to dress and act according to certain norms, and a teacher with a psychological or physical illness does not fit within these rigid guidelines for appropriate behavior (Alsup, 2006).

Alsup also mentions that our own teacher identities are often ingrained in us long before we set foot in an education course. If this is the case, how much has my teacher identity changed, or is my current teacher identity the identity that was ingrained in my from the beginning as Alsup suggests, lying dormant until now? I certainly always wanted to be the kind of teacher I am becoming now: one who focuses on the students and their needs and encourages them to succeed.

Identity as a Writer and a Reader

The teacher identity and the writer identity, for many, go hand-in-hand. Frager (2004) asked thirty two English teachers to describe themselves as writers. He identified three specific writer-teacher identities: reluctant writers, practical writers, and integral writers. Integral writers were teachers who saw writing as an important part of their identity. Frager goes on to hypothesize that the teacher who views writing as an integral part of her identity is the teacher who can help a student feel the same way about writing.

McCarthy and Moje (2002) note that “identity matters because it, whatever it is, shapes or is an aspect of how humans make sense of the world and their experiences in it, including their experiences with text” (p. 228). The way we experience writing forms our identity, and the role of text in a writer’s identity is important. Gee (2001) also sees text as a way identity is formed, particularly how we form discursive identities. Therefore, a writer has the unique ability to be able to control some of that discourse through his or her writing.

The role of writer is also the role of performer, as writing often becomes a “performance of self” (Watson, 2009). When we write about personal experiences, we recall and reimagine those spaces and experiences (Ellis, 2004) and perform a certain identity within our writing. Personal writing often places the writer in the role of researcher, looking for what was lost or learned from an experience and searching out what can be gained through the writing of it. Teaching is another “performance” that writers put on: Cremin & Baker (2014) conducted a study in which they examined teachers who position themselves as writers, and use that identity of writer in the classroom to inform instruction, often sitting with their students. In this performance, the teacher hopes to set the students at ease with their writing by showing the students that even life-long writers can struggle with writing.

Gere (2001) associates writing with psychoanalysis, positioning writing as a type of therapy. We learn more about our experiences particularly through writing and sharing those experiences: “the very process of writing our experiences informs our understanding of that experience, and our understanding is informed by other stories” (Coia & Taylor, 2013). A writer can act as her own therapist, able to write through experiences for better understanding. A study by Cooper (2014) of a woman suffering from schizophrenia and depression found that using writing as therapy helped the patient maintain a sense of identity even in the darkest places; in fact, when her writing was the darkest, the patient identified her own feelings as very positive, as if a weight had been lifted.

Writing itself can be a healing experience for many people, and the identity of a writer is one that can assist survivors of trauma with understanding that trauma. The role of writer is also the role of performer, as writing often becomes a “performance of self” (Watson, 2009). When we write about personal experiences, we recall and reimagine those spaces and experiences (Ellis, 2004) and perform a certain identity within our writing. Personal writing often places the writer in the role of researcher, looking for what was lost or learned from an experience and searching out what can be gained through the writing of it.

Smyth and Pennebaker (1999) found that writing about a trauma is a “powerful therapeutic agent that may account for much of the healing process. When people put their emotional upheavals into words, their physical and mental health seems to improve remarkably” (p. 80). However, the muse does not always flow so easily. Some patients find it difficult to write about their illnesses until they have passed through the worst of their experience and come out on the other side, while others can write about it but experience overwhelming emotions when they do so. In these cases, the writers might choose to “tell it slant” (Baker, 2009) and write stylized or even fictionalized versions of their experiences.

A writer, however, cannot be a writer without a love of reading. McCarthey (2001) posits that we construct our identities through our literacy practices. An avid reader considers the ability to read and read well part of his or her identity: “Especially for the avid readers and writers, much of their identity seemed to be tied to their literacy achievements” (McCarthey & Moje, 2002, p. 230). The sudden loss of the ability to read during an illness can be a traumatic experience to someone who had prided themselves on being a “good reader.”

Bibliotherapy is described as the use of reading to work through traumatic experiences. Wolpow and Askov (2001) discuss the power of "witness and testimony" in bibliotherapy, in which the act of reading about an experience from another person's perspective can allow the reader to come to terms with their own feelings. Additionally, simply getting lost in a book can be therapeutic (Walkpow and Askov, 2001).

Identity as a Patient

I identify my role as patient as both a Discursive identity and an I-identity. This identity functions as an I-identity in that it is an identity that was given to me by an institution (the hospital). The Discursive identity is an identity that is constructed through speech and story, through how we talk to each other and the words we choose (Gee, 2001; Cremin & Baker, 2014). The patient identity became part of my identity as I began to lose authority over my own body and became labelled as "psych patient" or "neuro patient". My identity as a patient with a rare illness, particularly one that affected my speech and cognitive abilities, affected not only how I spoke, but also how others entered into discourse with me.

Though encephalitis is not a chronic disease, the repercussions of the disease can affect the patient in various aspects of her life, much like a patient of chronic illness. McGonagle & Barnes-Farrell (2014) found that stigma surrounding illness can affect the identity of the patient in the workplace, and can have a negative effect on the patient's perceptions of how well they do their job. Dyck's study of women with multiple sclerosis (1999) found that this particularly affected women, who often find that the structure of the workplace and the "fast-paced" social norms of the American worker do not offer a place for a woman who is disabled in any way. In these situations, women must negotiate a new space and a new identity in their career.

Identity as a patient is one that the person both ascribes to themselves and if viewed by others to be. The posturing of this identity also plays into the world of social media (Ytre-Arne, 2016). Patients who experience illnesses with long-term recovery periods often reach out to social media platforms, whether through every day media like Facebook, or searching out blogs for fellow patients. In a study of women with breast cancer, Orgad (2005) found that the patients dealt with their diagnosis by turning to the internet to tell their stories.

Reconstructing Identity

Experiencing trauma leads to the creation of a new N-identity: the identity of survivor of trauma. Regardless of the degree of the trauma, the negotiation of this identity is difficult and long coming. Ellis (1995, 2004) found the path to understanding the trauma of her first husband's death and her mother's ailing health through the cathartic experience of writing. Using "emotional recall," Ellis recreates every emotion she felt at that exact time and place. Liggens, Kearns, and Adams (2012) used a writing group to come to a place of healing, forming a dialogue between a counselor and two patients under her care. Other graduate students like myself who have experienced trauma have also found healing and understanding through writing their experiences (Fabris, 2014; Weil, 2001).

In a 2005 dissertation, Bevilacqua studied the identities of teachers (the author included) with Multiple Sclerosis (MS) and how their identities shifted/formed in regards to their illness. This study resonated with me because like me, the author took a six-week medical leave from work and returned to a different school. She describes a period of shattered self – an in-between period where her confidence as a teacher was low and she found that she must rebuild her identity as a teacher.

Asbring (2001) discusses the idea of "biographical disruption," (p. 313), the experience of life being disrupted by illness. These disruptions often are harder on patients who lived very active lives prior to their illness and often forces them to reconsider their identities. Asbring found that women who are diagnosed with a chronic illness often take a long time to recover a sense of identity after this disruption (p. 317).

Dewar & Lee (2000) identified three phases of recovering identity after diagnosis: finding out, facing reality, and managing reality. The researchers in this study found that patients did not progress through these three stages in a linear fashion, but rather flowed back and forth through them and sometimes experienced them simultaneously, much like the stages of grief (denial, bargaining, acceptance, anger, and depression). Reflecting on her work with women living with HIV/AIDS, Smithies (2007) remarks that when the study was conducted, a diagnosis was analogous to a death sentence, but as time progressed, the disease became more manageable. Yet, this livability brought new issues to these patients: "There was cautious exuberance, confusion, and even depression as so many faces the restoration of life and with it, responsibility and the need for new identities" (p. 79).

In the next chapter, I will explain my methods; specifically, why I chose autoethnography and what is autoethnography. I will also discuss my data sources and issues of validity in autoethnography.

CHAPTER THREE:

RESEARCH DESIGN

Autoethnography

This study is auto-ethnographic for many reasons, most important of which is my focus is on the personal. I did not go into this work with the idea that my story will somehow be applicable to everyone who has ever been hospitalized. Instead, I hope to share my experience and shed some light on what it is like to be the patient who is helpless and possibly hopeless.

An autoethnography, by nature of its name, must concern two things: the self and culture (Ellis, 2004). In autoethnography, the researcher situates herself within the context of a particular culture and explores her own role within that culture. For this study, I have examined my identities as they have shifted and morphed through the experience of illness and recovery.

The act of writing allows me to better understand my situation and how it has affected my identity; as Richardson (1994) notes, "writing is a method of knowing." The kind of narrative I have attempted in the work is "about the micropolitical practices of representation, the metanarratives within which inquiry is embedded, the relation of its questions, and the effectivity of its practices to the sociocultural horizon" (p. 44) rather than simply a write up of my experience. I wanted to explore the narratives within the narratives, the story within the story. Lather (2007) discusses the need to "get lost" in the data, and the importance of including the "tales not told, the words not written or transcribed, the words thought but not uttered, the unconscious: all that gets lost in the telling and the representing" (p. 13).

As an English major and teacher, language was always my first love. The intricacies and nuances of it fascinate me, and the power that language holds leads me to this type of qualitative research. I am using language to help reconstruct an experience, to create "a particular view of reality" (Richardson, 1997, p. 26). My background as a fiction writer called out to me when I first considered "doing" autoethnography, and I have answered that call.

This work has already gone through multiple drafts. The first time I tried to put my experience to paper was just a month after I was released from the hospital. I had been put back to work proctoring tests, neither trusted to teach children, nor considered ill enough to continue leave. I spent the seemingly endless hours in the school media center reading, writing, and jotting down my memories of my illness. Ellis (2004) encourages multiple drafts, allowing the story to change over time. My story changed many times, from a story of illness, to one of recovery, to one of identity.

I did not set out to write an account of being a patient in a psych ward, but as I sat down during my recovery to write an account of everything that happened, I found that I kept returning to the time I spent in the psychiatric unit. And it is no wonder: psychiatric units play prominently in my favorite fiction works, notably in Dick's *Valis* (1981) and Kesey's *One Flew Over the Cuckoo's Nest* (1963) but they have also become a topic of choice in personal narratives. Autoethnographies often turn to psychiatric events to explore the experience (Fabris, 2014; Liggens, Kearns, & Adams, 2013). These explorations of "madness" help to personalize what is often othered and swept aside.

Costa and colleagues (2012) warn, however, that these narratives can sometimes be co-opted by the psychiatric community, taking the power of voice away from the patients. This also takes away from the doctors' and patients' original purpose of patient narratives, which is to promote social change and question the stigmas associated with mental illness. Doctors may present these narratives in a way that removes the agency from the author and turns it into what Costa et. al. refer to as “patient porn.”

Richards (2008) raises similar concerns that autoethnographies can sometimes objectify their authors. In their qualitative study, Liggens, Kearns, and Adams (2013) use dialectic authorship to add multiple perspectives to autoethnography and to attempt to bypass this. In this piece, Liggens writes of her experiences as caregiver, mental health worker, and patient, and how she negotiates these spaces. The other two authors seek to come to a better understanding of inpatient care through Liggens’ narrative.

Many autoethnographies of illness come from others who care for their sick loved ones. In many cases, these are stories of children who have cared for sick parents, or spouses who watch their partners die. Ellis (1995 & 2004) chronicled her experience watching her husband die of emphysema, and later recalls caring for her aging, ill mother. Perhaps the most famous recent memoir of illness, and conveniently, of a young woman with anti-NMDA receptor autoimmune encephalitis, is the *New York Times* bestseller *Brain on Fire: My Month of Madness* (Cahalan, 2012). Cahalan’s story is much like mine: a young, successful woman finds herself questioning her sanity with bevy of doctors unable to give her answers.

Autoethnography allows the researcher to “break outside the circle of conventional social science and confront, court, and coax that aching pain or haunting memory that one does not understand about one’s own experience” (Allen & Piercy, 2005, p. 159). Within autoethnography, I hope to gain understanding about my experience through the writing of it. Ellis (2004) tells us that “there is nothing more theoretical or analytic than a good story” (p. 194), and by telling a story, the researcher can explore various aspects of that story.

Data Collection

“No self or personal-experience story is ever an individual production” (Denzin, 2014, p. 56).

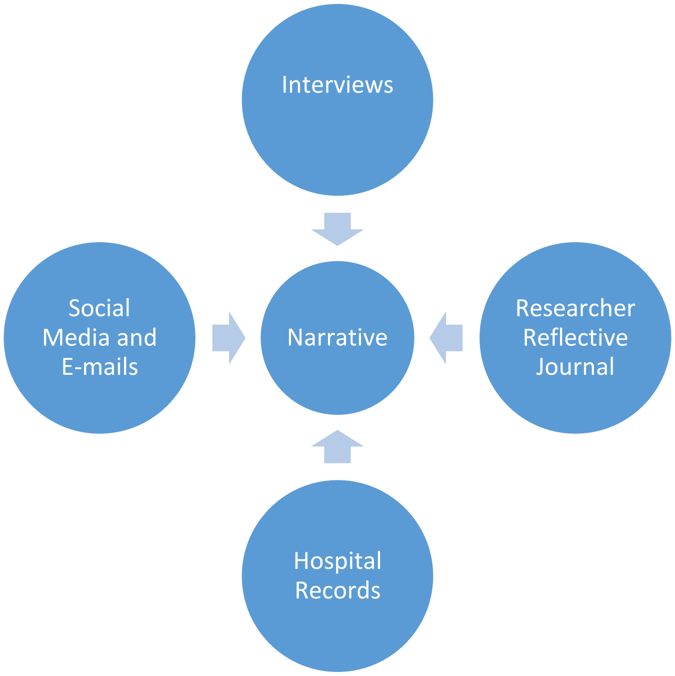

Figure 2: Different data sources informed the narrative

The majority of the data for this autoethnographic narrative comes from my own memory. While my memories may not always be accurate, it is my experience and how I experienced it that I wish to investigate. Richardson (1994) described the goal of autoethnography as meeting the literary criteria of “coherence, verisimilitude, and interest”. The concern of autoethnography is not accuracy of data, but the truth of the experience as the writer experienced it. Denzin (2014) discusses exploring the “facticities” of an experience: “how those facts were lived and experienced by interacting individuals” (p. 13). How does an experience differ from various perspectives?

Ellis (2004) discusses the idea of emotional recall, of putting yourself back into the scene. This is best done when the researcher is still close to the experience, so that the intensity of the moment is still there. Ellis cautions, however, that we must be careful to also look at these moments when we are farther removed from them, in order to see from an outsider's perspective.

Using my memory and Ellis' method of emotional recall, I tried to put myself back in each scene as I wrote. I thought about each action I took and everything I could remember. While we can never remember every detail about what happens to us, the important moments stick in our heads, and that is what I focused on. My narrative of my experience is written in chronological order, focusing on the moments that still come back to me. I have also included some poems that I wrote during this time period. When I began teaching again, I also began writing poetry and fiction again – in fact, the first thing I asked my husband for when I was released from the hospital was a copy of the novel I had written several years earlier – I wanted to reread and revise it. These bits of writing help reflect my recovery and illustrate how writing (even fiction writing) helped heal my fractured mind.

Other data sources include hospital and medical records, which help frame the time I spent in the hospital and where I spent it. Additionally, Mark used social media sites such as Facebook and a feminist forum I frequent to keep others updated on my status, which I used to help me triangulate the data and form a stable timeline of events. He also kept daily logs in my own personal planner of who came to visit, who babysat our daughter, and where I was at all times.

Another source of data, and perhaps an unusual one, comes from the novels I read during my recovery. Each one seemed to speak to me in a different way, to tell a different part of my experience, and helped me deal with my recovery in a different way (Walpow & Askov, 2001).

From the moment I decided on autoethnography as my method, I began keeping a researcher reflective journal on my thoughts and memories of my experience as I relived them by writing about them all over again. Ellis (2004) suggests beginning a journal as close to the event as possible in order to remember the event, and then go back and revisit it later from a different perspective. This journal became invaluable, as I was able to jot down flashes of memories that would come at the most unexpected times. I also used this journal to record notes during my interviews, and to reflect on the interviews after they were conducted.

Finally, I interviewed six people who experienced my illness along with me in very different ways than I did. Because I am interested in the variation of narratives from my own to what others experience, these interviews are crucial to the framing of my own story. I interviewed three family members and three friends, two of whom are coworkers who came to visit me while I was in the hospital, though I do not remember them coming at all.

Reflexive Interviews

Just as I would not be the healthy, working, thinking person I am currently without the help of those around me, I would not be able to complete this work without the stories of my friends and relatives. I have used the data from these interviews to fill in the gaps of my memory and to help provide a different facet to the story.

To recruit participants for my study, I had to turn to those nearest to me. However, this raised some red flags with the Institutional Review Board, who were concerned about the potential for my participants to feel pressured into participating due to their close relationship with me. To avoid this (and to appease the IRB), I recruited participants using a snowball sample, with my husband acting as my informant and recruiting my participants.

In all, I interviewed six people for this study (all names have been changed to protect their privacy):

Mark: My husband of nine years, who at the time of my hospitalization was a stay-at-home dad to our then two-year-old daughter.

Dad: My father, who is a personal injury lawyer, who thanks to his profession has a vast array of medical knowledge and a healthy mistrust of doctors.

Mom: My mother, who sat by my side every day.

Veronica: My best friend since I was eighteen, who visited me while I was recuperating at my parent's house.

Marjorie: My friend and former coworker who watched me try to get back to work after my hospitalization.

Faith: My mentor and friend, the woman on which I based all my ideas of what a teacher should be.

While my doctors certainly played a large role during this period, I did not interview them for this particular study. Since my focus is on my identity and how it has changed, I did not feel that interviewing the doctors who only knew me for these brief pockets of time would help me answer any questions about how I have changed as a person, or especially how I have changed as a teacher. While I would probably feel a great deal of satisfaction from confronting the doctor who diagnosed me as having a psychotic break, or from thanking the doctors who ultimately saved my life, I do not think it would serve any purpose for my dissertation.

I set out intending for these interviews to be reflexive dyadic interviews (Ellis, 2004) where the interviewer becomes involved in the interview process and engages in meaningful reflexive thinking, and the interview becomes more conversational. Given the emotional content of these interviews, it made sense to me to make it more of an open conversation than a question and answer session. I wished to get to the meat of the matter, and these stories will help me reach that. While I planned for these interviews to be conversational, I did go in with some guiding questions (see Appendix B). The participants were asked to bring any notes, e-mails, or journals that they may have kept at the time to share at the interview. My father provided me with a newsletter his law firm had sent out documenting my journey while I was still undiagnosed, and my husband provided several e-mails.

While I planned for these interviews to be reflexive, my first interview with my husband did not turn out that way. When he started talking, there was no stopping him, and we ended up having to break his interview into two parts. In the year between my decision to focus my dissertation on this topic and getting to actually sit down for the interview, any time I would bring up this time period he would say “let’s save this for the interview,” and that is exactly what he did. He shared every minute detail. This interview helped me arrange the events of my narrative, as well as provided insight as to how my identity changes during this process.

After this interview I decided to be a bit clearer with my participants about what kind of interview they were in for. Since my husband had provided me with the “blow-by-blow” account, I could focus the rest of my interviews on the messy stuff: the emotional side of things. The most difficult interview was with my father; we have an excellent relationship, but he is a very emotional person and is prone to crying, and no child likes to make their parent cry. On the opposite side of the emotional spectrum, interviewing my mother made me realize that she and I deal with tough issues the same way – by finding the humor in it. My interview with my mother involved both of us laughing often.

The interviews were conducted either at my home or at the home of the person being interviewed. I recorded all interviews with an audio recorder, and allowed the participant to decide if they were comfortable with being videotaped as well. My father and my husband agreed to be videotaped, which is especially helpful in my family as we are a bunch of gesticulators. The interviews were then transcribed by me and analyzed (see section on data analysis). As I wrote my narrative, I used these interviews to supplement my story and to help me see how others viewed my journey. I also used these interviews to triangulate the timeline of this journey, adding these interviews to my narrative to situate the moment. Therefore, I did not include the entirety of each interview, but rather I wove in pieces of each interview. I hope that these interviews, together with my own writing, would form a fuller, compelling story.

Constructing the Narrative: An Unreliable Narrator

When I begin a novel with my students, the first thing I ask them is to consider the narrator. Can you believe them? Are they worthy of your trust? Am I an unreliable narrator in this story? I experience much of my time in the hospital as if I were in a dissociative fugue; like Nick Carraway, I was “within and without, simultaneously enchanted and repelled by the inexhaustible variety of life” (Fitzgerald, 1925, p. 35).

The narrative of this autoethnography consists of my experience exactly how I remember it, however flawed or “inaccurate.” My experience will always be different from what my family members, friends, doctors, co-workers, and students experienced. However, this narrative will be interwoven with the story as my friends and family members experienced, hopefully forming a rich, full narrative of illness, recovery, and identity. These interruptions will demonstrate the “multiple shifting reals” (or realities) (Lather, 2007, p. 43) of the story.

In writing the narrative, I have used the data (interviews, hospital records and forms, researcher reflective journal) to help form a scaffold for my story. Then, using Ellis’s (2004) technique of “emotional recall”, I put myself back into that moment in time in order to fully describe how I felt and what I saw. I used my reflective journal to help remind me of specific moments, while e-mails, hospital records, and other data will serve to fill in the time-line.

I have only a vague recollection of my experience, yet at the same time parts of it are very real. I found that I was able to uncover more of my experience through my narrative with the help of my friends and family, and I hope my readers will experience this along with me as I try to fill in the gaps of what happened.

By incorporating the voices of those who experienced this illness by my side, using their own words, into my story, I have come to a better understanding of how my identity has changed since my recovery. I also have come to understand more fully the experience of the caregivers in situations of extended diagnosis and illness.

I chose to include my journey in my new teaching position, as I see that as a direct result of my illness and inextricably linked to it. My evolution as a teacher was not an overnight process, so I included my first year at the new school in my narrative. In doing so, I feel that I was better able to address my first research question regarding my changing teacher identity.

Data Analysis

Alsup (2006) describes analyzing narratives as a way to understand identity and its development. If what we live are "storied lives" (Bruner, 1986), then the telling of those stories should, in theory, reveal some of our identities. After conducting the interviews, I transcribed all the interviews myself and then began to code the interviews, looking for common themes. I found that many of the ideas included in these interviews helped inform the narrative, and I was able to use parts of these interviews to drive the narrative and provide a more cogent timeline.

The data collected from these interviews are interspersed with my own recollection of events to almost interrupt the narrative (Lather, 1992).

After adding the data from the interviews to my narrative, I reread the narrative I have written and looked for continuations of the ideas I found in the interviews, and found that these themes overlapped and were addressed in both. I have interpreted my story alongside the stories of the other participants, in order to triangulate the data (Carter, et al., 2014). This was a recursive process in which I continuously read and reflected on my data as I considered the themes. Denzin and Lincoln (2005) view the process of analyzing an autoethnographic work as inductive rather than deductive: "The qualitative researcher uses inductive analysis, which means that categories, themes, and patterns come from the data (p. 389)." Using this inductive analysis, I looked for themes and patterns emerging from my final written narrative, which included sections of the interviews. After identifying several themes, I organized these themes by how they related to my research questions. The themes I identified then led to the findings.

