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DEFINING DIAGNOSIS: A REFLEXIVE ACCOUNT OF A CHRONIC DIS-EASE PROCESS

By

Brandi Barnes

A Thesis

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Master of Arts

Major: Sociology

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DEDICATION

This thesis is dedicated to anyone who has ever felt as if they did not have a voice.

ACKNOWLEDGEMENTS

I would like to thank Drs. Carol Rambo, Gretchen Peterson and Wesley James for their unrelenting encouragement and support throughout this process. Special thanks to Dr. Rambo for believing in me, guiding me, and showing me the strength in myself when all I could see was weakness. It is difficult to say how much I value you and what you've taught me. Because of you, I've grown into someone I can respect. Thank you.

I would also like to thank Tj for all the late-night coffee conversations, for understanding all of my tears, challenging me when I need to be challenged, and being my best friend. I could not have done this without you. To my friend, Sean Bradley, who has saved my life a thousand ways