Verisimilitude and Trustworthiness

Bochner (2000) argues that there is no such thing as a "more valid" paradigm for research (p. 268). Each paradigm must adhere to its own conception of validity, which can be very different in an autoethnography. One method of establishing trustworthiness in autoethnographic research is through crystallization. Crystallization asks that we immerse ourselves in the data (Janesick, 2003). The use of a researcher reflective journal, as well as the careful analysis of the interviews and narrative, allow me to immerse myself in the data. Additionally, every day I am immersed in the data, as every day I am reminded that I am still a patient "recovering" from trauma. It is there when Mark asks me if I am okay after I stutter, every time I drive the forty-minute drive to my new school, a drive I would not have to make had this not happened.

Through crystallization, we view our data from all angles, examining all facets. Crystallization "provides a deeper, complex, thoroughly partial understanding of the topic. Paradoxically, we know more and doubt what we know. Paradoxically, we know there is always more to know" (Richardson, 1994, p. 943). Research, like any piece of writing, is never finished; it is always iterative. This dissertation began as a graduate class assignment in the fall of 2014, and after many revisions, these first three chapters began to take shape. The writing of the narrative took a month of writing for several hours a day to complete the first draft, which then became a second draft, and a third, before it was ever seen by another person.

When judging ethnographies, Richardson (2000) asks five questions: (1) What does the piece contribute to our understanding of the topic? The work I have written allows the reader to understand not only the experience of a person suffering from a sudden debilitating illness, but also shows the journey through recovery. (2) Is it aesthetically pleasing and enjoyable to read? Is it engaging? I can only hope that it is – I have taken the pains and time to craft a story that I can feel proud of and speaks to my personal aesthetic. (3) Is the author reflexive in her writing? Through data analysis, I have maintained a constant analysis and reflection on my writing. The researcher reflective journal has been my tool for reflection on my writing process. (4) Does it have an impact emotionally, intellectually, or in some other manner? My story is an emotional one, and I hope the reader can sense the emotion that I felt as I wrote these words. (5) Does it show a true lived experience? My story tells the truth of my lived experience, not only as I lived it but as those around me lived it as well. Ellis (2000) describes similar criteria, lauding impact and aesthetics above others.

Ethical Considerations

“Curiosity invites danger; adventure involves risk. Trauma research illuminates the ugly and unpleasant” (Reilly, 2013, p.8).

Researchers who engage in autoethnography about illness and disability run the risk of objectification, becoming what Richards (2008) labels as “patient porn”. This is particularly true with patients of mental health, and while I ultimately was not diagnosed with a psychiatric disorder, it is the reality I lived for a good amount of time and the part I remember the most, and has become a major part of my narrative. Liggens, Kearns, and Adams (2012) attempt to discourage this type of objectification by using a type of dialogic autoethnography, in which Liggens recounts her experience with mental health care and the others add to her experience and anchor her place in the story.

Even though this is very much a personal experience, I have chosen to involve others. Reliving these moments was emotionally painful for some of my participants – my father cried many times during our interview, though in my defense, he has gotten sappier with old age. My husband was so apprehensive about the process that he put off our interview until I told him that it was “now or never.” However, all participants were informed that they were welcome to remove themselves from the interview at any time they felt uncomfortable. One ethical issue I struggled with is how to provide verisimilitude and honesty in an autoethnography while avoiding potentially hurting those mentioned in my experience. Ellis (2004) discusses her own research concerning her ailing mother, whom she writes about, yet never shared that writing. She notes that if we do not allow others to read our work, “we had better have a good reason for doing so” (p. 145). For a long while after my hospitalization, my husband refused to talk about it; now, he feels he is comfortable with doing so, and I no longer feel any qualms about involving him in my study. I have always been, as Mark calls it, “honest to a fault,” and I hope that this honesty helps the verisimilitude of my study show through.

I had originally planned on interviewing my sister, who suffers from anxiety and depression. She and I had not spoken for over a year before my illness, and I assumed (rightfully) that our reunion would be part of my narrative. However, our relationship is still very much in the rebuilding stage, and I did not want to jeopardize that by putting any unnecessary stress on her during the interview process.

The nature of my illness forced my family to experience what is called an “ambiguous loss” (Abrams, 2001), where the patient is physically present but mentally missing, as is the case in many issues of mental health. I know that for many of my friends and family members, the most painful part of my illness was that I did not know who they were, and I do not remember many of my friends even visiting me at all. Unfortunately, these memories came up in our conversations. Obviously, I do not wish to cause my loved ones any harm or discomfort, and as mentioned, they were welcome to excuse themselves from the interview process, but I did not have any issues with this.

The act of writing this dissertation was emotional, rewarding, challenging, confusing, and frustrating. I often asked myself why I was doing this, why did I chose something I could not remove myself from. At the end of the day, I cannot take off my researcher hat and go home to my family, switching gears from researcher to wife/mother. I must come home to more hospital bills, more doctor’s appointments, more e-mails about test results. I do not get a break from this research; it is my life now.

As I wrote I found myself laughing at things I had not laughed at before, and crying at revelations that I made through my own writing. I have admitted things in this text that I have never spoken out loud, and revealed things that I have said and done that I am still embarrassed by. I have laid myself bare for this work, because I believe that in order for a work to be true, it must be all there, be all in. Enjoy.

CHAPTER FOUR:

NARRATIVE

> One describes a tale best by telling the tale. You see? The way one describes a story, to oneself or to the world, is by telling the story. It is a balancing act and it is a dream. The more accurate the map, the more it resembles the territory. The most accurate map possible would be the territory, and thus would be perfectly accurate and perfectly useless.
>
> The tale is the map that is the territory.
>
> You must remember this. (Gaiman, 2001, p. 545)

For the narrative, I started at the beginning – at the first sign that something was wrong, or as close to that as I could get. Using emotional recall (Ellis, 2004), I put myself back into moments, and tried to remember everything that happened, while focusing on the facets of my identity that shifted and mutated throughout the experience.

In the Beginning

December 2013

It all started with the cat.

It was the cat's fault, really. Miles was a loveable but dumb black cat, rescued from Hurricane Charley in 2004; a fluffy, dark, and dull mass that drooled when you pet him. Every night he would howl at the bedroom door to be let in, but if you let him, he would just rub his face against yours all night.

When my daughter was born, she and Miles became quick friends. He was never afraid of her, like Ella, our other cat. She would pet him the wrong way and he would stay drooling contentedly, not a care in the world. He was always a little slow, so when he started acting a little strangely and not quite making it to his litter-box, my husband, Mark, and I chalked it up to his old age.

But when a year went by and he hadn't gotten any better, despite numerous trips to the vet and expensive procedures and medications, we made the difficult decision to let him go. When Mark took him to the vet the last time, he weighed a scant seven pounds, five pounds down from before he got sick. It hit everyone in our family pretty hard, but we never thought that we might be looking back at those days that Miles was ill with such scrutiny, looking for clues that might link Miles' illness with my own. But at the time, he was just a very sick cat, and we were a family in mourning.

In December of 2013, Mark, our daughter, and I had gone to my parent's house for the holidays, but both of us only remember one incident from this trip. We had gone out to eat lunch at an Italian chain restaurant, the kind that serves far too much food to suburban families, and as such, we found ourselves with a large amount of leftovers – leftovers that I was very much looking forward to eating in the future. After we ate lunch with my parents, we packed up the car and began the two hour trek back to our own home. We were only five minutes away when my mother called to inform us that we had left the food behind.

Mark and I are both stubborn people, and that is where the bulk of our arguments incubate. I, of course, wanted him to turn around and get the food. He, out of whatever peevish mood he had found himself in, refused. This was not the first argument we had over food. Normally, I would call him an asshole and that would be that, or I would ask nicely until he relented. Today, though, his denial sent me into an inexplicable rage.

> … you started really laying into me, screaming at me in a way that was that was kind of beyond just "turn around and go get it." Part of me was like, "wow, I can't believe you're acting this way to me over food." I didn't want to relent and turn around, and as we're driving, you kept getting increasingly more mad, up to the point where you grab the steering wheel as we were driving…. I couldn't believe you would put our lives in jeopardy and risk by doing something like that over food. That was like… I mean I lost it at that point. I mean we had to pull over.
>
> -Mark

My complete disregard for the safety of ourselves and our child was shocking to him; to me, it seemed entirely justified. His refusal to turn around and get the leftovers was a personal insult and a direct sign of disrespect towards me and my wants and needs. However, when I tried to grab the steering wheel - that was enough for him. After he parked the car, Mark left our daughter and me in the car while he walked around the parking lot for a few minutes to calm down. In our usual fashion, we made up quickly, and drove the rest of the way home in silence. This would be the last time we would ever fight about food.

Body in Revolt

January 27th, 2014

Beat beat beat. The sibilance of feet on pavement. Beat beat. My ponytail slaps against the back of my neck, trailing sweat in raked patterns over my shoulders. Beat, crackle.

Electricity runs through my left arm. Beat beat beat, crackle. One more mile to go, one more mile to ignore it. Beat beat, crackle.

The goal had been set. February 21, 2014, I would run my first Walt Disney World race. 3.1 miles. I had been training for months, spending early hours in the gym and weekends on the bay, running. Now it was January, and it was going well; I was up to running the entire length without stopping, however slow. Then the tingling began. When I ran, I began to feel an odd sensation, like tiny fireworks shooting through my left arm and leg every several steps.

I was so consumed with my goal that at first, I ignored what my body was saying. I thought it was temporary, like a shin splint, or just a nagging pain, like the ball of nerves in the ball of my foot that bothers me on long runs. It was almost a month before I mentioned it to anyone.

"I've been having weird tingling sensations in my arms and legs," I told Mark finally.

"That doesn't sound good." His own mother had suffered a stroke the past July, and no doubt the idea of any tingling or numbness did not conjure up good things for him.

"I'm sure it's nothing."

I brought it up to my dad. As a personal injury lawyer, he is always quick to provide a diagnosis, but this had him stymied.

"You need to go to the doctor," he told me. And as always, I listened to my dad.

Evidently, having numbing sensations on the left side of your body raises a lot of red flags for a doctor. My Primary Care physician sent me to get an MRI immediately. I was not overly concerned – I had always had excellent health, good blood pressure, great cholesterol, never a concern in the world. I was certain that this would be nothing as well – and part of me was excited to have an MRI for the very first time.

It was not as exciting as I had hoped. I spoke to my closest work friend, Marjorie, over Google Chat the next day:

Me: my mri made me nauseous and I barfed

Marjorie: Oh no! Why?

Me: idk i think it was a combo of the contrast, the mri, hunger, and a headache

it was not pleasant

Marjorie: It doesn't sound fun. I'm sorry honey

But hopefully they'll figure out what's wrong

Me: yeah hopefully

hopefully it's not cancer or blood clots

It didn’t take long for my doctor to call me back with the results. My MRI showed that my brain was mostly normal, except….

“It did show some white matter on your brain,” my doctor explained.

“What does that mean?” I asked.

“Well,” he sighed, “It could really mean anything. It could be a result of the migraines you’ve been having, it could be M.S., and it could be anything in between.” Great. Clear as mud. “We will keep an eye on it. I’d like you to come back in for another MRI next week.” Another MRI. Wonderful.

Still, I was sure that I was fine. There was no way I had M.S.; it just didn’t happen to people like me. Besides, other than the migraines and numbing sensations on my side, I was still perfectly healthy.

I also had my doctoral classes. I was hoping to finish my coursework over the summer, or by fall for sure. It was the last class our doctoral cohort would have altogether, and we were enjoying every minute of it. I was using that particular class to research writing groups. My other class that semester was about gender and gender roles in education. I was learning things that would truly further my research towards my dissertation topic: how can writing and writing groups help pregnant teens? I had not hammered out the details, but I had a lot of ideas.

Everything in my program had seemed to lead me in this direction, but recently, something had been off. In his written account, Mark noted that "her [my] classmate in her Ph.D. program reported that she didn't interact in her class or offer her insight on that day's discussion. She is one of the most opinionated and talkative people and before all of this you couldn't stop her from talking about what she was working on." However, I noticed nothing – I thought I was just fine.

February 2nd, 2014

As I was growing up, my dad always had season tickets to our local NFL team. He loved it, even though most of the time, they were losing. I chose them as my team simply because of my father… I never felt the need to watch any games, with the exception of the team's one Super Bowl (they won). I also happened to go to a major football university, one of the best in the nation (though I went for the academics. Really.), and I still never got into the sport. However, when I met Mark, he somehow managed to turn me into a bona fide football fan. A season-ticket holding, Fantasy Football playing, sports news reading fanatic.

Super Bowl weekend had become a tradition in our family, but a small one; we usually spent it just the two of us. In 2011, the occasion became tinged with a slight sadness as well as overwhelming joy, as that would be the weekend that I experienced a miscarriage while my husband travelled to Dallas to watch his team win the Super Bowl. Since then, it always seemed as though it was important to spend that weekend together.

Usually, I don’t stay up for the entire game, since it is a Sunday and I am always at work by 6:30 A.M. at the latest. For this game, however, I had the idea that I was going to stay up and watch the whole thing. We did not have much in the way of snacks; we had not gone to the grocery store in a while. Mark was a stay-at-home dad, and did not enjoy trying to wrangle our daughter at the grocery store, so it was typically my job to do the grocery shopping. I had not had the time, between work, graduate school, and a two-year-old.

After I put our daughter to bed, I joined Mark in his office. We watch all the sports in Mark’s office. He never has fewer than three screens going at a time, and sometimes he can have up to five. On a typical College Football weekend, he will be watching all games at once. It was an obvious choice for Super Bowl Sunday.

What was not an obvious choice was my choice of attire for the occasion. When I went into Mark’s office to watch the Super Bowl, I was completely naked. Mark was surprised: “It wasn't like ‘oh hey it's this fun thing you're gonna do,’ you just wanted to sit around naked. And it's not like you're not comfortable with yourself, it's just not what you do.” I didn’t want to do anything other than watch the game, I just wanted to do it while I was naked.

While I was watching the game, Mark also noticed that I was behaving strangely (aside from the casual nudity).

> That was the game where the first play... Peyton Manning snaps the ball and it goes over him and he loses it and it's a touchdown. It's a safety, sorry. And you literally had no reaction to it. Here's the image: we're like in my room, and you're just sitting there, not even reacting to one of the most pathetic beat downs in Super Bowl history. You had no

> reaction to it. It was odd to me, but I thought you were just super bored by the game. But you just sat there. Like, nothing. Like no wheels turning. And I would ask you about the game and you would give short answers. 'Eh', you know, nothing elaborate. Like 'oh hey, Peyton Manning sucks’ or 'oh hey, Russell Wilson this' or that, you were just quiet.
>
> -Mark

When Mark mentioned that I was behaving strangely, I heartily disagreed. I was just confident with my body, what was wrong with that? I began to believe that he was trying to police my sexuality, that I was suddenly too liberated for him.

February 4th, 2014

I volunteered to chaperone an AVID (Advancement via Individual Determination) field trip to a university, about two hours away. The field trip was during the school day, and I would be one of two chaperones – the other one was my friend from work, Autumn. Autumn and I had covered many field trips before, and I had been looking forward to spending the day with her.

The kids piled on the bus, arguing over their seats. The A/C of the charter bus hummed as Autumn and I plopped our things down in the front row.

“How’s it going?” She asked me as she waited for the rest of the students to find their spots.

“Fine.” That had become my go-to response. How was I? Fine. Everything was fine, just fine.

She got up to inspect the students, and I stared at my phone as she barked out orders, warning them of the horrors that await them if they are not back on the bus when they are supposed to be. As she sat down, I turned to her.

“I don’t feel well,” I said.

“Are you going to be ok?”

“Yes, I’ll be fine.”

I had a headache, I told her. That’s all. Just a headache. I took some aspirin. Then I took some more. Finally I put my head down against the edge of the seat in front of me, appreciating the coolness of the metal against my head. The trip seemed to last a lifetime.

“We’re here,” Autumn finally announced to the students. “We will have an hour for lunch, and then meet back here at the bus.”

How odd, I thought. *To come all this way for only an hour*. I got off the bus with Autumn and we followed the herd of students to the school’s food court. Each moment seemed to take an hour. We stood in line at a bagel shop, the bright lights beating into my brain. When we reached the front of the line, I could hardly order.

“Pizza bagel, please,”

“What kind?” the worker demanded.

“Cheese.” I handed over my card, and moved over to let Autumn make her order.

“This doesn’t work,” the worker said to me over the glass divider, holding up my card.

“It should,” I began to argue, but Autumn stepped in.

“Just use mine, its fine.” Normally, I would argue and say no, I can pay for my own food, but today I did not have the energy for politeness. I let her pay for my meal and we took a seat at a picnic table outside. It was sunny, but cool, and I desperately needed some fresh air.

“Are you sure you’re alright?” Autumn asked me again.

“I feel a little nauseous.”

“Do you need to go to the bathroom?”

“I just need to put my head down, I think.”

“Ok.”

I put my head down on top of the table and closed my eyes. I could almost see the pounding in my brain behind my closed eyelids. I did not know how I was going to make it through the day.

“Well, I think it’s time to go back to the bus.”

Finally, I thought. We got back to the bus and it suddenly dawned on me that our trip had just begun – the first part was just to travel to the school, and now we were having our lunch break; our full campus tour had yet to begin. The bus drove us to one of the classroom buildings, and we all got off to tour the hallways and classrooms. The halls were bright white, covered with fresh paint. The university was a newer one, and it smelled of it. The brightness of the halls and the disorienting vertigo I was experiencing left me feeling like I was stuck in some futuristic spacecraft, and at any moment the HAL9000 was going to shoot me out of the airlock. We finished our tour of the building and headed for the bus.

But again, it was a short trip. The next visit was to the dorms, and by the next time we got on the bus I could not take it anymore.

“I really don’t feel well.” Everything hurt; my head, my stomach, my feet.

“Why don’t you just stay on the bus?”

“Are you sure?”

"Of course," I knew Autumn was just being polite, but at that moment I do not think I could have stood up. She handed me a plastic bag in case I got sick, and got off the bus with the rest of the students.

For the next hour or so I did not move from that position – I was physically unable to. When the kids finally got back on the bus and we headed home, I could barely even lift my head anymore.

When we arrived back at the school, I rushed to my car and headed home, rolling down the windows so I could get some fresh air as I drove. I hoped that I could make it home before I became sick again. Suddenly it dawned on me that it was almost 4:30 p.m., and Mark would be wondering where I was. I sent him a quick text:

"On my way!"

When I got home, he was less than pleased to see me. I was supposed to have gone to the grocery store, but I had forgotten and besides, I was in no state to get that done. He was also upset that I had not told him that I was even going on this field trip; however, Mark has a habit of forgetting things that I tell him. As he tells it:

> That day I wanted you to go grocery shopping. But you didn't tell me you were doing this field trip and it would take this extended time. I remember I sent you the text like 'hey, I need you to go to the grocery store and get this, this, and this' and at no point during that time did you text me and say 'oh, I'm going on this field trip, I'm taking this amount of time, I won't have time to do this, and I'll be home at this time.' We're with [our daughter], and she's like two, we're on a typical schedule, we needed food for the house and I fully expected you to either do it or tell me you weren't going to do it and you had something else going on. When you came home without it, I was like... what's going

> on? And you were like 'I don't know... you know I just wasn’t feeling good today and I had these headaches,' and we're you know, I'm thinking.... And we're also skipping over the part where you had your MRI and it came back with an abnormality. Whatever that meant. We were still in that limbo phase where like, hey, something is going on, we have physical proof that something medical is happening in your brain and whatever you symptoms are appear to be getting worse. It wasn't like 'hey, we're just figuring this out.' I know, and you knew that that stuff was happening. And this was another episode. The worst one yet - of what was going on. But when you came home you didn't tell me, you didn't go into extreme detail of like, how sick you were feeling. What happened on the bus, all of that stuff.
>
> -Mark

So now here we were, without groceries, and to further complicate things, Mark and I had tickets to see one of our favorite bands, Queens of the Stone Age, at a theater downtown. We were all hungry, and there was no food for dinner. Mark offered to go get some food, and asked me for my debit card. I handed him the card from my wallet.

“This isn’t your debit card.”

I looked at it, then at him.

“Yes, it is.”

“No, it isn’t this isn’t your debit card. Your debit card is blue. Where is your debit card?”

I pointed emphatically to the card I had just handed him.

“Erin,” he said, becoming exasperated, “I promise you this is not your debit card.”

“Yes it is! Just take it.”

"Fine," he said as he stormed out the back door.

It was not long until he returned, without food, and madder than when he left.

"Where's the food?" I asked. At this point I was starving, and still suffering from the worst migraine I had ever had.

"There is no food. Your card was declined."

"That's impossible."

"Well that's what happened!" He slammed the card I had given him down on the counter. "I'm going upstairs. You are in charge of taking care of our daughter." He stomped on each step as if to punctuate his point, and slammed the door to his office.

Whatever, I thought. The baby still needs to be fed. But of course, we were still out of food. There were not a lot of options for her available, but I made do with what was there; or at least I thought I had.

> But at that point I'm sitting in my room thinking, like, I don't trust [our daughter] with you. I've got to take care of her. There's something wrong - you didn't want to be a mother. The way you were talking with her downstairs, I could hear everything going on downstairs. It wasn't your usual interactions with her. I remember coming down here and you had prepared a meal for [her]- and this is what you gave her. A pack of gummies, just like, bullshit snacks. It wasn't your usual - you would make a meal for [her] but you had just, you were just like, here's hello kitty gummy snacks, that's your dinner. And I was like, that's it. When I got down here and I saw that, I was like, just go, you need to go away, and you went up to your room.
>
> -Mark

Though that’s not quite what happened – at least I don’t think. In my own memory, I gave her a full meal (for a toddler) – yogurt, some cheerios – and the gummy snacks were her “dessert.” But that was all that Mark saw when he came down that night, and I was too tired to even argue with him. Instead, I went upstairs and fell asleep.

After he put our daughter to bed, he came in to ask me where the tickets for the concert were, and if I was still going with him.

“No,” I told him. “I really don’t feel well.”

“Ok,” he seemed resigned at this point. “You still have to print out the tickets for me.”

“Ok.” I climbed out of bed and wandered into his office, where the printer is. I tried to log into my email, but I couldn’t get it to work. I tried every password I could think of, back to when I first had dial-up internet and my password was inspired by my first celebrity crush, Eddie Vedder. But even Eddie was not coming through for me now.

“Erin,” he said, again using my name for emphasis, “I really need you to find these tickets. It is imperative.”

“Look, I can’t do it, ok? Just go to will-call and see if they are there.”

“Erin, I…”

“I said I can’t do it, okay?” I began to cry. The day had been too much, and Mark had no clue what to do.

> I felt like it was dealing with a child. You were crying and you were defiant, but yet completely clueless. I was just like, are you literally fucking with me? What are you doing? Why are you acting like this? And you were sitting there going “I don't know! I don't know!” And it was just so weird and I got the point where I was just like “you know what? Go to bed, close the door, I'm just gonna go to the concert. I let you be. That

wasn't.... Maybe that was the way I just dealt with the situation. I wasn't thinking… "Wow, there's something medically wrong with you that I need to do something about it."

I went to bed with the headache that had bothered me all day. I was not angry. I was too tired to be angry, and besides, it all worked out in the end. Mark got to go to the show, and when he came home later, he had reconsidered some things.

"Hey," he said, waking me up.

"How was the show?"

"It was great. I wish you had been there."

"I felt way too bad."

"Yeah, I'm sorry for yelling at you earlier."

"It's ok."

"Alright, go back to sleep."

The Great Escape

February 5th, 2014

My mother became concerned that week because my text messages to her had become pithy, to the point of concern.

"How's everything?" She texted me one night.

"Fine," I responded.

"How's my granddaughter?"

"Fine."

"Are you alright?"

"I'm fine."

These responses caused enough suspicion for her to call me.

“Erin, are you feeling alright?”

“Yeah, I’m just really tired.”

“Ok, get some rest.”

The next day, February 6th, my husband decided he had had enough. My behavior was becoming increasingly odd, and he finally called some of my friends to see if I had been acting strange. Marjorie felt uncomfortable divulging information; when Mark called, she told him that I had been a bit shorter with her than usual, but nothing outrageous. As she remembers:

> So I talked to Mark, and after I talked to Mark, I talked to Autumn because I didn't want to... because it felt weird, I'm like saying stuff about Erin behind her back, like I don't feel ok about this. So I called Autumn to talk to her to find out what was going on, because I knew he talked to her too, and we both agreed that it was a little strange… and we just had no idea what was going on. It was scary.

Faith, my good friend and mentor, had not really seen any changes… except in hindsight:

> I think at that point of time, and I was shocked when he asked me if I'd seen any changes like when you were over here, and I was like ‘No.’ And now looking back, and you talking about the things that other people had said about you just being bolder, and nothing major, but maybe you dropping an F-bomb here and there where you usually didn't. And now I look back like maybe you were just a little… maybe a little bolder that way, but… there wasn't anything major.

After speaking to them in the span of a few minutes, my husband called my mother and told her I was acting strange.

“Strange like how?” She asked him.

"She's not really responding to anything, she keeps getting confused about things, she doesn't listen when you are talking to her."

"Well, where is she right now?"

"That's the weirdest part," he said, "she's sitting right here, right next to me and she's listening to all that I'm saying, but she's not reacting at all."

"Put her on the phone." He handed his phone over to me.

"I'm fine, mom," I exclaimed. I was. I was fine. Mark was overreacting. There was nothing wrong with me other than a couple of headaches. "There's nothing wrong with me. I'm fine."

"Ok, put Mark back on the phone."

"Mark," she said after I handed the phone to my husband, "can you call the doctor now? She doesn't sound right."

"I will call them right now."

He hung up the phone and went to look up our doctor's number when, in a twist of fate, the phone rang.

> As all this is transpiring, [the doctor's] office called. Like crazy, like out of the blue. They were calling to schedule your follow up appointment to your MRI… and I'm like, 'so funny that you called, I need to tell you about what's going on right now'. And so I rattled off everything that I had known until that point. The headaches, the acting out of character, the nausea, I thought you literally had a stroke or something serious, or were about to have something serious…. So that's what I talked about with the nurse. And the nurse, she's like, ok, now that you've told me all this I need to go consult with [the doctor]. And so she went and talked to him, we were on hold. You were up in your

> room, and she came back and was like 'The doctor recommends that you go to the emergency room right now.' and that's all I needed. That was the go.
>
> – Mark

Everyone was on board: Mark, my mom, my doctor… the only one who was not on board was me. I was fine! Why would I need to go to the emergency room?

"I'm not going," I declared, feeling very much like I did when I was a preteen and I decided I did not want to take piano lessons anymore. Adding to my resistance was my absolute hatred of emergency rooms. Most people do not like hospitals, and I am no exception. The last time I was in an emergency room almost exactly three years prior, I found out that I was having a miscarriage and was left sobbing to myself for four hours before they finally released me. The last thing I wanted was to be stuck alone at a hospital again.

"Erin," Mark always does this when he is trying to be serious, as if telling me my own name will somehow make things more imperative. "You have to go to the hospital. Something is wrong."

"Nothing is wrong! I'm not going anywhere!"

Mark and I have been married nine years, and he knows that there is always one person whose opinion matters more to me than his: my dad.

> …he explained the situation to me, you got on the phone, we talked for a little bit and I could tell there was something wrong. I didn't have any idea what it was. And I said to you "Erin, you've always trusted my judgment on medical issues." And you said, "Yes," and I said "I think you need to go to the hospital," and you said, "Ok," and that's when they took you to the hospital.
>
> - Dad

> We were in that room, in the kitchen, and your dad explained to you... I don't know what he said but as soon as you were done with the phone you were like, ‘Let's go to the emergency room.’ Like you completely changed, like that.
>
> - Mark

The emergency room was crowded. It was February in a tourist town and everyone seemed to be there. Mark had no choice but to bring along our two-year-old daughter, who was completely unaware of where she was and only wanted to explore, leaving Mark in charge of babysitting both her and me. While we waited, Mark called our family members to see who would be able to come and take care of our daughter while he was taking care of me. His mother, who lived three hours away, agreed to come right away, to do anything she could to help. Those three hours of driving for her were three hours of waiting in the ER waiting room for the three of us. Finally, we were brought into a room and met with some doctors. I remember talking to them, smiling and nodding as they responded to me, but I do not remember anything of what was said. Mark remembers a little more clearly:

> …we have an initial talk with the doctor, explain everything that's going on, you're alert, you are talking, you're communicating, you're saying you have headaches, you still can talk on your own, you know, you're of your own person, and dealing with the doctor you're not completely removed from the situation.

From there, I was led into a room where they asked me to change into a hospital gown. At some point between meeting with the doctors and this room, Mark had left to go drop off our daughter at our house with his mother.

The doctors and nurses told me something, but I did not understand what they had said. Then, I was left alone.

I thought about the time I sat in an exam room in the ER, having a miscarriage, for several hours while I waited to be discharged. I thought several times about just getting up and leaving that night, but I stayed. Until 2 a.m., I stayed. But this night, I was not going to stay.

Surely they were done with me. At this point they had not been back to say anything for a while, so I figured they were getting ready to discharge me, and I would do them a favor by going ahead and leaving myself. I pulled my clothes out of the bag they had given me to store them in and changed back into my work clothes. It was one of my favorite outfits: a black and white midi-skirt with a tribal print (and pockets!) with a black fitted top and my signature sparkly flats. I grabbed my purse and searched for my phone to call Mark.

It wasn't there.

For some reason, Mark had decided to take my phone with him.

No matter – I would just use the phone at the front desk.

No, there was too long of a line. I would just walk home.

On the way out the front door, two security officers watched me walk out to the street.

"Hey," they said as I walked by, "where are you going?"

"Home," I said, nonchalantly.

"Do you know where you're going?"

"Yeah, it's just down the street," I responded, pointing vaguely in the direction of our house. I was not wrong. I was less than a mile from our house, a straight shot – although through a very questionable neighborhood. In the dark. But I knew the way. I would be safe.

Somewhere in the haze of my mind I got confused and took a wrong turn, heading north when I should have been heading east – a little off the most direct route, but still vaguely in the right direction. As I passed by a drug store, I heard someone yelling from a car.

“Erin!”

I turned and saw a car stopped in the road. It was the driver calling to me. I did not recognize her.

“Where are you going?” She called to me.

“I’m just walking home,” I replied.

“Do you need a ride?”

“No, thanks.” I didn’t know this person, why would I accept a ride from her?

“Okay,” she said, sounding uncertain, and she drove off. As she drove away, I thought about how much she had looked like Beatrice, a woman I worked with.

Disoriented from this exchange, I turned around again. At this point, I began heading in the complete opposite direction of my house. I was heading west, toward the highway.

It was not long before I realized that I was lost. Hopelessly lost.

The street numbers kept going up when they should be going down. I found myself in an industrial park with no real streets. Finally, I found some railroad tracks. I decided that if I walked along them long enough, they would lead me to somewhere familiar.

This was when I became truly scared.

I was heading further and further into darkness, no streetlights, nothing. It was cold, and I was missing my sweater. I turned around, decided to head back to the nearest road I could find. I passed a man on the tracks.

“What are you doing out here alone at night?”

“I’m just walking home.”

“It’s not safe out here.”

His face was kind but his words were not reassuring. Finally I found a road, one that cars were actually passing on. I tried waving down a taxi as it passed by; if I could only get back to our house, I would be fine. After a few more moments, I grew more desperate and starting trying to flag down any car that drove past, knowing full well that if I was one of those drivers, I would not stop for some madwoman standing on the side of the road, so why would I think any of them would? I began to pray that a police car would happen to pass by; surely they would stop to help someone in need, even if they thought I was crazy.

My prayers were answered moments later when two police cars passed by me. I thought it was by chance; it turns out, it was not fate that led them to me.

> So I get the call and I don't recognize the number and I'm like 'Hello, and like, the doctor says hi, this is doctor so and so, is your wife with you. And I ... everything just stopped right there. I was like, what do you mean, is my wife there. Is she not in the room? And the doctor said 'she's gone' and I just lost it right there. I was like 'what do you mean she's gone' she's literally gone. I'm like, you have to call the police, you know? She's not right…. We're between 8 and 9 pm that night, I guess, and as I'm coming back around I get a call on my phone, on my cell phone… and it's been like 30 minutes after you got lost and I didn't recognize the number. And it's from the police. The police officer called me. He was like "we have found your wife."
>
> -Mark

When the police got out of their cars, they asked me the standard information: who was I, did I have identification, etc., but I was not concerned about any of that stuff. I handed over my driver's license.

"Can you please take me home?" I gave them my address.

“No ma’am, we can’t take you home.”

“I just want to go home, please.” I could not understand why they would not just put me in the car and drive me home. I was scared, and lonely. I tried to open the back door of the car so they would take me home.

“We can’t put you in the backseat unless you’re under arrest, ma’am.”

“Oh,” I said. I always acquiesce to authority, it’s in my DNA.

“Do you know your husband’s number?

“Of course.” I rattled it off for them. One of them called Mark and told him I had been found.

“We’re going to wait for him to come get you,” he said after he hung up the phone. It seemed like it took forever, but it was probably only a matter of minutes. Soon, a red car pulled up.

“Is this your husband?” The officer asked me. It was my car model, but my car was gray, not red…. It took me a minute to realize what was going on.

“Oh, yeah, that’s him… but that’s his mother’s car…”

“But that is your husband?” He had gotten out of the car by now and was walking towards us.

“Oh yeah, that’s him.”

He came over and thanked the officers profusely for finding me. A wave of relief washed over me; finally, I could go home with my husband.

We got in the car, and he started to drive away.

“I’m so glad to go home,” I said.

“Home?” He replied. “We’re not going home, we’re going back to the hospital.”

"What?" I was incredulous. "No! Take me home right now!"

"Erin, you're sick, you have to go back…"

"NO. Take me home RIGHT NOW! I won't go back there!"

Mark knew that he would need help to get me back to the hospital.

> So I had to ask the police to literally escort us all the way back to the hospital. And they looked at me like... I don't know, can we do this, is this an official thing, and they saw that we needed help and they helped.

-Mark

The police escorted us back to the hospital, but when we arrived, I still was not having it. But Mark knew that once again, my reputation as a rule follower would come in handy.

> We got back to the hospital and you refused to get out of the car. You were just sitting there. And I had to go to the police officer and I had to ask her, you know, can you say whatever, you know, please get her out, because you were not listening to me, you were being incredibly belligerent. But again, your default programing, you're completely obsequious to authority figures. That is your default programing. You listened to her. Because she had a uniform on - I don't know what clicked, but you bounced right out of the car and marched right into the ER.

-Mark

The moments up until here are fairly clear in my mind. I remember the ER, I remember walking out, I remember everything – up until the moment I walked back into the ER. After that, I must rely heavily on the memories of others. In my husband's account, it seems like this is the point where I shut myself off. As Mark tells it:

> You literally shut off. And you were like, no emotion, just... dead. And I remember when they were like, “we're taking you to the neuro unit, you're undergoing observation.” I remember when they took you out I had to take your jewelry and all that stuff, and you were just in your scrubs and you were in a wheelchair, and you had this look on your face like you completely surrendered yourself to the moment. You were gone. And that was terrifying. That was like... I thought, this is it, this is how you're gonna be the rest of my life. You weren't ever coming back. And that's literally the worst day of my life.

I’ve Lost My Mind

My first full day at St. Andrew’s Hospital would be a day of many wondrous and terrible things all happening at once. That morning, my parents arrived at the hospital to keep me company, but they also brought along someone unexpected. My sister.

My sister and I had not seen nor spoken to each other for a year and a half. The story, in short, is that my sister and Mark got in a fight over college football on Facebook (I told you we were really into football), and we had not spoken since. We had separate holidays with my parents, separate vacations, separate lives. Somehow, despite living in neighboring cities and attending the same university, we managed to avoid each other. Until now.

We did not have much of a reunion; there were no balloons or tearful hugs, at least on my part. I saw her and I thought, *Oh, my sister’s here*, and that was about the extent of it. I left it up to Mark to make the overtures and peace offerings:

> … that happened instantaneously. I mean, Mark looked at her, she looked at him, and I think he did it spontaneously: he swore [a fight like this] will never happen again. And I don't think it ever will.

-Dad

I had tried several times over the past year to mend our relationship by reaching out to her in various ways, offering to go to family therapy, and number of things, but it took something like this to get us back together as a family.

My first doctor at the hospital was a neurologist. He ran tests, and gave me an EEG to read my brain waves. When he found nothing indicating a neurological issue, he suggested they bring in a psychiatrist.

My paternal grandmother, who died well before I was born, dealt with psychiatric issues all her life. When we were young, the stories my dad would tell about her seemed almost funny, like a family secret wrapped in a punchline. As we grew older, however, the gravity of those stories and the horror it must have caused my father came into view. My dad believes that his mother suffered from depression or bipolar disorder, but from his stories I have always believed she may have been schizophrenic. So of course, when the psychiatrist, Dr. McMurphy, asked my father about our family history, he supplied her with more than she needed.

> She took us outside, so she talked to [your dad] and of course your dad told her his family history, his mother's and all this….

- Mom

“I shouldn’t be here,” I said to Dr. McMurphy as she jotted something on her clipboard. “I don’t belong here.” I did not know where I was, but I knew I was not supposed to be there. Dr. McMurphy ignored me and wrote her notes.

“I’m not supposed to be here,” I repeated to Dr. McMurphy. She didn’t respond. She was about to go on her honeymoon, and I knew if I had a chance of getting out of there, I had to do it before she left. I was unsuccessful, but she did do one thing for me: fill out a request for medical leave from my job, courtesy of the Family and Medical Leave Act (FMLA). Under the reason for seeking leave, she wrote: “[patient] is suffering psychiatric disorder being treated & medications. Still not stable.” When asked when the end of the leave would be, she put a “?”. Just a few lines - that was all it took to keep me in the psych ward.

> When the decision was made to put me in, no one believed what they were hearing. [Dr. McMurphy] started thinking that it was a psychotic break. That you snapped, and that was the most... it just seemed implausible at the time because there was nothing that really led up to it. You know, you still seemed like you were in there, it didn't seem like you were gone for good, it seemed like a fixable problem at that point, and that was when real frustrations with St. Andrew's started settling in because we were sort of scratching at any sort of lead that would clue us into what was going wrong with you… I felt like it was the wrong turn, but, I completely regret that we didn't intervene and say you know what, let's try another hospital and figure this out.
>
> -Mark

> She jumped to the conclusion it was something psychological, and I told her you know, no way, you've never had any psychological problems. I felt in my heart of hearts that there was nothing with you psychologically. You aren't that person. That isn't your issue.
>
> -Dad

> She was going to recommend that you be evaluated in the psych ward, and you know… [Your dad] and I are both thinking no, that doesn't sound right, that's not something… That just doesn't sound right.
>
> - Mom

In some ways, the psych ward was better than others. We were allowed to wear our own clothes, for one. No hospital gowns, though we were required to wear hospital-issued socks with treading on the bottom to avoid slipping. Later I would read in Philip K. Dick's *Valis* that this was the norm for psych wards – it helps the patients feel a little bit more normal, I guess. However, the rules of the unit stated that we were only allowed two changes of clothing at any time, and clothing must be "appropriate. Logos promoting drugs, alcohol, sex, race, ethnicity, religion, etc., are not permitted. Staff may ask you to change clothes if it is determined that your clothing is not appropriate." It was almost like a school dress code.

We could shower, if we asked for it; I never did, I was too afraid. My obeisance to people of authority became crippling. In addition, I had reverted back to my childhood days, when I was painfully shy. I did not want to make a peep. I got my period while I was in the psych ward, but I was too afraid to mention it to the nurses, and when it was discovered that I had bled through my underwear, the nurse handed me a package of pads with a sigh, as though I was just another burden in her life.

When my hair became too matted to comb and it was clear that I had not had a shower in days, my family had to step in.

"Can she get a shower?" My mother asked.

"Of course, she just needs to ask."

Easier said than done.

"Erin, you need to ask for a shower."

"Okay," I gave the answer as lip service, never really intending to ask for a shower. My mother did not fall for it.

"You're getting a shower." She made sure that the nurse knew that I was going to get a shower, and they would have to take me to it.

There were only two showers, and the shower had a door that locked – from the outside. There was no shower curtain, only a room of yellow-beige tile and a showerhead protruding from the wall. After the nurse locked me inside ("I have a lot of things to do, will you be ok by yourself? Ok, yell if you need me") I struggled to remember how to make the water hot. The shower did feel nice, I had to admit. I crouched over, barely able to stand, but enjoying the hot water and the shampoo. But not for too long; I did not want to hog the shower - that would be rude.

When I emerged, clean and warm, I toweled off and tried to walk to my clothes. The slippery floor, combined with my weakened legs and deteriorating coordination skills, caused me to fall to my knees. I was unable to get up. I attempted to grab my jeans and pull them on while sitting on the floor, but I was only able to get my feet in the legs. I was stuck. I could not stand, I was half-naked, and I was locked in a bathroom.

"Can I get some help please?" I said through the door, hoping that the nurse would be standing at the other side of the door, waiting for me.

No answer.

"Hello? Is anybody out there?" I thought maybe they just couldn't hear me.

"I need help please!" I said a little louder.

I heard a man chuckle on the other side. Another patient waiting for the bathroom.

"Can you get help please?" I had been too worried to be embarrassed. Now I got to be both.

"Yeah, sure lady," murmured the faceless voice on the other side.

“Thanks,” I said, a programed nicety even though his tone was not so nice.

It seemed like forever before the nurse finally opened the door.

“What is going on?” She exclaimed. I must have been a sight: half naked, jeans around my ankles, sitting on the floor. She realized that I was not just looking for attention – I really could not clothe myself, or get off the floor. “Oh, honey, let me help you up.” The nurse offered a hand to me and listed me off the floor. Together, we managed to pull my jeans up and on.

“Do you want to brush your hair?” she asked, looking at the ratted mess my hair had become.

“No, thanks,” I was too embarrassed to stay any longer. I just wanted to go back to my room. That was the last time I would attempt to shower in this part of the hospital. Instead, I spent most of my days in bed.

The beds in the psych ward reminded me of when I would go to sleep-away camp in upstate New York. The beds were wooden, as opposed to the standard plastic hospital fare, and they had cute little drawers built in to them where we could keep our clothes. I had dreams that I was back in my summer camp, which was an acting camp; dreams that we were preparing for the summer productions. Those dreams often spilled over into my reality becoming hallucinations.

In one vivid dream, I dreamed that I had become a viral singing sensation when my parents secretly videotaped me singing “Let It Go” from the Disney movie *Frozen*. My sudden fame won me an opportunity to sing background vocals for Idina Menzel when she performed the song at the Oscars. To me, it was very real – I really was a viral video superstar.

One day, they had a surprise for us.

“You’re going to go outside today,” one of the nurses told us excitedly, “get some fresh air!”

We were not going to go *outside* outside of course – that would be ludicrous, to allow all these crazy people to go out and mingle with the general population. The hospital, it turned out, had a basketball hoop on the roof. If you look really hard, you can see it from the highway as you pass the hospital. There were also some benches, but mostly just flat white roof, a rusted hoop, and some partially deflated basketballs of varying shades of orange. Still, I thought someone, any one of these people might have smuggled a spare cigarette… if I found that person, I thought that maybe we could make fast friends.

As they led us through different wards of the hospital, I fell in line with another patient who was around my age. I do not remember what he looked like, though when I imagine this conversation he has dark hair and is taller than me.

"I hear we are going to get to play some basketball," he said to me. These are the most words I had heard from another patient.

"Yeah."

"Do you like basketball?"

"Sure, I used to play in school." Usually, this doesn't surprise people. Of course the six-foot tall girl played basketball. But he was shocked.

"Really? You used to be an athlete?" I can tell he was noticing my slumped posture and shuffling feet. It was hard to pick them up to walk recently.

"Yeah, I used to be a runner." The minute I said it, I knew something is weird about that phrase, *used to*. I amended it: "I'm supposed to be running a race this weekend."

He laughed a little, clearly not believing a word I just said.

To get to the makeshift basketball court, they had to lead us through the other psych ward. The floor was split into two wings, 4SW and 4NW. I was in 4SW. As we walked through the patients of 4NW, we all stared at each other, wondering which side was the *really* crazy side.

Outside, there were three basketballs in desperate need of some air. We all took turns tossing the ball at the hoop. The ball felt like an anchor in my hands, and it took all my effort to try to get it to go anywhere near the hoop. I threw it as hard as I could, but the ball landed well short of the rim.

One more time, and one more missed basket, flying far left this time. I was surprised it did not go straight off the roof and hit a car on the busy street below.

"She used to play basketball," I heard my new friend say, though I could not tell if it was amazement or sarcasm.

I chucked the ball in the air a third time; this time I made the basket. I decided to quit while I was ahead, and spend the rest of the time watching the few people who actually wanted to play basketball.

That night, Mark had a dream, so he wrote a poem about it. Mark had been a poet, a great one even, in college. His best friend and peer reviewer went on to become a published poet and a writing professor, but after college, Mark did not write poetry any more. I cannot remember him writing poetry at all, until he wrote this one the day after his dream:

The tornadoes come straight at you in your dreams.
They explode the buildings into splinters
The blackness envelops the gas station completely
The prices keep falling, yet no one enters

The farmland beyond is irregularly tilled
Scarred from left to right
This dream is not your heartland
The distance is the expected fright

As it nears, the thing about your ears
is it can do them the most harm
Sirens blast not for the tsunamis
This factory makes the same alarm

Take shelter. Take the Bible
A prop you will never read
Do whatever it takes to
wake yourself from this dream

Fall on your knees and accept the Earth
As the thing comes closer to your heart
Rip your shirt and accept the wind
As the stop sign tears you apart

When you design your grisly fate
As the grey maelstrom suggests

It's brave enough to act stupid
If that's what your mind accepts.

“Let me show you something.” Mark leads me through the beige hallways and florescent lighting to something hidden in a corner that he wants me to see.

“Do you know what this is?” he asks. He’s showing me a phone. Of course I know what a phone is.

“It’s a phone,” I say.

“You can use it any time. To call me.” He looks at me for some sign that I know what is going on. “Can you show me how to use it?”

I look at him, give him the look. The look that means ‘are you kidding me’? I have a Master’s degree, I can use a damn phone.

I pick up the receiver and look at the buttons. I know I’m supposed to press them, but I don’t know what order and I don’t know what I’m supposed to do. I hang up the receiver and Mark looks defeated.

“It’s ok,” he says. “We can try again another time.”

I go back to the phone later when he’s not around. For some reason, that takes a little of the pressure off. I wait until no one else in around; I’ve seen the movies about these types of places, you can’t just use the phone whenever you want to. I will have to be sneaky. The phone is in a hallway, hidden away a bit for privacy’s sake. I go back to it and try to remember what I am supposed to do. The phone is black with big silver buttons, like a pay phone. I remember when I was a teenager and they still had pay phones, and I would have to call someone to meet up with them or call my parents to come pick me up from the mall. If I didn’t have a quarter, I would call collect. That was it! I thought. I just have to call collect.

I dialed a zero. Nothing happened. I tried those old numbers from the 90's, the 1-800 ones. Still nothing. I gave up.

The next day, I returned. This time I knew the answer – I just had to dial the area code. That was all. It never occurred to me that I was already in that area code, and dialing the area code would get me a wrong number.

Finally, on the last day, I figured it out. When the call went through, Mark sounded amazed.

"You called me!"

"Yeah."

"That's great! You remembered my number!" I did not really understand what he was talking about – I had known his number the whole time. I forgot a lot of things, but one thing I always remembered – when I was talking to the police, when I was giving information to doctors, when I was trying to use the phone – I knew those seven numbers. I also suddenly remembered one important thing.

"Hey, aren't we are supposed to go to Disney today," I said. My race, the one I had been training for. Wasn't it coming up? Isn't it soon?

"I'm so happy you called me, Erin."

"But what about the 5K?"

"That's not going to happen, we had to cancel the trip. We gave the hotel room away to Autumn, she's taking her whole family. They will have a great time. Don't worry about it."

"Okay." I was still worrying about it.

"How are you? How are you doing?"

"I'm okay. Just tired."

"Do you want to talk to your dad?"

"Yes," I wondered why my dad was there with my husband.

"Hello, Erin," he said.

"Hi dad, weren't we supposed to run a 5k this weekend?"

"We had to cancel it, sweetheart."

"I really wanted to do it."

"When you get better, I promise we will do another one."

"Okay."

"Do you want to talk to your daughter?"

"Yes." This is the first time I've talked to her in over a week. Visitors under 18 are not allowed in the psych ward. I could hear her breathing on the other end – she still had not quite figured out how to have a phone conversation.

"Hello honey," I said. "I miss you. I love you." I could hear her in the background – I must have been on speaker. She didn't respond.

"She's just looking at the phone," Mark explained.

"Ok, I've gotta go." I said to Mark. I did not want to be on the line too long – our phone calls were limited to ten minutes.

"Ok, I love you," there was hope in Mark's voice.

"Bye."

Violet Light… And a Hum

> His attention began to swing grandly through the full arc of his life, passing into death, which was violet light. There wasn't anybody else there, or anything. There was just violet light—and a hum. (Vonnegut, 43)

My last night in the psych ward was one no one was there to witness; including myself. Strung out on a mix of anti-depressants and barely able to speak or move of my own volition, I remember nothing from this evening, but my actions would take me out of the psych ward for good.

My husband had come to visit me, like he had every night during visiting hours. Sitting with me even though I did not acknowledge him, trying to hold a conversation with a woman who could not remember his name half of the time. That night when he left, something flipped "on" in me. I remember they were getting ready to leave – it was Mark and my father – and I had already hugged them goodbye. But then, just like in the movies (at least in my mind's picture), I ran after Mark again to give him one more big hug and kiss.

Then, there are two accounts. The first is my own; the second is what I have been told.

I opened this section with a quote from Vonnegut's *Slaughterhouse Five.* I've read it a thousand times, taught it for ten years, and this line never stood out to me before. In the book, Billy Pilgrim can travel through any point in his life. He can be six, or eighty-six, and he can experience his birth as well as his death. He describes death as being nothing except a violet light and a hum. My light was green.

After I ran after Mark for one last hug, I went to my room for lights out. The next thing I remember is the color green. I was covered in green, like I was under a green sheet and I could see a light beyond the green sheet, but I had to climb my way out of it. It was hard to breath.

There was hum, like a room full of computers that have been left on. I struggled against the green, reaching towards something, when I heard a voice say this:

"Do you see your daughter?"

And I looked and I saw her; but it was not her as a two-year-old; she was a newborn.

"Reach for her."

And I smiled and I did, and when I did, I was out of the green and I could breathe again.

Mark learned about this second hand, when the doctor called to tell him that I had passed two pulmonary embolisms during the night:

> You were trying to get out of the psych ward. Like you were being very combative, from what the nurses told me, and you were like, you kept saying I don't belong here, I don't belong here. And you were like, where's my husband, and all that stuff. And during that whole thing, I mean, they checked you out I guess and you had a serious medical problem and that was the night you came the closest to death. And that was terrifying.

My primary doctor was called in to examine me as my vitals went into overdrive. My oxygen levels and blood pressure were extremely low and it became glaringly obvious that what I had was a medical issue and not a psychological one. Dr. Hopkins pulled me out of the psych ward on February 13th and sent me to a medical floor.

> All of my apprehension about you being in there and my fear of having to fight to get you out of there and finding out what happens next, all that went away, Dr. Hopkins gave us the call, gave me the call that you had suffered two pulmonary embolisms and he transferred you up to the fifth floor and got you a hospital room because at that point, it stopped being a psychological issue and finally turned into a medical issue.
>
> \- Mark

So, Now What?

Here is where it gets fuzzy. Mark and my family were becoming desperate for answers, especially now that a psychological diagnosis had flown out the window. Mark turned to an online forum I had frequented since I was in high school, a group of hundreds of women from all over the world. Even they had noticed my behavior had been odd, even through my online postings, and when I didn't post for almost a week, they became concerned.

Mark wrote out the story, every detail he could remember, and posted it to the forum. He told everyone what was going on as far as he knew, and if anyone had any insight, to e-mail him. Many did, to offer help or condolences, but one stuck out.

> She said you know, your story is a lot like this one book that came out last year, it's called Brain on Fire by Susannah Cahalan, and it turned out that she interviewed Susannah Cahalan for some article. She was like, you should read this book and see what happens, see if any of that makes sense.
>
> \- Mark

Immediately, Mark went out to buy the book. In it, Cahalan describes her battle with a rare and difficult to diagnose disease. She is labeled a flight risk, put on anti-depressants. She is acting weird, distant. She can't think straight. After a month of misdiagnoses, one neurologist finally discovers she has anti-NMDA receptor encephalitis, a rare autoimmune disease that didn't even have a name until 2007.

To Mark, the book was a beacon of hope. "It didn't take me long to read it, and um, I was convinced at that point that that was what you had. I was like, her story mirrored your story exactly." He took his new knowledge to the neurologist who had been assigned to my case, and his response inspired the title of this study. He simply told my husband “we don’t go chasing zebras.”

Instead, Dr. Templeton, the neurologist, was convinced that I had multiple sclerosis (MS). The only symptom I had for MS was the white matter that had shown up on my first MRI back in January. Dr. Templeton sent me for another MRI, which showed the same white matter, but no new developments. In the notes on the MRI, the radiologist writes that the white matter is “consistent with migraines,” while Dr. Templeton concluded that the white spots were “too numerous to be consistent with migraines.” Two doctors, looking at the same image, seeing different things. Dr. Templeton was an expert in MS – it was how he made his name. So when he looked at me, all he could see was a patient with MS, and he was quick to dismiss Mark’s ideas.

Dad also read *Brain on Fire*, and he agreed with Mark – there might be a connection there.

> I had finished the book about a day before we saw [Dr. Templeton], and I had suggested to him, couldn't it be an autoimmune? ‘Yes, but you have to test the spine, you have to do a spinal tap, and we did one, we'll send it off.’”
>
> \- Dad

Dr. Templeton told my dad that the treatment would be the same, whether it was an autoimmune disorder or MS. They would pump me full of large amounts of steroids. So that’s what they did.

The nights were the hardest. I have a famously small bladder and my husband likes to call me a “nervous pee-er.” If I know I cannot use the bathroom, it makes me have to go a hundred times worse. When they brought in the IV bags of steroids at night, it was a whole production to get up and go to the bathroom. I would have to call for a nurse or wake up my husband to grab all my wires and tubes and help walk them over to the bathroom. Every night, without fail, the minute they attached everything was the minute I had to go.

These nights were also the beginning of the most prevalent reoccurring dream I would have. I dreamt that we were on some kind of travelling tour, but our mode of transportation was like an old-timey circus train. My dad and Mark were with me and we were travelling across the country, but every time I laid down on the hospital bed in my dreams, the train would begin to move so fast that everything was a blur. And then it would hit me – I would have to pee. So I would ask them to stop the train so I could use the bathroom, and Mark would complain about me stopping the train so often to pee. Not all of this was a dream; real world Mark was also not pleased about being woken up fifty times a night to accompany me to the bathroom.

The worst part of the dream was the end. At the end of the dream we would always end with my father taking me out of the hospital for good, and putting me in his car (it was always his car, for some reason) and driving me home. But when we got home and pulled into the garage, it was the parking garage of the hospital and I was back in my hospital bed again. It happened over, and over, and over again, like the worst parts of *Groundhog Day*.

Out, and In Again

February 25th, 2014

But the steroids worked, in a fashion:

You improved for a short period of time, he started you on a Monday, and you improved that Wednesday afternoon and I can remember saying out loud 'we got our baby back, we

> got our Erin back,' and then the next day Thursday, you were back to baseline again. For no reason."

-Dad

I started to come back, and when I was able to sit and talk and the five day course of steroids was over, I was discharged and sent home. Kind of.

> You were still very out of it and your parents and I made the decision that you were better suited going home to [your parent's] because at least your parents, you know, you didn't have our daughter there, I couldn't watch both you and her and make sure your safety was ensured because you could have walked up and left the house any time.

-Mark

> You couldn't go home with Mark. He couldn't take care of you and the baby. We brought you home, we knew we had to treat you like a baby, so we had to get video monitors, audio monitors, lock situations, just as we would with a one or two year old.

-Dad

There is a picture of me from this day. I'm wearing a t-shirt of my favorite band, Against Me! I remember I had asked Mark to bring me an Against Me! shirt when I was in the psych ward, and he had brought me the wrong one (I have quite a few). That wrong one is the one I am wearing in this picture. I had just showered and my hair is still wet. My eyes are glazed over. I'm not really looking at the camera, but I'm not really looking at the photographer either. My daughter is there next to me, being held in place by Mark. We are sitting on top of her toy box. I remember every detail of that picture without looking at it. I can tell you exactly how my hands are placed, what hair tie I am wearing around my wrist, but all I remember is the photo, not the moment. I have looked at that picture many times, trying to remember what I was thinking or feeling, and how a woman who is about to be separated from her child again can look so calm and collected.

So I packed up a suitcase, my parents collected me in their car, and they drove me two hours south to their home, the home I had grown up in.

My dad was not exaggerating about the added security measures. There was a video camera in my bedroom, the same kind I used as a baby monitor for my daughter. The locks they had had installed to keep my daughter from wandering out into the lake were now meant for me. I learned this quickly when the next morning, I fell back into my old routine and got up to go for a run. I had packed my gym clothes – some shorts and a tank-top, sports bra, and my beloved Saucony running shoes – and gotten up with the sun so I could go for a run. When I went to go out the front door, however, I heard a beep – a setting on the house alarm system that is set off whenever someone opens a door.

My dad came into the hallway. “Erin, what are you doing?”

“I’m going for a run.”

“You can’t go anywhere by yourself,” he explained.

“Okay,” I said. I still did not see what the big deal was. I had been running through this neighborhood a thousand times.

“Why don’t you wait a minute and I’ll come with you?”

It was not a long run, just a little jaunt around the neighborhood. I had not exercised in almost three weeks, so he took it easy on me. We talked a little about the next race we would run together, like he had promised me.

After we returned and I showered, I put on a dress I had gotten for Christmas but I had not had a chance to wear yet. It was a blue dress with happy little hot air balloons on it. It was a little short, but then again, I am an unusually tall girl, so most things are shorter than intended on me. Again, I wore my signature sparkly ballet flats.

Mom was not allowed to leave me alone, so she told me I had to go with her to the grocery store. I do not particularly like going grocery shopping, but I did not have a choice in the matter, and besides, mom told me she would let me get whatever treats I wanted. Twinkies for lunch? Sure.

We were walking through the aisles as mom grabbed the items from her list. She stopped to say hello to people she knew, and I smiled at them and was silent. If we ran into anyone I knew that day, I did not remember them. Finally, we had finished and were in the check-out aisle. I stood there waiting for the cashier, a woman I had seen probably a thousand times since that grocery store opened when I was a kid, to finish scanning all mom's groceries. I tried to read the headlines on the magazines, but they didn't make sense to me.

The next thing I remember is waking up on the floor of the grocery store. *Oh, God,* I thought, *I hope my underwear isn't showing.* I found my mother, kneeling next to me on the floor.

"What happened?"

"You had a seizure."

The look on her face was one that I had seen exactly one other time in my life. We were visiting Iceland, and they have famous horses. The horses should really just be called ponies, because they are tiny. But I love riding horses, and so I requested that we spend part of our day riding. The joke was on me, because I got the worst horse of the bunch. When my horse got spooked and took off running, I fell off and landed on my head. That is the only other time I have seen the look of complete and total terror on my mother's face.

“I had a seizure?” I’d never had a seizure before, and I had assumed that when you had a seizure you knew it. That wasn’t the case. I did not remember anything, not even falling to the ground. My mom helped me up off the floor and started walking me outside, where an ambulance was waiting for us.

“Where are we going? Are we going home?”

“No, honey, we’re going to the hospital. I have to ride in the front, okay? I can’t ride in back with you. I’ll see you when we get there.”

The ride to the hospital was so long, for a minute I thought that we were headed back to St. Andrew’s, but when the ambulance stopped, I saw palm trees and no buildings other than the massive hospital.

There were no beds available so I was set up on a hospital cot in a hallway while I waited for more tests: another MRI, some blood work. When everything came back clear, they released me and sent me home again.

The next day, my dad sent me to see Dr. Hicks, one of the few doctors my father (in his work as a personal injury lawyer) actually trusted. Dad describes him as “ultra-conservative, and this is true of all defense experts. The great majority of them are just very conservative people, but they are intellectually honest. When I use that term “intellectually honest,” they will not go beyond the boundaries of how far you can push and still not being a lying sack of potatoes.” In other words, my dad trusted this man to know what he was doing and more importantly, to know when he did not know what he was doing.

“What did the neurologist at St. Andrew’s think in the way of a diagnosis?” Dr. Hicks asked my dad as we sat in his office, which is conveniently located just across the street from my parent’s subdivision. We sat in cushy leather seats, a far cry from the dated ‘90’s furniture of the hospitals.

“He was convinced she has MS,” my father replied, though anyone could hear in his voice that he did not believe it.

“Hmm,” Dr. Hicks thought for a minute. “Looking at all the symptoms, I don’t think its MS. The only symptom she really has of MS is the lesions on the brain, but that could have been caused by any number of things. It could even have been there since birth.”

“That’s what we’ve been saying,” my dad said, and I could tell he was relieved to finally be talking to someone with some sense.

“Let me review all her hospital records, get the ones from St. Andrew’s, and I’ll review them and call you.”

The best part of staying at my parent’s house was my proximity to friends. Veronica, my best friend/maid of honor/confidant/partner in crime still lived in my hometown, and staying with my parents meant I got to see her. She came over later that day to visit.

> I came over and I think I just talked to you. But even then you seemed... like you had regressed as far as maturity goes. Like you seemed much more like a teenage girl, like even possibly a young teenage girl. I didn't feel we were having the same kinds of conversations we normally have. I don't remember what we discussed but I remember like, thinking, this is so weird and this is not Erin. Not like, the Erin I know. Maybe the Erin I knew, I don't remember, ha ha. I don't remember you being like that. It was just odd. I felt like we weren’t connecting on the same wavelength, it felt like there was almost an age gap between us at that point.
>
> -Veronica

After Veronica visited, I continued to regress until finally, I did not know my own name. I could not respond to any questions or prompts. I either lost the ability to speak or just did not want to. However, I did not lose one ability – music. One day my parents decided that I needed to get out of the house, so they put me in the car and took me for a drive around the city. A song came on by the band Vampire Weekend and I began singing.

> We had the radio on and some song came on and this was during the period in time where you couldn't even answer questions I mean you are just dead silent and you said word for word every lyric of that song I was amazed.
>
> -Dad

To my parents, it was a sign that there was still something of me inside this shell. Later my dad would do research and discover that music is stored in a different part of the brain than the part that was affected by the illness. However, not all of my musical ability was left untouched. When I tried to play the piano, I could make it through about two bars of a Chopin waltz before I had to take my hand off the piano and declare that I could not do it.

Despite this glimpse of normalcy, I did not get any better. My parents and husband made the decision to send me back to the hospital again, this time under the watch of Dr. Hicks, and this time, I got a room to myself.

Dr. Hicks told us that he would be hooking me up to an EEG monitor and would be leaving it on for 24 hours. When he came into my room the next day, he brought his entourage of residents with him.

“This can’t be good,” my mom said.

“Well,” Dr. Hicks says, as he looks at his notes, “your daughter is having 30 second seizures on the left side of her brain every three or four minutes.” He stopped to look up at my parents. “It’s very interesting.”

“Well, maybe for you, but it’s not interesting for us!” My mother replied.

“We’re gonna hit her with all we’ve got,” Dr. Hicks assured my parents.

Around this time, Mark also got some news from the principal of my school, Southwest High (all names have been changed):

> I mean I talked to your principal, we were in correspondence, I sent him an email letting him know about your health and um, at that time I got the email from him telling me that he was going to put you on involuntary[1] transfer. And I was like, I was livid at that point. I mean, I understood, insofar as that we didn't know if you could ever teach again, and so that decision was made. We had a feeling that you could get better, but we didn't think that it was going to be happening that year. Since it was already midway through February so we thought you were done for the year and he thought so to. So yeah, but I was devastated, because you might not have a job if you did get better, if you came back.
>
> -Mark

When he told me this news, I could not really process the gravity of it. I’m pretty sure my response was, “oh, that sucks.” It would not be until much later that I would feel the full brunt of it, as I prepared to go out and find a new job.

True to his word, Dr. Hicks tried everything he had in his arsenal to get my seizures to stop. But they did not stop. They were still coming every couple of minutes, varying in degree.

---

[1] Involuntary transfers occur when a school cuts a unit of instruction (teacher), as opposed to a voluntary transfer, when a teacher leaves of their own free will. With an involuntary transfer, the teacher is still guaranteed a job in the district (assuming she has tenure), just not at that particular school.

For a moment, they considered putting me into a coma to try to get the seizures under control. But that was when Dr. Hicks said enough is enough.

“Look,” he told my dad on the day they planned to put me in an induced coma, “I can’t figure out what’s wrong with her. I’m not your guy. But there’s a guy at University Hospital that is an expert of seizures. He’s the guy to go to. I made some calls and he’s going to take her on as a patient.”

And just as quick as he said it, they packed me up and loaded me into a patient transport van and drove me the two hours to University Hospital.

> …it all went real fast, and I felt so bad, they put you in a mobile patient transfer van and took you before, you know, I couldn't even get stuff together to go up there with you, and you were all by yourself, and I felt so terrible you were all by yourself in that van.
>
> -Mom

A Big Fish

When Dr. Hicks made the decision to send me off to University Hospital, he did something that no other doctor had been willing to do until that point: admit that he could not figure it out, and send me to the person who could.

That person ended up being Dr. Jackson, the seizure expert at University Hospital. It was like being on an episode of *Grey’s Anatomy*; the head doctor would come in followed by a resident and a gaggle of interns. One of the delusions I experienced during this period involved these interns – I imagined that there were hundreds of them, and when they would roll me in for an MRI or a CT scan, they would clap and cheer for me as I went in and came out. I guess being famous is not a bad delusion to have.

At University Hospital, they hooked me up to an around-the-clock EEG monitor. Not only did it sound an alarm when I would have a seizure, but it also would turn off all the electricity in the room – lights, T.V., everything. The nurses would come running in, and Mark would complain about the T.V. shutting off in the middle of whichever Olympic event he was watching. Mark needed the distraction of something other than watching his wife have seizures every few minutes.

> You were out of it. At that point, you had lost completely your whole verbalization. You had no ability to speak any more. You had already gone past remembering what our names were, at that point you were nonverbal, you were completely aphasic. If I would come into the room, you hadn't seen me so I would come in and take over for the night shift after taking care of our daughter all day and finding someone to take care of her at night, I would come in and you would just start instantly crying. And that was the only way you could communicate with me. And that was the only way I knew you were still in there.
>
> -Mark

Dr. Jackson, the head of neurology, and his resident, Dr. Vorenus, listened as my family told them the whole history, just like they had told every other psychiatrist, physician, and neurologist I had seen since I was first brought to the emergency room. This time, however, when they talked to them about the possibility of anti-NMDA encephalitis, the Drs. listened.

“We’ll have to do a lumber puncture,” they informed my parents. St. Andrew’s had done a lumbar puncture, or spinal tap, but had not tested for encephalitis and had then “lost” the rest of my spinal fluid. “The treatment for that would be large doses of steroids, so we will start her on that.”

“She was on steroids at St. Andrew’s, and it seemed to help, but then she got worse,” my husband interjected.

“Yes, but they didn’t keep her on long enough,” Dr. Vorenus explained. “We will put her on an aggressive treatment of steroids here, and if she improves, we will send her home with a prescription for those same steroids.”

The key had been there all along – there was a reason I had gotten better at St. Andrew’s. They had the right treatment… I just did not get enough of it. The doctors at University Hospital started giving me IV bags of steroids again, and my seizures became 10-15 minutes apart, and then only a few a day, and then they were gone altogether. The fact that the doctors were willing to listen to my family and their theories about the illness I might have gave Mark the hope he needed.

> Through [*Brain on Fire*], there was a way out. Ok, so if she really did have this, she should be completely better 100% at the end. So we just kind of stayed positive and [University Hospital] took care of you and they figured it out.

The best part about University hospital was that there was a McDonald’s downstairs. My dad recalls it being a highlight as well:

> I remember many tender moments though, I can remember watching various TV shows together. You didn't know I was your dad, you knew my name but you didn't know I was your dad, but you know, we would watch a show and they have the McDonald's there and I'd say, “what do you think, hot fudge sundaes?” and you’d get a big smile on your face, and I go get us a couple hot fudge sundaes.

By the time I got to University Hospital, I had lost about 15 pounds from a combination of bad food, not eating the bad food, and the loss of the muscle mass I had built up from working out four or five days a week for the past year or so. My parents were happy to fatten me up, something that would continue long after my release.

I became more verbal, and was able to name people in my family and answer simple questions.

“She’s doing a lot better,” Dr. Jackson, the neurologist, said one day while making his rounds with his entourage in tow. “She’ll be able to go home any day.”

“Do you think she can come home today?” My father asked.

Dr. Jackson thought for a minute, and looked around the room at the interns.

“Well,” he began, “can anyone think of any reason that this woman can’t go home today?”

The interns looked around at each other, but no one said a word. Dr. Jackson turned back to my father.

“She can go home today.”

The next moments felt like a whirlwind. There’s a section in the book *Big Fish* where a son is caring for his ailing father, and suddenly the father tells the son that he wants to escape from the hospital and have one last adventure:

> And he smiled. Then he cast his gaze around the room, and he winked at me. He winked!
>
> ‘Let’s get out of here,’ he said in a hoarse whisper.
>
> ‘Out of here?’ I said. ‘Dad, you’re in no condition—‘
>
> ‘There’s a fold-up wheelchair in the bathroom,’ he said. ‘Wrap a blanket around me. As soon as we get off this hall, we’ll be in the clear. But we don’t have much time. Hurry, son!’ (Wallace, 1998, p. 173)

He wheels him out of the hospital and into the world. My own exit from the hospital made me feel as though I was acting out this scene from *Big Fish*. One minute, I was in the hospital and the next I knew, my mother was wheeling me out of the hospital and shoving me into the car, like we were pulling of some great escape. In the book, it turns out to be part of the son's imagination; in my version, my escape was real.

Reboot the System

March 12th, 2014

Like the last time I came "home" from the hospital, my family decided that it would be best if I went back to their home and not to my home with my husband and daughter. Mark and the baby would come visit on the weekends, and I would rest and get better.

My mother took the opportunity to baby me, which was appropriate because I wanted baby things. I wanted to drink chocolate milk and eat macaroni and cheese, to watch the things I had watched when I was a kid. I could not figure out how to work the television (although, in my defense my mother does have an unnecessarily complicated remote system involving an orchestra of remotes which each serve their one minute function) so my mother had to be nearby at all times to pause, or change channels, or increase the volume. I think she enjoyed it.

The first few nights I was back with my parents, my husband (when he was visiting my parents and me) or my father slept on a blow-up mattress in my bedroom, while our daughter slept in a crib in the guest room. I thought it was just to keep me company since one of them had always slept in the hospital room while I was there, and they thought I would miss the company. However, the real reason was to ensure that I would not get up and walk out of the house in the middle of the night. After a few nights, they decided I could be trusted and the air mattress was deflated and put away.

My mother asked Mark to bring all my unfinished projects. As a knitter, I had compiled quite a mass of yarn and sweaters with no sleeves (the sleeves are the most tedious part to knit). She also purchased a bag full of board games. Both of these were objects of hope, hope that some part of me was still in there and still wanted to knit or absolutely destroy the competition in a game of Clue. They sat in a corner for weeks.

I asked my husband to bring a couple things from home that I had forgotten. One of the things that I told him it was very important to bring was the manuscript of the book I had written several years previous. I must have told him a dozen times that he had to bring it to me, along with my laptop so that I could continue to work on it. I wanted very badly to finish editing it, even though I had no touched it in years. More so, I wanted to send it off to literary agents and finally get it published. That was what I was going to do with my free time.

The first thing I did was reread the whole thing. *Man*, I thought, *this is really good! I did an excellent job on this.* When I wrote it several years ago I was bringing an idea to fruition that I had had since I was a young child. The plot of the novel had grown in my mind for decades, and I had finally put it on paper. When I began my doctoral studies, I shelved it away and placed it in the virtual "future projects" file. Now, as I read the story I felt a connection to the first time I imagined the world and the characters of the novel.

When I finished rereading and editing it, I became obsessed with it. I talked about it constantly, posted about it on Facebook, asked people who had read years ago to talk to me about it. I even discussed self-publishing with my dad, who had self-published his own book

(*Metaphysical Ramblings: The Secret of the Universal Psychic Force*, $12.95 on Amazon). This signaled the beginning of a new trait I had picked up: the insufferable braggart.

On a visit with Veronica, my best friend, I could not stop talking about it.

“I think I’m going to self-publish my book.”

“Oh, really?” She was surprised. I had spent several years talking about reworking the book, transforming it into a series, but I had always insisted that the goal was traditional publishing. “Well, are you gonna send it to editors or anything?”

“Nope, it's just ready!”

> And I was like, that doesn't really seem quite like Erin. I mean, it's a good story, and I know she knows that, but for her to just forgo everything and just get it done, get it published, is kinda like, hmmm doesn't seem very thought out.
>
> -Veronica

While I was in the hospital, I had carried one book with me from hospital to hospital like a totem: *Gone Girl* by Gillian Flynn. I had purchased it before I got sick, and had planned to read it then, but it sat and collected dust. During my stay in the psych ward, I asked my mother to bring it to me so I could read it. I did not read it. I brought it to my parent’s house during my first release from St. Andrew’s. I even read some pages out loud then; I had heard them talking about me and I knew that they did not think I was competent, so I read aloud to prove that I was still smart. I read the same pages over, and over again. I thought I was doing a wonderful job, but the words coming out of my mouth were just nonsense. My mother sat with me as I read and recalled: “you were reading *Gone Girl*, and you kept reading the same page. I said, ‘How is that book?’ and you said, ‘it's good but...’”

Now, however, I had read my own novel, and I was ready to try to read again. I picked up *Gone Girl* and finished it within a few days. My love of reading and literature came back with a vengeance; my parents took me to Barnes and Nobles to get more books, and my mother was more than happy to oblige. When I was not reading, I was trying to work on the sequel to my own novel. And when I was not doing that… you could find me on the couch, watching T.V.

But it was not just any T.V. I started with the cartoons I watched as a kid. *The Little Mermaid, Swan Lake*. As time progressed, I watched the movies from my teenage years, *Can't Hardly Wait, 10 Things I Hate About You.* Finally, Mark suggested I watch *Buffy the Vampire Slayer.*

I originally started watching *Buffy* when it first aired, during my sophomore year of high school I had been a fan of the movie version, as cheesy as it was, and had dismissed the show at first. But then I got sucked into this world, with its strong, female protagonist and supernatural themes, and became a lifelong fan. My bookshelf is littered with books about *Buffy* or philosophical musings about the show. I own props, (pretend) weapons, board games, video games, dolls, clothing, anything from the show I could get my hands on. I wrote a college seminar paper on *Buffy* for a class called "Ancient Magic and Mysticism." I got an A on it.

I credit *Buffy* with a lot of things in my life; it was my first foray into feminism, the first show I watched that normalized gay relationships, and now I credit it with helping me recover during this period.

> From your middle school then you graduated to *Buffy* and *Angel*[2] and uh, you know, we rant through all those, and by the time you were done with Buffy you were back to lucid.
>
> -Mom

---

[2] A *Buffy the Vampire Slayer* spin-off

In addition to watching the shows I had watched growing up, I also ate the foods I liked growing up. Every morning I had chocolate milk and an Eggo waffle. I ate Bagel Bites and cottage cheese and Twinkies and Quarter Pounders with Cheese. It seemed like forever, but by the time I was done watching *Buffy*, my parents and Mark decided I was ready to go home.

April 3rd, 2014

It had been three weeks of nothing but eating, watching T.V., and more eating. I had gained back all the weight I had lost in the hospital, and then some. It had all caught up with me, and I had begun to feel sluggish and yearned for a return to my regular life. I was ready to go back to my normal diet and running schedule. Most of all, I was ready to get back to my daughter and Mark, to get to see them every day and be there when they woke up.

My parents drove me the two hours to my house. When we got there, it was lunch time, so I asked if we could all go out for lunch together. Mark and I decided we would walk with our daughter to the restaurant, since it was just down the street and the weather was nice. My parents would drive, since my mother has trouble walking long distances.

As Mark, our daughter, and I walked, the conversation turned to the future.

“I can’t wait to get back to work,” I said.

“Uh huh.” Mark had a habit of not always listening to what I said and responding with platitudes.

“Do you think I could go back to work at Southwest for the rest of the year?”

“What?” That shocked him back into reality. “No, don’t be stupid.”

“What?”

“You can’t go back to work. You’re not well.”

"Um," now it was my turn to be incredulous. "I think I'm just fine, and anyway, I have to find another job for next year anyway."

"Yeah, that's for next year. You are in absolutely no shape to teach a class."

"Like, ever?"

"Maybe." That was when I started to cry.

"Erin, you can barely talk, what makes you think you can teach?"

"My parents think I can."

"Yeah, well, your parents are idiots."

That didn't help.

"Go away. Just go away." That was my go-to response when I did not want to deal with him anymore. I had learned a long time ago that threatening divorce was an unnecessarily rude and very idle threat. So instead, I would just ask him to go away.

"Fine. I'm going home," he said as he turned and headed home. I continued the two block walk to lunch with my daughter.

When my daughter and I arrived at lunch, my parents could tell I had been crying.

"What's wrong?" my dad asked me.

"I don't want to talk about it."

"Did you and Mark have a fight?"

"… Yes."

"About what?"

"He doesn't think I can teach anymore."

They looked at each other and sighed.

"Well, he's an idiot." *That's what he said about you guys*, I thought.

After I had calmed down, Mark thought better of it and joined us for lunch. We made up, but this fight would continue for the rest of the week.

By a remarkable coincidence, on the day I returned home, we received a call from the neurology resident, Dr. Vorenus at University Hospital. She had the results of the final lumbar puncture they had done.

“You were right,” she told Mark over the phone. “She had the same thing as that girl in that book. She had anti-NMDA receptor encephalitis.”

“No way,” he responded.

“I’d like to come by next week and talk to you both in person, and ask your wife some questions.” We were surprised that she was willing, even eager, to come make a house visit. I thought those had gone by the wayside.

“Of course.”

Mark felt vindicated. Everything he had tried to tell the doctors from the beginning, that it could be what this woman in *Brain on Fire* had, it all had come full circle. He had been right.

The next day we celebrated the best way we knew how: with a trip to Disney World. We packed up our daughter and headed off to see a mouse about some princesses. I decided to take along my knitting to pass the time on the car ride. However, when I picked up the yarn to begin knitting, I couldn’t remember how to cast on, how to knit a stitch, or how to do anything.

“Huh,” I said, after I had stared at the yarn for a while, willing it to work for me.

“What?” Mark asked, glancing over as he tried to keep his eyes on the road.

“I can’t remember how to do it.”

“Like, at all?”

“Nope.”

"Wow," he said. "How sad." It was a small comment, and a flat one, but I could tell to him, my inability to do something that had been such a constant in my life was a depressing thing.

We continued on our ride for about thirty minutes, when I decided that I was going to knit, goddammit, and I was going to knit now. So I did what any millennial would do – I pulled out my phone and started looking up instructions on the internet.

By the end of the car ride, I was back to knitting and purling and frogging and cabling with the best of them. I had reloaded the software into the hard drive of my brain.

When Dr. Vorenus, the neurology resident, came to visit the next week, Mark could not wait to tell her about all the progress I had made. She was more excited about my diagnosis.

"It's a very rare disease," she explained. "It is an autoimmune disease. Basically, your brain shut down because it was fighting off some kind of infection somewhere else in your body."

"We read it could be associated with ovarian tumors," Mark interjected.

"Yes," Dr. Vorenus began. "But it also can happen without a tumor. We checked Erin for tumors, and she was clear."

"So… am I done?" I couldn't believe that this ordeal had such a succinct ending. "Am I healed?"

"Well, I'd like to go through a test like the ones we did in the hospital, if you don't mind."

She sat down on the couch with me and pulled out a worksheet. On the worksheet were several boxes, not unlike a graphic organizer you would give an elementary school student. In the first box, there was a circle.

"Can you draw a clock face on this circle?"

"Sure." I dutifully numbered the clock from one to twelve.

"Do you remember doing this in the hospital?"

"No, not at all."

For the next task, she asked me to use that same clock I had just drawn and make it say ten minutes to ten. I did.

"Very good!"

Next I had to finish a picture of a horse – the worksheet provided the back legs, and I had to draw the front and head. I'm a terrible drawer but hey, this was kind of fun.

"Next, I want you to name as many words as you can think of that begin with the letter 's'." *Oh, this will be easy,* I thought. I was wrong.

"Sailboats, sail, sails, snail, sat, seat, sheet," *shit, shat,* I thought, but I was too polite to say out loud. "Snack, snacks, sea, seize… um, Skittle…"

"That's ok, that was a good first try. We'll try again."

On the next try I got many more.

"Wonderful." She turned to Mark. "Her recovery is just amazing. I would never expect her to be this far along so quickly." I could not believe what she was saying; I mean, I just had trouble coming up with words that start with 's'.

"That's great to hear."

"If you guys need anything else from me, just call me, alright? I'm so glad you're doing so well, Erin."

Though I'm sure Dr. Vorenus' visit was meant to be a joyful one, and for the most part it was, it also made me unsure of myself. For the first time I started to agree with Mark; maybe I was not ready to go back into the classroom. I did not have long to worry about it though – I only had ten days to prepare for the job fair.

Here Time Turns Into Space[3]

April 17th, 2014

I was terrified. I had gone through two job interviews within the past year, and though I had gotten through various rounds of interviews for both jobs, I did not get either one. On top of that, I was still not quite back up to snuff, and Mark had made it pretty clear that he did not think I was ready. But we did not have any other options. I had to attend the involuntary transfer job fair in order to remain employed in my district.

Being an involuntary transfer carries a stigma with it. When someone new would come into my original school, Southwest High School, we would whisper 'oh, she's an involuntary transfer,' as if that was a blinking light overhead announcing that the teacher was a screw-up. I assumed all involuntary transfers were teachers who had been let go because of their incompetence, but now I was one of them.

The involuntary transfer job fair was held at the same high school where the ELA department had their professional development trainings during the year. It was almost like being back to work, sitting in the main room of the school, waiting to be herded into the auditorium for a group meeting before the break-out sessions. Before the job fair, the county had e-mailed those attending the fair with a list of schools who would be represented and what subject areas they were looking to fill. As I looked down the list, my heart sank. Only two high schools were looking for English teachers, and one of them was a 40 minute drive from my

---

[3] From *Valis*, (Dick, 1981, p, ?)

house, on the complete other side of the district. I had spent the day before the fair looking up various routes to both schools, checking what was nearby, seeing if either option was viable. I finally decided that I would play it by ear.

Before the interviews began, we all met in the auditorium to go over the day. We would choose where we wanted to interview and sign up for times. There were a few job openings listed and, and more would be posted after the informational meeting (let it be the school down the street!). We could not interview for a subject area we were not certified for (there go my hopes of being a history teacher). And finally, one piece of advice that helped more than any other:

"Remember," the facilitator said, "no one knows why you're here, or why you were on the involuntary transfer list." No one would know I had been sick, I told myself, or think I had gone crazy like they had heard at Southwest. I was just a teacher with one hell of a resume and a friendly face.

The first thing I did was check the updated job postings; no such luck - no other English positions were posted. I sighed and signed up for my interview times – first, with the school that was 40 minutes away from my house, then with the other high school that was ten minutes closer. I considered signing up to interview with a middle school who was looking for an ELA teacher, but I could not bring myself to do it. It was high school or nothing.

The principal of the first school, Edinburgh High School (name has been changed), had been an Assistant Principal when I was starting out at Southwest. He recognized me and when he realized I was interviewing for his school, his face lit up. *Oh, it's in the bag,* I thought, and every nervous thought I had instantly disappeared.

"You're interviewing for Edinburgh High?" He asked.

"I sure am!"

"Are you certified to teach dual enrollment courses?"

In order to teach dual enrollment in our district, you have to have eighteen credit hours in the subject area and a Master's degree. I had both.

"Yes, sir. I've taught dual enrollment at Southwest for the past three years."

"Great, I can't wait to see you in that interview."

At that point, I knew the woman in the auditorium had been right. No one knew why I was there. I just had to be my charming self, and everything would be just fine. And I was right – after the interview, the principal called me to let me know that they would be offering me the job.

Suddenly that forty minute drive I had been so concerned about did not seem so bad. There were a lot of pros to a long commute: I would not know any of the students or parents already, I would have a nice relaxing drive early in the morning. I began to look forward to the new year, to getting a fresh start at a new school in a new town.

May 5th, 2014

It took a couple weeks for the job offer to become official. When I called Human Resources to let them know I had accepted the position and would be going back to work in the fall, I had another surprise waiting for me.

"What do you mean 'in the fall'? You're scheduled to go back to work today."

"What?" I exclaimed. Mark looked at me curiously.

"Oh, wait, I'm sorry. It's not today." I let out a sigh of relief. "It's tomorrow."

"What?" Though my husband and I thought my leave was scheduled through the end of the school year, it turns out that when he filled out the paperwork, he had only taken a 60 day leave of absence, and that leave was over. I had to go back to work. At the school that had, for all intents and purposes, fired me.

"Yes, you go back to work tomorrow." There was a pause. "Thank God you called me when you did!" She laughed. I did not think it was funny.

I hung up the phone and told Mark what she had said.

"Well, you have to call your principal and tell him you're coming back." I knew he was right, but I did not want to talk to him at all. I am a firm believer that there are just people in the world that you take an instant dislike to. Not because of anything you did, or they did, but perhaps some kind of cosmic retribution, or some past life squabble. For Mr. Sterling, the universally beloved principal of Southeast high, I was that person. I mean, the man fired me in an email. To my husband. While I was nonverbal in the hospital.

"Well, that is interesting," Mr. Sterling said when I told him the news. "I mean, I'm glad you're feeling better, but I thought you weren't coming back this year."

"Neither did I." Wow, this was awkward.

"Come see me in the morning when you come in, and we'll discuss things."

"Alright."

I hate going to the principal's office. That's one thing we share with the students – the principal's office is a scary place. His desk is gigantic. What does he need that gigantic desk for? He's never even in his office.

I sat outside the office door in the large, cushy chairs reserved for visiting parents or nervous teachers, waiting for him to let me know it was ok to come inside. When he finally called me in, he was already sitting at his desk. He didn't stand to greet me.

"Well," he smiled. "It's nice to see you back here."

Liar.

"I'm glad to be back."

Also a lie.

"So, I've been doing some thinking about your situation."

"Okay."

"See, the kids in your class have gone through quite a few subs, and we just got this new long term sub in there, and he's really doing a great job. He finally got the kids on board with him, and I really don't want to move him out of there."

"Okay." Where is this going?

"So I was thinking that we would keep him in your room with your students, and you could spend the last month of school helping the guidance department proctor tests."

"Okay, I can do that." Of course, I wanted to see my students again, to have another shot at helping the seniors who were about to step out into the real world or head off to college. But in my mind, I was already an employee of Edinburgh High School, and part of me was ready to just pass the rest of my days at Southeast without too much hassle.

That day was a mixture of torture and joy. I saw my friends, and they were happy to see me. I passed my children in the courtyard who ran to me full-hilt and nearly knocked me over with their hugs, while I spent the rest of the day trying to figure out who the hell they were.

I spent the day with the guidance counselors in the media center, helping administer the state reading assessments or the Advanced Placement (AP) tests. Tedious is too polite a word. I became so bored that I started reading the books on nearby shelves. I was seated next to the section on left-handers (a whole section) and began reading about something called "left-hander's syndrome."

The next day I vowed that I would never be that bored again. We went to the library to get some new books for our daughter, and I picked up a few of my own: *Valis*, by Philip K. Dick, *Never Let Me Go* by Kazuo Ishiguro, and *Atonement* by Ian McEwan. I also brought my laptop so that I could keep working on that ever important sequel to my novel.

I wanted to read *Ubik* and they did not have *Ubik*, so I chose *Valis* because it was the only Philip K. Dick book they had. I had wanted to read *Ubik* because I have never read it, yet I have a poster for the book hanging in the hallway of my house, and I was tired of being a fraud. I would stay a fraud some time longer – *Valis* would have to do.

As it happened, *Valis* worked out for more than I bargained for. As I read, I learned that this was a book about a man named Horselover Fat (a character based on himself; I suppose he felt he had to outdo his own unfortunate name) who was in a mental hospital. *How apropos*, I thought. As I read about Fat I learned that his experience mirrored mine. I kept reading and I couldn't believe how he was describing everything I experienced. I double checked the date of publication – 1981. Nothing had changed in mental health care in thirty three years.

As I drew the parallels of Fat's world with my own, I thought back to my first qualitative methods course. The professor assigned us an autoethnography, and I had written about my experience with miscarriage. This time, I decided to use Fat's story to weave into an autoethnography of my experience.

Over the next few days I spent most of my "proctoring" time writing down my account of my illness, focusing on my stay in the psych ward, and interweaving excerpts from *Valis*. I researched my illness, and began to pull articles from the online databases on anti-NMDA receptor encephalitis. I even found an article about instances of the disease in cats (was this the link to Mile's illness? Did he give me this disease?).

Whatever time I didn't spend proctoring, I would spend locked in my coworker Marjorie's room. Marjorie and I had both been hired at Southwest at the same time, and had sat through the same new teacher meetings together our first year. We were the same age, and we became fast friends – a friendship that grew over the years. She visited me in the hospital as much as she could, and even helped babysit my daughter when Mark needed an extra hand. She was the first person I went to see when I came back to school.

At first, Marjorie was happy to see me: "the first day you walked in, I was so excited it was like, cool, Erin's going to come hang out with me. The second day you walked in my only thought was, 'oh dear God how can I make her leave.'" I was loud, obnoxious – like an unruly student, but one she could not send away when things got out of hand: "you were very rude. You were very… just unrefined, and very loud, and you had no filter, no sense of what was going on." She wasn't the only one who felt like that. I began to feel like people were finding excuses not to be around me. At the time, I thought that people were responding to me because of the rumors that they had heard, and there were many of them. I had a tumor, or a heart attack, or I had moved to some tropical island. Marjorie worked to try to quell those rumors, but they were persistent.

The most pervasive rumor was the simplest one, and the one that hurt the most.

“Mrs. Luta told everyone you had a mental breakdown.” Mrs. Luta was the English department chair at Southwest, a woman who I had the utmost respect for. When I discovered that she had told students and staff that I had a breakdown, I became paranoid. I began to imagine the various machinations she may have put into order to have my unit cut. I talked about it constantly.

Not only was I constantly talking about Mrs. Luta and the rumors, but I was becoming insufferable. One trait I had not “rebooted” since my release from the hospital was my confidence – that was one piece that would take longer than the others to return. But, I believed in the power of “fake it ‘til you make it,” so I pretended that I was confident. My friends could see right through it.

> You could kind of tell too that you were very insecure. And that's the part that I had the most trouble with, because you're probably one of the smartest people I've ever met, and it was like every sentence out of your mouth had something to do with how smart you are, and that you're working on your Ph.D., and just very cocky. And you should be proud of everything you're doing absolutely it just wasn't you. You didn't present it the way you normally do. You did a lot of, not necessarily talking down, but sometimes I would talk to you and then feel like total shit about myself afterwards.
>
> -Marjorie

My other work friends did not know how to deal with me. They had no idea how long I would be like this: this rude, this petty. Most of my work friends no longer seemed to want to spend time with me by June. Perhaps some of them thought it was permanent. By the time the school year ended at Southwest, I had about ten pages of autoethnographic writing and about three fewer friends.

A Methodologist

That summer, we were forced to deal with the mountain of paperwork necessary to undo the unraveling that Mark had done with my life. Unsure that I would ever again join the waking world, Mark had closed my bank account, withdrawn me from the University, and changed every. Single. Password.

We spent weeks ironing out the details, but I was adamant about the first thing I wanted to tackle: readmission to the University. I had been so close to being done, I just needed to finish. Mark was not so sure.

“Are you sure you’re ready for that?”

“Yes, I have to finish my coursework so I can start my dissertation.”

“I don’t think you’re ready.”

I really did not care what Mark thought. So we filed the paperwork to get back on track for my program.

I refused to lose any more time. I had already lost an entire semester, and now my cohort was moving on without me, getting ready to take their qualifying exams and move on to dissertation land. I, however, still had to nail down my committee members – and I needed a methodologist.

I knew I was doing a qualitative dissertation. That was not even a question. I had taken two qualitative methods courses with two different professors, so surely one of them would agree to be part of my committee, right?

I learned that the reality was much more complicated. The first professor was simply too busy – she had too many people on her slate and could not possibly take on another. The second was recovering from an injury and unsure if she could commit. I began to panic, worried that I would not be able to find someone who would be able to guide me as I focused my study. In my panic, I turned to my major professor.

“There’s another professor in Measurement in Research,” my major professor told me. “Why don’t you talk to her and see if she might be available for your committee?”

“I can ask someone to be on my committee even if I’ve never had them as a professor?”

“Of course. Why don’t you meet with her and talk to her about your ideas, and see what happens. You know,” she added, “You can always change your committee later.”

So, at my major professor’s advice, I made an appointment to meet with a professor I had never met to ask her to be on my committee for what turned out to be a long, ever-changing process. I have never been the student who shows up for office hours – not because of a lack of concern for my academics, but because of a crippling shyness and anxiety that if you told anyone about, they would probably laugh. I’m outgoing and confident, but put me in a room alone with someone who is, in my view, my “higher up,” and I am a nervous wreck. It’s something I’ve learned to hide, but from a young age, seeing “see me” at the top of a school assignment struck a fear into my heart that has never really gone away.

I was halfway up the stairs to her office when I realized I had forgotten to flip my septum ring back up into my nose.

I knocked timidly on the open office door.

“Hello,” she said as she greeted me at the door, looking much younger than the photo on the university website had led me to believe. And shorter. And with an eyebrow ring. I felt silly for hiding my septum now.

I gave her my spiel about needing a methodologist for my committee, and that I was having trouble finding one.

“Why don’t you tell me a little bit about your project?”

I told her my ideas to look at how a writing group might benefit pregnant or mothering teenage girls, and I wanted to look at it from a critical perspective. I hadn’t worked out the details, but that was about as far as I had gotten. As I spoke, I rambled on and began explaining why I was behind in my program, talked about my illness and how it had sidelined my studies for a bit.

“Wow,” she said when I was done. “Can I ask you something?”

“Sure.”

“Have you thought about an autoethnography?”

I thought back to that first attempt at an autoethnography I had worked on while I was proctoring tests.

“Yes,” I replied. “I started working on one. I think I might publish it later.”

“Well, you could do an autoethnography for your dissertation.”

The thought had not occurred to me. I assumed that I would need to do a traditional study for my dissertation. I thought about it for a minute.

“I don’t know. Like I said, I might do something with that later, but I think I’m going to stick with this idea for now.”

“Well, I’m on board with either idea.”

“Thanks.” Well, at least that was done – one more step on my way to the finish line.

Break Out the Bagpipes

I walked on to the campus with a smile on my face. This was it – my new home. I had a thousand hopes for my new job – that I would be liked, that the other teachers would be nice, that my classroom would be bigger than my last (which was not even classified as a classroom), and maybe even have a Smart Board. A large painting of a man in full highland regalia – kilt, sporran, stockings – greeted me as I walked up to the administration building for the new teacher orientation.

“Are you here for new teacher orientation?” Asked a short woman with brown hair sitting patiently in the front office.

“Yes,” I replied.

“I’m Rachel, I’m the mentor for new teachers here.”

“Oh, nice to meet you. I’m Erin Parke.”

“Oh! You’re teaching English. I teach English, too. We actually have quite a few new English teachers here this year.”

“Oh, great. I look forward to meeting them.”

We waited for more new teachers to wander in before we all moved into the principal’s conference room. The principal arrived, a large, bald man with a large personality. He walked over to shake my hand.

“It’s nice to see you again, Mrs. Parke.”

“You too.” We had only worked together for a year at Southwest, and I doubted he remembered me at all, but I appreciated that he at least pretended.

During the meeting, he presented us with a PowerPoint presentation about the school and its various programs. You could feel the pride for the school coming through in his voice as he spoke. I actually began to feel a little bit of pride myself, and I might have even choked up a little bit. Just a little.

After the presentation, the principal gave us the good news: first, that the hospitality committee had put together welcome baskets for us, and second, that we could get our keys and check out our rooms.

Most teachers will tell you: nothing excites us like free stuff. The baskets they gave us were stuffed to the brim with supplies, mugs, a t-shirt, anything you can think of. But the real gift came when I got the keys to my classroom.

When I opened the door, I thought there had been a mistake. There was no way this gigantic classroom was mine. The room was easily three times the size of my classroom at Southeast, with one wall lined with bookshelves and cabinets (with locks!) and the other lined with windows looking out on a bright courtyard. Later that year, the autistic unit would plant their garden out there, so my windows would look out on their vegetable and flower garden. And the bookshelves! They were filled with books of all genres and sizes, just ready for someone to read them.

I heard a knock on my door.

“Hey,” the man said, “I’m Cam, I’m in the room across the hall.”

“Hi, nice to meet you. Hey, do you know whose books these are?” I pointed to the books on the shelves.”

“Oh yeah,” he said. “Those were Jody’s. She was in this classroom last year, she had some problems and just left. Never came back.”

“Oh,” I said. “So what do you think I should do with these?”

“Keep them, I guess. Let me know if you need anything, I’m right across the hall.”

“Thanks, I will!”

I looked at all the books, labeled with the name of the woman who had this room before me. I wondered what had happened to her, and wondered what the people in my hallway were saying to the teacher moving into my old classroom right now. The sense of excitement I had felt when I arrived that morning began to disappear and a sadness began to wash over me. Would I like the other teachers in my hallway as much as I liked the ones at Southwest? Would I regret taking this job?

I opened the cabinets to begin putting my own things away, only to find that Jody, whoever she was, had been a hoarder. The cabinets, files, and even the desk drawers were filled to the brim with everything you can imagine. One cabinet was stuffed with lose files and collapsed down on me when I opened it, drowning me in a sea of tests and lesson plans. This was going to take some work.

Over the next few days I cleaned out everything that had been hers and made the room my own. I hung my posters and decorated, and every day more and more people stopped by to introduce themselves. By the end of the week, I knew the entire English and Reading departments, and most of the Social Studies department. *I think I'm going to be okay here*, I thought.

I was making dinner that evening when I got a phone call from the HR department for the school district. By this point, the woman from HR and I were practically best friends, between the phone calls about leave, involuntary transfers, and the offers from Edinburgh.

"Hi Erin, how's it going?" She said. There was something in her voice, like she was about to tell me something unbelievable. "I have got some crazy news for you."

"Okay…" *What now?*

"What would you say if I told you there was a job available for you at Southwest?"

What? A job at the school that so unceremoniously decided I was the expendable one?

“I really wouldn’t know what to say about that.”

“I figured that was what you would say. Well, I will tell you that it is a 9th grade position.”

“All 9th grade?”

“Yes.”

I have never taught 9th grade – I’ve always preferred the older kids, juniors and seniors.

“Well, let me call Mr. Sterling and talk to him about it.”

“That sounds like a good idea. Call me after you talk to him.”

Immediately, I called Mr. Sterling to get the details on this job that had suddenly appeared out of the ether for me.

“I thought I might hear from you,” he said when he picked up the phone.

“Yeah, I heard there’s a position for 9th grade?”

“That’s right.”

“All 9th grade?”

“Yes.”

“If I took the position and then it turned out that you had to cut a teacher next year again, would I still be the one cut?”

“Unfortunately, yes.”

“Ok, that’s all I needed. Thanks.”

When I called the woman from HR back, I told her about our conversation and gave her my decision.

“I think I’m going to stick with Edinburgh High School.”

“I think that’s the best decision. I think you’re going to be really happy there Erin. Good luck, and hopefully you don’t have to talk to me any time soon.”

I’m an Idiot

The first week of school also meant the first week of classes at the University. I had signed up for two courses – one was my final research methods class, where I would (finally!) begin writing what would eventually become my dissertation proposal, and another one about research in reading and literacy. I could not wait to get back to graduate school.

The literacy class was just my speed. Small, intimate, and my cohort friend Kristen was in it with me – I like having a friend in the class because it alleviates the anxiety of having to find a partner when you are inevitably asked to partner up. I usually love small classes because I love to talk, but in this class something was not right. I would find myself beginning to add something to the conversation and then losing my train of thought, or even trailing off in the middle of sentence because I suddenly realized that I might not have any idea what I was talking about. I wrote about it in my researcher reflective journal, which I had already started as a part of my research methods course:

> As a student though, I find myself not as confident as in the past. I hold my tongue in class and when I do speak I find myself travelling off or acquiescing to the next person. It may be because I came into the reading research class late [I joined a week after the semester started] and behind everyone else, but I still find myself questioning as to whether I am really as smart as I thought I was or if I am even a good writer. I think my experience, but particularly my recovery, has definitely affected my confidence level.

My other class was going better, in theory. The methodologist from my committee taught the class, and the large class size put me at ease. I felt more comfortable talking and sharing, but when it came time to begin working on our dissertation proposals, I was stuck. I just could not figure out how to get my study to work. And would it be a case study? An experimental study? A phenomenology?

I was really struggling with these ideas when a classmate, Kristen, who was also a member of my doctoral cohort, offered her advice.

“Erin, I really think you should do an autoethnography.”

“Really?” I thought back to my conversation with the methodologist about doing autoethnography for my dissertation.

“I think your story is so interesting. It would make a great dissertation.”

The whole ride home, I couldn’t stop thinking about it. And the more I thought about it, the more excited about it I got. A song came on my iPod mix that I had heard many times before, but somehow in this context they seemed to make a different kind of sense. The song began:

My brain makes drugs to keep me slow
A hilarious joke, from some dead pharaoh

I thought about the problems I had during the other class and my lack of confidence, and thought about how, for me, personally, the most painful thing about this disease has been the second-guessing and the feelings of intellectual deficiency. And then the chorus came in:

You never held it at the right angle.

I thought of the doctors who looked at my disease and peered through my records and just would not look at it from the angle that would give them the correct diagnosis. I thought about myself, looking at my own experience from various angles.

When I got home, I shot an e-mail to the professor on September 19th:

> I've been thinking a lot about our conversation this past summer. I was talking to you about possibly writing an autoethnography about my experience with my illness this past year and my hospitalization, and you asked me why I wasn't thinking about doing that for my dissertation. That's been banging around in my head for a while and after talking to some people (you can blame Kristen if you want) I am thinking I might want to go in that direction. I wanted to see what your thoughts were and of course I'd be happy to re-do the 1st proposal task. I'd also be happy to meet with you in person if you wanted to talk about it face-to-face. I look forward to hearing your thoughts...

There's a meme I love that is a picture of a grad student painfully typing out a long-winded and very polite explanation, followed by a three word reply from the professor. I love it because that is me. My emails are usually overly formal and verbose and the replies I get are usually much more succinct, as was my response from my professor, who told me to follow my instincts and always remember that a dissertation is a long process – you have to choose something you can live with for a long time. I knew it would be hard to write about some of these things – some emotional, some embarrassing – but just the idea of writing it and telling my story excited me.

An Unlocked Door

August, 2014

Early on in my first year at Edinburgh High School, I made a revolutionary decision – I decided to leave my door unlocked whenever I was inside. As soon as I got there in the morning, I would unlock the door and leave it unlocked. At lunch, during planning, after school – unlocked. Those times of the day that I had previously put aside as "me time" at Southwest High School became an all access pass for students to come to me for whatever they needed at Edinburgh High School.

And they came. They came to talk about grades, to complain about boys or girls, to ask for advice about colleges and prom dresses. They came because they did not have anywhere else to go or because there was nowhere else they would rather be. They came when they wanted to gather together or when they wanted to be alone. They moaned when I had a sub and cheered when I would come back.

"Mom," they would call me, when they needed advice or when I was giving it out when they didn't ask for it.

Sometime around October I introduced literature circles, or lit circles. Lit circles have been around since long before "lit" would become a slang term for partying– since then, calling them lit circles in class has become way more entertaining for the students.

"So the idea behind lit circles," I explained, "Is that you will choose the book you are going to read. I am going to give you a list to choose from, but you will do the research and pick which one you think interests you most."

"But what if none of them are interesting?" There's always one of those students.

"That's why I said *most.* There's always one that's more interesting than others. Then, you will meet weekly with the other students who are reading your book, and discuss. Does that make sense? Keep in mind this is the bare bones, we will get into the details when we actually choose our books."

"Are these going to be boring books?"

I smiled – time to pull out my favorite line. "Only boring people are bored. And no, these are some of my favorite books. Here, I'll tell you about them." The students listened intently as I went through a quick book talk about each book. Some were already begging to borrow my copies, and others were signing up for their first choice so they knew no one else will snatch it from them.

When they got into their lit circles for the first time, I was amazed at how into it the majority of them are. One group was reading *Oryx and Crake* by Margaret Atwood and their discussion of bioengineering becomes so intense they didn't even notice when the class is over. Another group was reading *One Flew over the Cuckoo's Nest* by Ken Kesey, which I was rereading along with them. As I read, I made this note in my journal on October 23rd:

> Just started reading *One Flew Over The Cuckoo's Nest* today during fourth period. Reminded me of the time they finally let me take a shower in the psych ward - how I couldn't even get up off the floor. No wonder they thought I was crazy.
>
> "Is it actually like that in the loony bin?" One student asked no one in particular.
>
> "Yes," I heard myself saying, though my voice sounded far away.
>
> And the psych ward was frightening. It was just frightening. There's no way to describe it other than go look at the movie, *One Flew over the Cuckoo's Nest*. It hasn't changed in forty years. It's exactly the same.

-Dad

“How do you know?” The student looked at me. “Have you been in one?”

Do I answer this question? If I answer this question, am I setting myself up for something terrible down the line? Where is the line between being truthful with students and oversharing? I took a shot.

“Yes, I have.”

“What?” Now the whole group was listening, but thankfully the rest of the groups were still engaged with each other. “What happened?”

“Do you really want to know?”

“Yes!”

“Okay, it’s kind of a long story…” and I told the story, at least a shortened version of it.

“That must have been awful.”

“It was.”

“Hey,” one student said. “On our paper it says we are supposed to make a connection between something that happened in the book with something that happened in real life. Can we use you as the example?”

“Sure,” I said. They got back to work.

I felt as though something was lifted off of me that day – all the stigma I carried about being sick and the things I had gone through, my fear of someone finding out that I had this experience, it all went away when I simply just talked about it.

A few weeks later, our principal announced he was moving to another school and a new principal took his place. It was not long before I found myself in the new principal’s office, though I did not know what for.

"Hello, Mrs. Parke," he said. He was the complete opposite of the old principal – short and pale and bearded. "Do you know anything about the AP Capstone program?"

"No, not at all."

"Well, it's a new program we're starting here next year, and I'd like to put you in charge of it."

"Okay, sounds good so far," I replied.

"So, you would be teaching a course on how to conduct research, and we thought with your background you would be the perfect person for the job."

This was the first time in my career I can every remember someone telling me that I had come to mind when they were thinking of who to put in a particular position.

"That sounds right up my alley."

"I thought so. I'll get you more information on training and stuff when it get to me."

"Thank you so much."

I had been teased with the offer of AP courses at Southeast for eight years. I liked teaching regular classes, do not get me wrong, but sometimes you dream about teaching the higher level courses. And this course? I could develop my own curriculum and start the program from scratch?

When I got home and told my husband, he was ecstatic.

"It's about time you got the recognition you deserve."

Later that week I wrote in my researcher reflective journal on November 8th:

> I love my job, I love my kids, I love teaching. I love being here. I love getting to know their quirks and idiosyncrasies, their plans and wants, needs. Watching their brains work as they type on the laptops. I think I love my job again.

On October 26th, I met my dad at the football stadium for a game. He is a long-time fan and season ticket-holder, and I started buying season tickets a few years ago. Often I go to the games alone but meet my dad there, as Mark has nothing but disdain for our local NFL team. Two of my friends – a couple – have season tickets as well, and we often meet up during half-time of the game to spend time together.

This time, we had a lot of catching up to do – we had not seen each other in months. Naturally, we dallied a bit and it was about five minutes into the third quarter when I finally went back to my seat.

"Where were you?" my father asked in a frantic tone."

"I was talking to my friends…"

"I was terrified you had wandered off."

My dad had decided that I had wandered off from the game without telling anyone. Not only that, but he had called my mother and Mark as well. When I checked my phone, I had a message from Mark: "Where are you? Call me now." I texted him and let him know that I was fine, I was just with our friends and I never wandered off anywhere.

"God," he responded, "your parents need to calm down."

I agreed. I was angry – was this how the rest of my life was going to be? I could not be left alone for 5 minutes without someone thinking that I had wandered off or lost my senses? It had been seven months since I was released from the hospital, and not once had I given anyone any reason to doubt my sanity. They trusted me to drive forty minutes to work every day, teach, and come home, but not to make my way back to my seats during a football game?

Fatten the Arsenal

During my tenure as graduate student at the university, during both my Master's and Doctoral courses, one of the professors repeatedly stressed some tips for having a successful career. First, avoid negative conversations with other teachers at your school, and associate with other professionals who loved what they did. Second, read your professional journals. Third, attend your professional conferences. The first had been nearly unavoidable for me at Southwest – almost every conversation was negative. Now at Edinburgh, it was hard to be negative around such unfailingly positive people, like the 30 year English teacher whose mermaid blonde hair always entered the room before she did, who wore the school colors every game day without fail, and who somehow managed to attend every single school event, even when they occurred at the same time. It is entirely possible that people like this worked at Southwest as well, and I had just never encountered them in my seven years there. But at Edinburgh, they were everywhere.

Because I was still engrossed in my doctoral studies, meeting number two was simple. I continued to read and subscribe to professional journals, staying on top of the English Education world. The third, however, I had yet to conquer. Though I had attended one small conference two years previous, I had not attended or presented at any conferences since.

That November, I headed to Washington D.C. to attend my first National Council of Teachers of English (NCTE) National Convention. I had been accepted as a presenter with another cohort member. I would finally get the chance to present at a major national conference. Not only that, but I would also have the opportunity to take a mini-vacation – a hotel room all to myself and time to just relax.

The day I arrived at the hotel – a garish, over-sized behemoth with a courtyard big enough to hold an homage to a New England seaport, with fake cobblestone streets and storefront facades – I checked in and immediately took advantage of the wonderful November weather – I put on my running gear and rushed outside. A path ran by the Potomac, and I followed it across the river and halfway to the Washington monument. I was out of breath and sweating, but the cold wind on my face felt better than anything I had felt in a long time.

After that, I went to lunch with Kristen and Jean from my doctoral cohort, who snuck me into the luncheon they were scheduled to attend. We talked about our trips into the city and I told them about my run ad how wonderful it felt outside.

“But have you been to the exhibit hall yet?” Kristen asked.

“No… what’s there?”

“Oh my god, you just have to see it.”

Naturally, that was my next stop. And it did not disappoint. Publishing companies and agencies in little booths throughout the spacious ballroom, handing out free pens and tote bags and most importantly, free books. So many free books. But not just regular books, no – these were Young Adult novels.

Until recently, I would have proudly labeled myself a literary snob. If it was not a “work of literature,” I would not go near it. I scoffed at my mother’s beach readings and rolled my eyes at every *Hunger Games/Divergent/Maze Runner* copy that came down the pike. Never mind the fact that my favorite books of all time were young adult (YA) novels – *The Giver*, *The Vampire Diaries*, now that I was an adult I thought they were not for me. But these ones were free, and they were quick reads, so why not?

I became obsessed. Between my haul from NCTE 2014 and NCTE 2015, I must have read about twenty YA novels in the past two years. I began to think about how I could bring these works into the classroom, other than just setting them on the shelf and letting them gather dust. I started to rethink my curriculum, to plan how to include more YA lit in student reading. The next school year, I would make this plan a reality and work to pair YA novels with classics that we read in class. For the rest of the current school year, I worked to integrate YA literature as much as I could within the curriculum the English department had planned.

After Christmas break, I had my final check up with my new neurologist. He showed me results from my latest MRI, showed me that there were no new lesions on my brain and that there was no sign of continuing problems. When I left his office, I got in my car and started to cry.

Who Put Me in Charge?

That spring, I received my first class of wide-eyed undergraduates as I taught the high school methods course as a graduate assistant. It would be a lot of work maintaining a full-time high school job and also teaching at the university at night, but I was willing to give it a shot. I could not wait to get my own office, even if I shared with Kristen and another graduate student I had never met. I had my own desk, my own bookshelves, and a mini-fridge we all shared. I had my own key and my name on the door. It was perfect.

I had forgotten how eager undergraduates could be – several e-mailed me to introduce themselves before the first class. It worked – I remembered who they were when I called their names on the first night of school. I made it a point to save time at the end of every class for us to simply discuss and digest everything we had learned and done that week – it was also a way to save my sanity at the end of a very full day of teaching from 7 AM to 8 PM.

One group of students was reading a book about teaching students critical readings of texts.

"I'm worried that I haven't read a lot of the classics that I'll be asked to teach," one student said during our discussion time."

"I feel like I'm not well-read," another agreed. "I didn't read a lot in high school, and now I feel like there's no time for it."

"Is it really important for us to have read all of these books?"

A couple years ago and my answer would have been a resounding, "Yes, what the hell are you doing? Go read some damn books!" But as I looked at these students who were so passionate about teaching, passionate about reading and writing, and passionate about students, I thought back over the past half-year at Edinburgh High School. Why was I successful? I knew the novels I taught backwards and forwards, but not because I was a scholar of literature (though I am), but mostly because I taught them a thousand times. It was the students who made me successful, and my relationships with them. When I started to care about them and who they were as individuals, teaching the novels came easy.

"The novels and your knowledge of them will come," I told my class. "Your concern is to teach these kids the skills they need, and to teach them that reading isn't awful, like some of you believed in high school." They laughed a little but I could tell some of them were still nervous about the names being batted around in sample unit plans. Names they knew, but had not read (Fitzgerald, Twain, Hemingway), and names they had never heard at all (Hurston, Tan, Atwood, Kingsolver).

"When I first became a teacher," I continued, "I was having a conversation with another new teacher, a friend of mine from way back. Her mother was also an educator, life-long. She and her mother were having a debate as to what makes a better teacher. Is it the ability to teach, or knowledge of the subject matter?"

"What did you say?" A young woman asked.

"I said that I thought in order to be a good teacher, you had to have command of your subject matter. The teaching part would come later. My friend agreed with me. Her mother, however, did not.

"But if you asked me that same question today, I would give you the opposite answer. The knowledge of English and novels can be learned, but to teach? You have to be able to do that first. I'm convinced. And looking back, I think we should have listened to her mother – after all, she had been in the field a lot longer than we had." I had not thought about that conversation in years, but it seemed so poignant in that moment.

The desire to teach – that made the difference. When I was discharged from the hospital with no job and no idea if I was going to fully recover, the threat that I was never going to teach again was real. And it was frightening. I had been given another opportunity, a chance to teach when I thought I might never have that chance. I had not realized how prevalent that drive and desire to teach had been until I had almost lost it.

Zines

May, 2015

The final activity for my students that year was something I had toyed with for a while but never got around to trying with my former students. I decided that I would have them spend some time doing some personal writing, and then we would turn our personal writing into 'zines.' The idea had come from a friend of mine who held a "zine fest" for our city.

The students were fascinated by this assignment because the parameters were few – they could write about whatever they wanted (within reason), and include pictures they drew, magazine cutouts, whatever they wanted. It could be poetry, fiction, nonfiction, memoir, song lyrics… as long as it was mostly original (some students chose to do “found” poetry – poetry that uses existing pieces of text to form new poems).

As the kids worked on their writing, I joined in and did some writing of my own. I sat down and started writing this poem:

I used to lock my door.
Every morning, lunch, and afternoon
Without fail.

There was a trick to it –
I could unlock it just enough to open it
But not enough to let anyone else in.
That’s how I liked it.
Locked,
Alone.

I needed the “me time,” I said.
I need to think, I said.
To grade, to plan, to relax.
To browse the internet and catch up on Facebook.

But this year –
There was something different.

It was too weird

To keep them out and me in

So I unlocked my door and haven't locked it since. (May 3rd, 2015)

In my dreams, I was not always so sure of myself. I logged them in my journal:

"I had a dream where I was headed to work after the gym and even though I left the gym at 4 AM, I was late to work by over an hour. It was the morning after Spring Break. I called Mark because I was late and freaking out. He told me to pull over and he was going to come get me. I knew what that meant - that meant that he know I was losing it again. I started to protest but I stopped - I said okay, that he could come and get me." (May 15th, 2015)

Later:

"I had a dream last night that I was giving a speech but when I went to read, the sentences were all nonsense and awful. I stopped reading a bunch of times and finally gave up." (August 6th, 2015)

The dreams always seemed real. They reminded me of when I was in the hospital and believed that my dreams were real. Would I ever get out of these? Do they ever stop?

But What About Now?

It was only the first week of the 2015-2016 school year when I got suckered into something because of a student.

My new students were great – so full of personality and interests and different knowledge. One student in particular, Portia, stood out. She was one of those impossibly with-it students, the ones who take every advanced class AND run student government AND are in the band AND somehow have time outside all that to have some unusual and fascinating hobby.

“So, Mrs. Parke,” she said one day, “how busy are you?”

I laughed.

“I mean,” she continued, “I know you are in grad school and have a kid and all, but do you have any free time?”

“Where is this going?”

“Well,” now she put on her nicest smile, “the junior class needs a sponsor,” she paused and then let the rest of the sentence fall out like one long word, “and you wouldn’t really have to do anything, just plan the homecoming parade, which isn’t that big a deal, and maybe you might have to do prom somewhere down the line but they also said they might get a separate person to do prom so probably not and I’d do most of the work anyway.”

Notice how she snuck prom in there so casually?

I am not a fan of sponsoring things. I had been in charge of two school clubs at Southwest – a club that worked with a now defunct charity attempting to build schools in Uganda, and the Gay Straight Alliance. I chose to sponsor the latter because it required little effort on my part, just spending some time hanging out with some cool kids. But junior class sponsor? Filling out activity request forms, handling money?

I looked at her big, brown, pleading eyes. I had enough on my plate – a kid, a job, a dissertation to write - but I just could not tell her “no”. Somehow, the hard, strict teacher I had been at Southwest High School had turned into a giant softie. So I told her:

“If you can’t find anyone else to do it, I guess I can.”

I’m pretty sure she stopped looking after that.

I caught the school spirit bug pretty quickly. Between designing shirts for the junior class and organizing the homecoming parade, I became a believer. I brought my daughter to the parade and to the homecoming game, and even bought her a little red and black pom-pom to wave.

But that was just the beginning.

Soon, I was going to see my students in community theater productions, in band and chorus concerts, district volleyball games, any chance I could get. I had always known that students really appreciate a teacher who takes time out of their schedule to support them, but I had never really done it outside of the odd chaperone gig, most of which I agreed to because they benefited me in some way.

I found that this benefitted me as well. The students felt like they mattered, that I cared about them – and I did. The other teachers saw how involved I was, and so did the administration. Faith, my former mentor and close friend, noticed that my outlook had changed over the past two years:

> I don't think I've heard you say a negative thing since all of this, you know? You always turn it into a positive, and we don't always do that…. You've been very excited to try new things, and so excited to get this brand-new class and do this all this curriculum, so I think it's just all… and not that you were negative before, but we all get frustrated and it's the most frustrating profession ever, and I don't think I've heard you say one thing in any sort of frustrated way. (June 12th, 2016)

And yes, I planned prom.

The most stressful week is the week before prom. We held the last day of ticket sales on a Monday. The line was out the door during lunch, and almost an hour long after school (students are notorious procrastinators), but at the end of that day we made sure that every single senior that wanted to go to prom had a ticket in their hand.

My administration, in their infinite wisdom, had scheduled prom for a Friday – the 13th. With a full moon. We spent the majority of the week painting decorations in my classroom – my students would work on their final projects and the junior class officers would come in and paint. We went with *The Great Gatsby* as our theme, and I have vowed to only do literary themes as long as I am in charge of prom.

The night of prom, the venue was lovely and covered in black and gold decorations – it looked downright opulent. The best part of the night, however, was seeing the kid's faces as they saw how beautiful everything looked.

"Awesome job, Mrs. Parke," I heard all night long. It never got old.

My favorite memory from the night was towards the end. As the junior sponsor, my job is to stay until the end of the prom, even though the crowd had dwindled down. One of the last songs the DJ played was "Shut Up and Dance" by Walk the Moon, and as soon as I heard it I ran out to the dance floor. The only kids left were three of my students, and together we jumped up and down and sang the lyrics together. One of those students, a lonely, creative kid who was having a bad year and had been very melancholy recently, was jumping with us. After the song he stopped me and said:

"Thank you for the best night of my life."

"It's not fair," Cam, the teacher across the hall, said one day. We had a running joke that he was always the bearer of bad news.

"What's not fair?"

"I used to be the cool teacher," he whined in a playful way. "They all used to come hang out in my room during lunch, come to me for advice, but noooo." He smirked. "Now it's all 'Mrs. Parke this,' and 'Mrs. Parke that.'"

"That's right," I returned the smirk. "*I'm* the cool teacher now.

CHAPTER FIVE:

ANALYSIS, FINDINGS, AND REFLECTIONS

Epilogue

On my long drive to work, sometimes I pass the time by having imaginary conversations with people I honestly hope to never see again. I practice what I would say to them if I had the opportunity and all the odds were in my favor. This morning, that conversation was with the principal of Southwest High School.

I would tell him what a mistake he had made, and that it was the decisions he had made and the policies and curriculum he had implemented that had made me an ineffective teacher, that my constant fear of retribution kept me in line. That some of my colleagues were miserable, and their constant complaining made me just as miserable as them.

Mostly I would tell him what a huge favor he had done me. The truth is, I had been looking for a way out for a while, but every route I tried was a dead end. It took a month long stay in the hospital and endless anxiety to get where I needed to be.

I thought about this imaginary conversation at Edinburgh High School's last graduation, I got chills as I watched the bagpipers lead the graduates down the aisles and on to the stage. I looked around at my coworkers who were just so excited to be there and to cheer on the students who they had worked with for the past four years. I miss Southwest High School sometimes – my old students, the faculty, and staff - but I do not think I would go back, even if offered the perfect position.

Writing this autoethnography has provided me the time to actually sit down and think about my teaching practice and how I have changed over the past two years – it is an opportunity I might not have had otherwise. The process has felt like a type of closure; as my husband said to me in the car the other day, "I can't wait until you are done so we can finally put this whole thing behind us." I do not know that it is that simplistic. We tend to measure things in milestones: a birthday, an anniversary, a graduation, but when we are talking about the construction and development of identity, there are no set milestones.

Analysis

According to Richardson (1994), the goals of autoethnography are coherence, verisimilitude, and interest. With this autoethnography, I had worked hard try to make this experience as true and real as it seemed to me. Each moment is related back as I remembered it, and as I wrote I found I would remember more and more details. The dialogue is in no way meant to be a verbatim reconstruction of the conversations I had, but they convey the basic gist of what was said.

This is not a work of fiction – everything in it is exactly as it happened to me, with the only the names and places changed for the anonymity of my participants. In an effort to reach verisimilitude, I have tried to make the work "real" by painting a vibrant picture of my actions, feelings, and thoughts. I have also explored the "facticities" (Denzin, 2014) that appear when we add the experiences and perspectives of others to our own experiences.

The data analysis process for this study was recursive. As I wrote, I discovered emerging themes and identified them. Then, as I continued to write, I began to think about where I can address those themes in my narrative. I then reflected on my research questions, and focused my themes on their relation to those questions.

Writing about trauma is a difficult process, though it often becomes easier as one gets further away from the trauma (Smyth and Pennebaker, 1999). Ellis (2004) insists that the writer should approach the situation before they are too far removed from it. I began writing about my experience directly after I was released from the hospital, and continued to work on it for the next two years. In this regard, I have both addressed it while it was fresh and allowed it to simmer until it was at a comfortable distance.

Table A: themes (left column) and how they lead to the findings (right column)

Themes	**Findings**
Question One: **Finding Confidence** **Question Two:** **Struggles with Confidence** **Identity as Patient** **Question Three:** **Reading as a method of healing** **Writing the Narrative**	**Confidence and Teacher Identity**
Question One: **Effects of coworkers on identity** **Transition from pedagogue to facilitator** **Sharing my identity** **Question Two:** **Core Identity** **Identity as reader and writer** **Question Three:** **Writing the Narrative**	**Flat to Round Teaching**

Research Question One

How and in what ways has my identity as a teacher shifted as a result of my experience with major illness?

This question deals mainly with the idea of teacher identity – how my teacher identity has been affected by not only my illness, but also all the things that followed it. By teacher identity, I am not talking merely about the behaviors of a teacher, but also how I saw myself as a teacher and the kind of teacher I was/am.

As I wrote this narrative, and as I interviewed my participants, I began to wonder what was the major catalyst in my shift of teacher identity. Was it the experience with illness, a brush with death? Or was it the change of environments and staff that was the biggest influence? In reviewing the narrative as well as my interviews, the resounding answer seems to be a mixture of both – that I would not have one without the other. Therefore, I see both my illness as well as my new job as part of the same overall experience.

Effect of coworkers on identity. One theme I identified was the role my coworkers played on my identity as a teacher. In my narrative, I repeatedly mention my feelings about my coworkers at Southwest. I discuss how I felt unnecessary and even burdensome there. As I wrote, however, I found that this did not come up in my story as much as I thought. One thing I mentioned was the amount of gossip that surrounded every movement at that school. Against the best advice of one of my professors, I engaged in and became part of this process at Southwest, and it changed me as a teacher.

On the contrary, I write about the staff at Edinburgh High School as welcoming, some in even glowing terms. I see the change in work environment as a possible influence on my change in teacher identity. The idea that interactions with other teachers, both at Southwest and

Edinburgh, played a part in the construction of my teacher identities reflects back to Gee's (2001) idea of identity construction. Identities are not only constructed by the self, but also through our interactions with those around us.

Finding confidence. In the narrative, the period when I returned to Southwest High School before moving on appears as a period of "shattered self" (Bevilacqua, 2005). My coworker, Marjorie, described me as being arrogant in a way that indicated a lack of confidence. It seems as though I was trying to prove my intelligence, prove that I belonged. I would constantly talk about my achievements and laud myself above others because I did not believe, at my core, that I was good or smart enough. When I moved to Edinburgh High Schol, I was still dealing with that lack of confidence. The ability to enter a new classroom at a new school, where the rumors of my illness had not followed me, allowed me to begin to gain that confidence back.

Rebuilding confidence in the classroom also took the form of finding and developing new curriculum in the classroom, such as the literature circles and the zine activity. Schools that allow teachers to try new, innovative curriculum have happier teachers (Davies, 2013), and allowing me the space to try new things and experiment also helped me to earn back my confidence. Confidence also appears as a theme in regards to my second research question, which I will address later.

Transition from pedagogue to facilitator. English teachers often feel a divide between acting as a pedagogue of literature and focusing more on critical thinking (Doecke, Locke, & Petrosky, 2004). When I started my practice of teaching, I was definitely the kind of teacher who thought of herself as the "protector" of culture, that it was my job to ensure the next generation would revere Shelley and Shakespeare. Looking through my narrative, it is clear that my focus has shifted toward the teacher as facilitator. As I read over the section about teaching the undergraduate class, I am reminded how monumentally my views of teaching have shifted. The conversations with the undergraduates helped me form my ideas on who I was as a teacher. As I reflected in my narrative on my time spent teaching the undergraduate course, I realized how many epiphanies I had about teaching while I was engaging in conversation with these aspiring teachers. It was a unique situation, as I had just embarked on my first year at Edinburgh High School and was much like a new teacher myself. These students were full of hope, and they reminded me that there are so many wonderful things about teaching that I had forgotten about over the years.

When I recall the story to the undergraduate class about a conversation I had concerning what a good teacher is, my shift in teacher philosophy is evident. Whereas when I first started, I would have believed that knowledge of English language and literature trumped anything else, I believe something different now, something that fits more in tune with the idea of the teacher as facilitator. That is not to say that a teacher does not need to know their content area, just that there are more important and less tangible aspects of teaching that make a successful teacher.

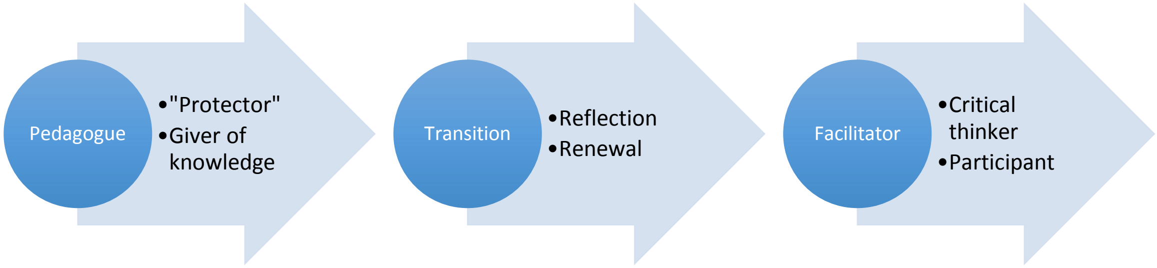

Figure 3: Transition from pedagogue to facilitator

Sharing my identity. In my narrative, I recall an incident where the students were reading *One Flew Over the Cuckoo's Nest.* In this scene I see the shift in teacher identity prevalent – the old teacher would never have divulged such personal information to students. Becoming more open with the students has changed the way I practice teaching for the better (Danielwicz, 2001). In being more open with the students, I would like to think they see me as a person who is willing to admit her faults and recognize when she is wrong, and encourage them to make mistakes and learn from them.

In order to become the reflective teacher that I knew I could be, I had to allow my core identity to become part of my teacher identity. This core reflection "provides a process for discerning, developing, and learning to draw upon the qualities and commitments already present within one's self" (Korthagen, 2012, p. 47). By aligning my teacher identity with my other identities, such as my identity as a student (learning as a life-long endeavor), mother (care-giver), reader, and writer, I am able to become more of the type of teacher I hoped to be. The process of aligning these identities was a slow process. In my narrative, I recounted my life at Edinburgh High School, which I see as a direct effect of my illness – without the one, I would not have the other. As I began to share who I was at the core with my students – a caring person with a passion for learning – I began to align those qualities with my teacher identity.

Research Question Two

How and in what ways have other aspects of my identity shifted as a result of my illness?

In looking at the narrative for shifts in personal identity, I identified several areas of interest. The first theme that I noted was the idea of a core identity, an identity that I maintained even when all other facets of identity fell away. The other aspects of identity that were prevalent in the narrative were my identities as reader and writer, and my identity as a patient.

Core identity. During my husband's interview, he kept returning to the idea of "default programming," and the computer metaphor was one that most of my family members mentioned. Mark refers to this default programming as the most basic level of my personality, who I am at the core. During the worst of my disease, he described it as my "base self," saying: "I attribute that to just your sheer force of will… that whatever makes you innately you, that is so fundamental and so strong that through all this external emotional stuff, the headaches, the illnesses, the reduction of the ego, all of that you just fell back on your default programming."

The idea of there being a basic, bottom level "Erin" at the core of my identity is fascinating to me. The idea of having a base self seems more philosophical than scientific, and is up for debate in the psychological realm (Khilstrom, 2012; Klein, 2014). According to Korthagen (2012), the successful teacher must look into this core identity in order to discover what type of teacher they might become. My husband describes me at my base level as someone who is headstrong and determined, qualities that I consider boons to my identity and if that is who I am at the core, then I am okay with that. In teaching, I have found this determination to be beneficial when dealing with difficult students. I have also seen this quality work against me, such as when I was at Southwest High School and would refuse to reconsider my teaching style.

Struggles with confidence. Confidence emerges again as a theme here. My struggle with confidence is related to this idea of a core identity. Bartlett (2007) argues that we must convince ourselves of these identities, and as I read about my return to Southwest and the reactions from my coworkers that I often came off as "being mean," I see this as an act of trying to convince myself that I was the intelligent person I had always prided myself on. Similarly, when I was not able to convince myself of this, I found myself struggling with my personal identity, as when I would find myself unable, and later afraid, to add to my class conversations.

As I have gone through the recovery process, I found that these struggles with confidence still occur, but on a much smaller scale. The episode I mention in chapter four about the football game with my family is a good example – their lack of trust that I was fully in control of myself caused a huge step back in my belief in my capabilities. At the time, I was back in the classroom at Edinburgh, and was still struggling to find the right footing in the classroom. In my personal life, I was still struggling with some words and relearning vocabulary, but also I was still earning back the trust of my family. With my professional and personal life combined, the struggle with confidence took over every facet.

Identity as patient. Looking over the narrative, I noticed that I spent a lot of time recounting what happened while I was in the psychiatric ward. I interpret the prevalence of this period two ways. The simplest explanation is that this is the period I remember the most about, the only part where I can recall specific scenes and conversations. Another reason occurred to me as I was going through the writing process – this is where I felt my identity was stripped away from me. The dehumanization, the over-medication, everything led me to, in the words of my husband, “give up.”

Looking over the orientation materials from the psych ward, I was struck by how much a person is stripped of the things that make them unique when they enter into that building. Reading the dress code from the patient packet, I could not help but be reminded of the student dress codes, which I mention in chapter four. Over the past two years at Edinburgh I have become more vocal with the students and staff on my dislike of the school dress code, and I cannot help but see a connection between my experiences and the experiences of the students.

A common theme that kept popping up during the interviews was the idea that I did not "belong" in the psych ward. As my father put it, and I mentioned in Chapter Four, "you aren't that person. That isn't your issue." Yet, with everyone convinced I was in the wrong place, there must have been some part of them that believed it could be possible, that the stress of graduate school, work, and motherhood finally got to me. If they truly believed I did not belong there, I must wonder why they did not try to get me released. However, my own view of my identity, in what my husband calls my "base self," never allowed me to see that this could have been the problem. "I'm fine" is the resounding chorus they heard from me, and the truth in it seems that I knew, at my core, that I was not crazy, though my medical records still list me as having psychosis as an ongoing diagnosis. On the other hand, had I not been admitted to the psych ward, I would not have had the benefit of a staff of nurses and doctors when I passed two pulmonary embolisms during the night. While I did not "belong" there, it was certainly where I needed to be in order to survive.

Identity as reader and writer. The way we interact with texts is affected by our identities (McCarthy and Moje, 2002). My various identities and their shifting statuses also affected how I interacted with texts and therefore affected my identity as a reader and writer. Before the encephalitis, I had not made time to read a book that was not part of my coursework in years. Since then, I have averaged about a book a week. Looking over the narrative, I see the idea of losing my identity as a reader as a driving force behind my desire to regain that identity. I talk about how I tried to read *Gone Girl* by Gillian Flynn in the hospital and then later after I got out, but it was only when I finally finished that book that I began to devour books again. Finishing that book helped me regain a love of reading, to rediscover that part of my identity.

In chapter four, the idea of writing appears repeatedly and in different forms. The prevalence of writing through my recovery experience, both in writing fiction and in writing autoethnography, shows the importance of my writer identity to my overall identity. The minute I was out of the hospital, my husband asked me what he could being me from home and my response was immediate: my laptop, and a copy of my novel I had printed when I had finished my first draft. I was searching for that identity, urging it back into existence after months of dormancy. Working on my own writing also allowed me to share my writer identity with the students. This is evident in the writing that I completed during class writing workshop sections, such as the poem shared in chapter four, or even this study, which I am not ashamed to say I worked on during class workshops.

Research Question Three

How can the writing of my autoethnography influence the healing process and my understanding of identity?

Reading as a method of healing. As I constructed my research questions, I did not consider the role that reading would play in the narrative of my recovery. In bibliotherapy (Wolpow & Askov, 2001), reading becomes a kind of therapy, particularly when reading works that mirror the experiences of the reader. Many of the works I read after my hospitalization dealt with psychiatric issues, issues of amnesia or forgetting, or I simply lost myself in endless amounts of science fiction.

Simply the act of reading was therapeutic as well, I spent the year after I was released from the hospital reading the entire *Outlander* series by Diana Gabaldon, a series I had always loved but only managed to make it through the fourth book. This time, I made it through the entire series – all eight books and 6,938 pages. After that, I moved on to the entire *Harry Potter* series, which I read the following summer. Completing these marathon reading sessions allowed me to not only learn to enjoy reading for pleasure again, but helped gain back some of that confidence that I had lost.

Writing the narrative. I looked at the process of writing the narrative as a healing exercise, a way to come to terms with my experience and perhaps gain some perspective on the process of recovery. Gere (2001) views the act of writing as a form of psychoanalysis. In going through the process of writing the narrative, in addition to the analysis of it, I have found some form of psychotherapy in it.

In the process of writing the autoethnography, I became an expert on anti-NMDA receptor encephalitis. Learning more about the disease through reading medical journals not only helped me write my narrative, it allowed me to gain a better understanding of how this disease works. As I continued to pull articles, I found myself looking for more answers: where does it come from (no one knows), why me (right age and gender), and is it gone for good (75% sure). I also got to learn many fun facts to pull out at parties, like Knut the famous polar bear (who I saw at the Berlin Zoo in 2013) died of anti-NMDA receptor encephalitis (Pruss et al, 2015) or that cats can carry anti-NMDA receptor encephalitis (Pakoszdy et al., 2012).

As I read I became angry when I would read cases in which the doctors saw a patient with my exact symptoms and immediately turned to encephalitis as a cause. In the years since I was diagnosed, the disease has become more well-known and is no longer last on most doctor’s lists. The process of researching the autoethnography led me to an uncommon understanding of the disease and my place in its history. More importantly, it helped me gain some sense of closure on my illness – knowing that I was not alone, that other people struggled with the same issue.

As I worked on this project, I also shared my work with my students. As I mentioned earlier, I would write during their writing workshops, but I would also let them know how my writing was going and share aspects of my process with them. In chapter four I mention the story about sharing my experience with the psychiatric ward, but I shared other aspects of my experience as well. Sharing this process with my students not only helped me in the writing of my dissertation, but also helped me teach the writing process to the students, particularly to give them some clue about the iterative nature of writing.

Findings

Teacher Confidence and Identity

The first finding that I uncovered from the analysis is the importance of confidence to the teacher identity. I am amazed at the role that confidence has played. If you asked anyone to describe me in one word, it would probably be "confident." Or arrogant, depending on who you were asking. I would have never thought that my struggle coming out of this illness would be my confidence – especially in the classroom, be it high school or graduate school.

Even the themes of reading and writing identity show a connection to issues of confidence. I wanted to see my novel because I wanted to prove to myself that I could write. I read everything in sight because I wanted to prove I could do it.

Finding confidence also meant accepting vulnerability. Part of my recovery has involved learning how to ask for help when help is needed. Before this experience, I was always the type of person who was unwilling to admit that they had no idea what they were doing. Afterwards, I have found a new kind of confidence in the ability to ask for clarification in the workplace, in the classroom, and in life.

Flat to Round Teaching

In reviewing the themes I identified from the narrative, it becomes clear that the most important revelation in this project has been the transition from one type of teacher to another. The teacher that I was before was static, flat. In reviewing the themes, it becomes clear that the increase of confidence, the transition to a facilitator teacher, and the involvement of self in the lives and learning of students resulted in a teacher who is more fully-developed and rounded. Though I would never advocate catching a rare disease, the disease was the catalyst that set this identity shift into motion.

So how did this shift occur? In my analysis, I found that there were many factors at work: a more like-minded faculty, a supportive administration, the transition to another school, supportive friends and family. All these combined with the experiences I had in the hospital – loss of agency and identity, having to relearn everything – shaped me into a different kind of teacher.

Significance of the Study

This study provides some insight into the experiences of teacher returning to the classroom after an extended illness. This study, though it is specific to my own experience, could help other teachers going through a similar transition to better understand their own experience. Reading about someone who has gone through something similar to you is a therapeutic experience (Wolpow & Askov, 2001).

This study also contributes to the literature regarding teacher identity, addressing gaps in the literature concerning that identity changing. Much of the literature concerning teacher identity focuses on teachers at the onset of the careers (Korthagen & Greene, 2012; Kempe & Reed, 2014) and does not address veteran teachers. Veteran teachers are just as likely to go through an identity shift as new teachers, particularly when faced with changing classrooms, grade levels, or schools.

Implications for Future Research

Implications for Teacher Research

The most important aspect of this study is the implications for further research in the lives of teachers. Specifically, what role does confidence play in teacher identity? Teachers who return to the classroom after an extended absence often report that they do not feel like they fit in any longer (Bevilaqua, 2005). What can be done to assist teachers in their return to the classroom?

Another area for continued research is the use of autoethnography as a tool for teacher identity. Writing this autoethnography has allowed me to look at my teaching practice holistically – how it relates to my personal life, and what aspects of my experience have shaped the teacher identity I now recognize as my own. Autoethnography can be a powerful tool for introspection. It allows the author to truly examine a particularly important moment in time and try to look at it from different angles.

Teacher researchers have a lot to gain from this type of autoethnographic study. This study has allowed me to look deeply at my teaching and how I became the teacher I am today, and where I can go moving forward. Regardless of whether or not another teacher has experienced illness or a change in employment like I have, she can use autoethnography to really examine her teaching.

Implications for Other Areas of Research

Anti-NMDA receptor encephalitis is still a relatively new disease, with a lot of unknowns. I hope that my story will help patients, doctors, and family members learn about the experience, first hand, of a patient with the disease. However, there needs to be more patient's voices in research. The patient's view and experience is a valuable addition to the medical field. Doctors often look for the symptoms of the disease instead of looking at the complete picture – a fuller view of the patient as a person and their thoughts and feelings may help to avoid some of the issues of misdiagnosis that I struggled with for months.

One aspect of this study that I would love to pursue in the future is the role of social media in the lives of patients with rare illness. As I was struggling to learn about my disease and figure out if it would ever come back, another woman on the same online forum in which Mark had found the answers he was looking for had a similar problem. She had some kind of strange neurological problem that included confusion, weakness, and fatigue. Like Mark and I, she turned to the online world to try to find answers. She now works for a non-profit (GBS-CIDP Foundation International) that advocates for people suffering from the same disease, ensuring that when patients go to the internet to find answers, they can find someone who has been through it as well.

Reflection

Writing this autoethnography has been a long time coming. I knew I was going to write it when I got out of the hospital – in fact, I knew I would write one long before any of this ever happened. When I first heard about autoethnography, I knew it was a research method that I was interested in. Apparently I just needed the right subject matter.

The process of writing this was exhausting, but I am sure that is the case for any kind of dissertation. However, in writing this dissertation I was forced to confront some uncomfortable ideas, and to reflect on the moments that I otherwise just would not have time for. I mentioned earlier that Mark told me he looked forward to me finishing my dissertation because then "this would all be over," I told him I didn't think it would ever be over. In some aspects, however, there is an end, and this work has certainly helped us, as a couple, address some issues that we had not confronted before.

On Confidence

While I was writing this section, I reflected a lot on confidence. When examining the theme of personal identity, one aspect of my identity that came up was confidence, or more importantly, a lack of it. As I am writing this paragraph, I am sitting in a training for a new course I will be teaching next year that aims to teach high school students college-level research methods.

During this training, I constantly have found myself in conversations where someone is complimenting me on my abilities and recommending that I pursue some leadership position. Before this experience, I may have played humble, but I would be agreeing with them in my mind. Now, these praises are welcome but from a different place – almost like a well that needs to be refilled in order to function.

Completing this project has also been about refilling the well. I had to prove that I could do it, that I could finish the marathon. In the past year, I have finished three literal half-marathons, and here is a figurative one to add to the collection. But this one matters most.

The Impact of this Study on the Researcher

Completing this project solidified my view of myself as a qualitative researcher, but also as an autoethnographer. I fell in love with the method when I first learned about it in Qualitative Methods 1, and though writing this work was emotionally taxing and hard work, there was also a sense of familiarity with it.

It is clear from my analysis and findings that I see this study as having helped me understand who I am as a teacher and how I ended up this way, but it also allowed me to fall back in love with creative writing. The last time I wrote a poem was in college, and my last short story was finished well before my daughter was born. Since I began this process, I have been jotting down ideas for stories and books, projects that I look forward to starting once this one is truly complete.

The other day, a student, Jorge, came to talk to me during final exams. He was bored – he is often bored, because he is much smarter than many of the other students and often finds himself out of things to do in class. We get along like gangbusters, though I often worry (and tell him as much) that he could very easily fall through the cracks, despite his obvious intelligence and great personality.

“What are you doing here?” I asked him, “shouldn’t you be taking an exam?”

“Man,” he said, “that class is such bullshit. He doesn’t teach us anything.” He began to fiddle with the variety of figurines I keep on my desk. “Besides, I finished my exam like, an hour ago. I have a pass.”

“Well, that’s okay, but you had better have an A in that class!”

“Oh don’t worry, it’s easy. I’ve got like, a 98 in that class.” He peeked over the desk to see what I was typing. “What are you working on?”

“My dissertation.”

“See! That’s what I’m talking about. I can’t wait to get to college and just work on the stuff that I want to work on. Like, stuff that’s actually interesting, not like these B.S. classes. No offense,” he adds as an afterthought. “I mean, your class is cool, and I really like English, but… you know what I mean.”

“Yeah, Jorge, I know exactly what you mean.”

“Alright, I’ll leave you alone so you can work on your stuff.” He got up to leave, then paused for a second. “It’s gonna be real cool when I get to call you Dr. Parke.”

“Yes, Jorge, that will be pretty cool.”

REFERENCES

Abrams, M. (2001). Resilience in ambiguous loss. *American Journal of Psychotherapy, 55*(2), 283-291.

Allen, K., & Piercy, F. (2005). Feminist autoethnography. In D. H. Sprenkle, *Research Methods in Family Therapy* (pp. 155-169). New York, NY: The Guilford Press.

Alsup, J. (2006). *Teacher identity discourses: Negotiating personal and professional spaces.* Urbana, Ill: National Council of teachers of English.

Ardovini, J. (2015). Consciousness-raising: A tool for feminist praxis in research and granting voice. *Theory in Action, 8*(1), 51-59.

Asbring, P. (2001). Chronic illness - a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing, 34*(3), 312-319.

Asztely, F., & Kumlien, E. (2012). The diagnosis and treatment of limbic encephalistis. *Acta Neurologica Scandanavica, 126*, 365-375.

Atkin, K., Stapley, S., & Easton, A. (2010). No one listens to me, nobody believes me: self management and the experience of living with encephalitis. *Social Science & Medicine, 71*(2), 386-393 8p. doi:10.1016/j.socscimed.2010.04.011

Baker, S. (2009). Tell it slant: History, memory, and imagination in the healing writing workshop. *Traumatology, 15*(4), 15-23.

Bartlett, L. (2007). To seem and to feel: Situated identities and literacy practices. *Teachers College Record*, *109*(1), 51-69.

Bach, L. J. (2014). Long term rehabilitation management and outcome of anti-NMDA receptor encephalitis: Case reports. *Neurorehabilitation, 35*(4), 863-875. doi:10.3233/NRE-141176

Bevilacqua, P. K. (2005). *Renegotiating identity: Exploring the impact of chronic illness on the identities of three high school teachers.* ProQuest Dissertations & Theses Full Text. (305363804).

Bochner, A. (2000). Criteria against ourselves. *Qualitative Inquiry, 6*, 266-272.

Bruner, J. (1986). *Actual minds, possible worlds.* Cambridge, MA: Harvard University Press.

Cahalan, S. (2012). *Brain on Fire: My Month of Madness.* New York, New York: Simon & Schuster.

Carter, N., Bryant-Lukosius, D., DiSenso, A., Blythe, J., & Neville, A. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum, 41*(5), 545-547.

Coia, L., & Taylor, M. (2013). Uncovering our feminist pedagogy: A co-autoethnography. *Studying teacher education, 9*(1), 3-17.

Cooper, P. (2014). Using writing as therapy: Finding identity. *British Journal of Occupational Therapy, 77*(12), 619-622.

Costa, L., & et al. (2012). Recovering our stories: a small act of resistance. *Studies in Social Justice*, *6*(1), 85-101.

Cremin, T., & Baker, S. (2014). Exploring the discursively constructed identities of a teacher-writer teaching writing. *English Teaching: Practice and Critique, 13*(3), 30-55.

Danielewicz, J. (2001). *Teaching selves: Identity, pedagogy, and teacher education.* Albany: State University of New York Press.

Davies, T. (2013). Incorporating Creativity into Teachers Practice and Self-Concept of Professional Identity. *Journal Of Educational Change, 14*(1), 51-71.

Denzin, N. (2014). *Interpretive Autoethnography.* Los Angeles: Sage Publishing.

Denzin, N., & Lincoln, Y. (2005). *The sage handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.

Dewar, A. L., & Lee, E. A. (2000). Bearing illness and injury. *Western Journal of Nursing Research, 22*(8), 912-926.

Dick, P. K. (1981). *Valis.* New York, New York: Random House.

Doecke, B., Locke, T. & Petrosky, A. (2004). Explaining ourselves (to ourselves) : English teachers, professional identity and change, *English in Australia*, no. 139, pp. 103-112.

Dyck, I. (1999). Body troubles: Women, the workplace, and negotiations of a disabled identity. In R. &. Butler, *Mind and body spaces: Geographies of illness, impairment and disability* (pp. 177-). Hoboken: Taylor & Francis.

Ellis, C. (1995). *Final negotiations: a story of love, loss, and chronic illness.* Philadelphia: Temple University Press.

Ellis, C. (2000). Creating criteria: An ethnographic short story. *Qualitative Inquiry, 6*(2), 273-277.

Ellis, C. (2004). *The ethnographic I : a methodological novel about autoethnography.* Walnut Creek, CA: AltaMira Press.

Evensen, J. e. (2012). Flat affect and social functioning: A 10 year follow-up study of first episode psychosis patients. *Schizophrenia Research, 139*(1-3), 99-104.

Fabris, E. (2014). Experiences labelled psychotic: a settler's autoethnography beyond psychosic narrative . Retrieved from ProQuest Dissertations and Theses.

Fitzgerald, F. S. (1925). *The Great Gatsby.* New York, New York: Scribner.

Frager, A. M. (1994). Teaching, writing, and identity. *Language Arts, 71,* 274-278.

Gaiman, N. (2002). *American Gods*. New York: HarperTorch.

Gee, J. P. (2000-2001). Identity as an analytic lens for research in education. *Review of Research in Education, 25*, 99-125.

Gere, A. (2001). Revealing silence: Rethinking personal writing. *College Composition and Communication, 53*(2).

Huan-Quan, L., Hong-Yan, Z., & Ling, C. (2015). Anti N-Methyl-D-Aspartate (NMDA) Receptor Encephalitis with Frustrated Diagnosis Course: A Case Report. *World Journal Of Neuroscience*, (5), 334.

Ioannidis, P., Papadopoulos, G., Koufou, E., Parissis, D., & Karacostas, D. (2015). Anti-NMDA receptor encephalitis possibly triggered by measles virus. *Acta Neurologica Belgica*, *115*(4), 801-802. doi:10.1007/s13760-015-0468-2

Janesick, V. (2003). *Stretching exercises for qualitative researchers.* Thousand Oaks, CA: Sage.

Kempe, E., & Reed, Y. (2014). Enabling/disabling English teachers' identities as innovative professionals. *English Teaching: Practice and Critique, 13*(3), 56-70.

Kesey, K. (1963). *One Flew Over the Cuckoos Nest.* New York: Signet.

Kihlstrom, J. F. (2012). Searching for the self in mind and brain. *Social Cognition*, *30*(4), 367-379. doi:10.1521/soco.2012.30.4.367

Klein, S.B. (2001). A self to remember: A cognitive neuropsychological perspective on how self creates memory and memory creates self. In C. Sedikides & M.B. Brewer (Eds.), Individual self, relational self, collective self (pp. 25–46). Philadelphia, PA: Psychology Press.

Korthagen, F. J., Kim, Y. M., & Greene, W. L. (2012). *Teaching and Learning from Within. [electronic resource] : A Core Reflection Approach to Quality and Inspiration in Education*. Hoboken : Taylor and Francis, 2012.

Lather, P. (1992). Critical frames in educational research: Feminist and post-structural persepctives. *Theory into practice, 31*(2), 87-99.

Lather, P. (2007). *Getting lost: Feminist efforts toward a double(d) science.* New York: SUNY Press.

Lewis, C. B. (2007). *Identity: Lost, found, and (re)constructed through healing narratives. an autoethnography of tragedy, travail, and triumph* (Order No. 3266065). Available from ProQuest Dissertations & Theses Global. (304834088). Retrieved from http://search.proquest.com/docview/304834088?accountid=14745

Liggens, J., Kearns, R. A., & Adams, P. J. (2013). Using autoethnography to reclaim the 'place of healing' in mental health care. *Social Science & Medicine, 91*, 105-109.

Lincoln, Y., & Denzin, N. (1994). The Fifth Movement. In N. K. Denzin, *Handbook of qualitative research* (pp. 575-586). Thousand Oaks: Sage.

Martinez, J. A. (2015). *Chronic illness in higher education: An autoethnography* (Order No. 1595011). Available from ProQuest Dissertations & Theses Global. (1710075112). Retrieved from http://search.proquest.com/docview/1710075112?accountid=14745

McCarthey, S. J. (2001). Identity construction in elementary readers and writers. *Reading Research Quarterly, 36*(2), 122-151. Retrieved from http://search.proquest.com/docview/212122290?accountid=14745

McCarthey, S. J., & Moje, E. B. (2002). Identity matters. *Reading Research Quarterly, 37*(2), 228-238.

McGonagle, A., & Barnes-Farrell, J. (2014). Chronic illness in the workplace: Stigma, identity threat, and strain. Stress & Health, 30 (4), 310-321.

Orgad, S. (2005) *Storytelling Online. Talking Breast Cancer on the Internet*. New York: Peter Lang.

Pakoszdy, A., Et al. (2012). Suspected limbic encephalitis and seizure in cats associated with voltage-gated poatassium channel (VGKC). *Journal of Veterinary Internal Medicine, 27*(1), 212-214.

Prüss, H., Leubner, J., Wenke, N. K., Czirják, G. Á., Szentiks, C. A., & Greenwood, A. D. (2015). Anti-NMDA Receptor Encephalitis in the Polar Bear (Ursus maritimus) Knut. *Scientific Reports*, 12805. doi:10.1038/srep12805

Riessman, C. K. (2015). Ruptures and sutures: Time, audience and identity in an illness narrative. *Sociology Of Health & Illness*, *37*(7), 1055-1071. doi:10.1111/1467-9566.12281

Richards, R. (2008). Writing the othered self: Autoethnography and the problem of objectification in writing about illness and disability. *Qualitative Health Research, 18*(12), 1717-1728.

Richardson, L. (1994). Writing: a method of inquiry. In N. K. Denzin, *Handbook of Qualitative Research* (pp. 516-529). Thousand Oaks: Sage.

Richardson, L. (1997). *Fields of play: Constructing an academic life.* New Brunswick: Rutgers University Press.

Richardson, L. (2000). Evaluating Ethnography. *Qualitative Inquiry*, *6*(2), 253-255.

Richardson, L. (2000). Writing: A method of inquiry. In N. D. (Eds), *Handbook of qualitative research* (2nd Edition ed.). Thousand Oaks, CA: Sage.

Rui-Jin, W., Bu-Dong, C., & Dong, Q. (2015). Anti-N-methyl-D-aspartate receptor encephalitis concomitant with multifocal subcortical white matter lesions on magnetic resonance imaging: a case report and review of the literature. *BMC Neurology, 15*(1), 1-4. doi:10.1186/s12883-015-0366-5

Sansing, L. H. (2007). A patient with encephalitis associated with NMDA receptor antibodies. *Nature Clinical Practice, 3*(5), 291-296.

Schneider, C. E. (2010). *Running for normalcy, identity development, and the disability blues: An autoethnography that explores one man's quest to understand his identity* (Order No. 3433981). Available from ProQuest Dissertations & Theses Global. (849651428). Retrieved from http://search.proquest.com/docview/849651428?accountid=14745

Smithies, C. (2007). If we held a reunion, would anyone come? In P. Lather, *Getting lost: Feminist efforts toward a double(d) science* (**pp.** 79-82). New York: SUNY.

Smyth, J. M., & Pennebaker, J. W. (1999). Sharing one’s story: Translating emotional experiences into words as a coping tool. In C. R. Snyder, *Coping: The psychology of what works* (pp. 70-89). New York: Oxford University Press.

Tarantino, K. L. (2016). *Framing the degree: An autoethnography of trauma in the graduate student experience* (Order No. 10111598). Available from ProQuest Dissertations & Theses Global. (1794166929). Retrieved from http://search.proquest.com/docview/1794166929?accountid=14745

Titulaer, M. J., & Dalmau, J. (2014). Seizures as first symptom of anti-NMDA receptor encephalitis are more common in men. *Neurology, 82*(7), 550-551.

Tsutsui, K. e. (2012). Anti-NMDA-receptorantibody detected in encephalitis, schizophrenia, and narcolepsy with psychotic features. *BMC Psychiatry, 12*(1), 37-45.

Vonnegut, K. (1973; 1991). *Slaughterhouse Five: Or, the Children's Crusade, a Duty Dance with Death.* New York: Dell.

Wagner, J. E. (2013). Quantitative FLAIR analysis indicates predominant affection of the amygdala in antibody-associated limbic encephalitis. *Epilepsia, 54*(9), 1679-1687.

Wallace, D. (1998). *Big Fish: A Novel of Mythic Proportions.* New York: Algonquin Books.

Watson, C. (2009). Picturing validity: Autoethnography and the representation of self? *Qualitative Inquiry, 15*(3), 526-544.

Weil, A. (2001). *The best of times: An autoethnography of a cerebral Vascular Accident.* ProQuest Dissertations and Theses.

Wolpow, R., & Askov, E. N. (2001). Widened frameworks and practice: from bibliotherapy to the literacy of testimony and witness. *Journal Of Adolescent & Adult Literacy, 44*(7), 606-609.

Young, E. (2001, Oct.). Autoimmune disease risk for teachers revealed. *Townsend Letter for Doctors and Patients*, 48.

Ytre-Arne, B. (2016). The Social Media Experiences of Long-term Patients: Illness, Identity, and Participation. *NORDICOM Review*, (1), 57. doi:10.1515/nor-2016-0002

Ziaeian, B., & Shamsa, K. (2015). Dazed, confused, and asystolic: Possible signs of anti-N-methyl-D-aspartate receptor encephalitis. *Texas Heart Institute Journal*, *42*(2), 175-177.

APPENDIX A:

INFORMED CONSENT

USF
UNIVERSITY OF
SOUTH FLORIDA

Informed Consent to Participate in Research Involving Minimal Risk

Information to Consider Before Taking Part in this Research Study

Pro # 00019826

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called:

Chasing zebras: rediscovering identity after illness

The person who is in charge of this research study is Erin Parke. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. She is being guided in this research by Dr. Patricia Jones.

The research will be conducted at the participant’s homes.

Purpose of the study

The purpose of this study is to explore the Principal Investigator’s identity after illness. The study will look at how identity changes after illness and how it effects the multiple facets of a person’s identity.

Why are you being asked to take part?

We are asking you to take part in this research study because you were a close friend or relative to the Principal Investigator during her illness and recovery, from January 2014-present.

Study Procedures:

If you take part in this study, you will be asked to:

- Agree to an audio and visual recording of an interview, approximately 1-2 hours in length
- Share your recollections about the Principal Investigator and her illness and recovery
- Conduct member checks of all transcripts to ensure accuracy

Total Number of Participants

About 6 individuals will take part in this study at USF.

Alternatives / Voluntary Participation / Withdrawal

You do not have to participate in this research study.

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

Benefits

We are unsure if you will receive any benefits by taking part in this research study.

Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Compensation

You will receive no payment or other compensation for taking part in this study.

Costs

It will not cost you anything to take part in the study.

Conflict of Interest Statement

There are no outstanding conflicts of interest in this study.

Privacy and Confidentiality

We will keep your study records private and confidential. Certain people may need to see your study records. Anyone who looks at your records must keep them confidential. These individuals include:

- The research team, including the Principal Investigator, study coordinator, and all other research staff.
- Certain government and university people who need to know more about the study, and individuals who provide oversight to ensure that we are doing the study in the right way.
- Any agency of the federal, state, or local government that regulates this research.
- The USF Institutional Review Board (IRB) and related staff who have oversight responsibilities for this study, including staff in USF Research Integrity and Compliance.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

A federal law called Title IX protects your right to be free from sexual discrimination, including sexual harassment and sexual violence. USF's Title IX policy requires certain USF employees to report sexual harassment or sexual violence against any USF employee, student or group, but does not require researchers to report sexual harassment or sexual violence when they learn about it as part of conducting an IRB-approved study. If, as part of this study, you tell us about any sexual harassment or sexual violence that has happened to you, including rape or sexual assault, we are not required to report it to the University. If you have questions about Title IX or USF's Title IX policy, please call USF's Office of Diversity, Inclusion & Equal Opportunity at (813) 974-4373.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an unanticipated problem, call Erin Parke at (727) 247-2578

If you have questions about your rights as a participant in this study, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638.

Consent to Take Part in this Research Study

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

____ ____________

Signature of Person Taking Part in Study Date

____

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in their primary language. This research subject has provided legally effective informed consent.

____ ______

Signature of Person obtaining Informed Consent Date

____

Printed Name of Person Obtaining Informed Consent

APPENDIX B:

INTERVIEW PROTOCOL

Interview Protocol:

Introduction: I would like to talk about my hospitalization in 2014. My goal for this interview is to be more of a conversation, however, I do have some questions to get us going. If you ever feel uncomfortable at any time during this interview, please let me know.

1. How would you describe your relationship to me?
2. How would you describe me to others?
3. What was your first indication that something was wrong?
4. What do you remember about my hospitalization?
    a. How did you find out?
    b. What did you do?
    c. How did you react?
5. What did you notice about my behavior and personality?
6. Would you say I have changed since then? How?

APPENDIX C:

IRB APPROVAL LETTER

USF
UNIVERSITY OF
SOUTH FLORIDA

RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-7091

April 4, 2016

Erin Parke
Teaching and Learning
Tampa, FL 33612

RE: **Expedited Approval for Initial Review**
IRB#: Pro00019826
Title: Chasing zebras: Rediscovering identity after illness

Study Approval Period: 4/2/2016 to 4/2/2017

Dear Ms. Parke:

On 4/2/2016, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

Approved
Item(s): Protocol
Document(s):
Protocol USF.docx

Consent/Assent Document(s)*:
Adult Consent, V#1, 3.24.16.pdf.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-

5638. Sincerely,

John A Schinka, Ph.D.

John Schinka, Ph.D., Chairperson
USF Institutional Review Board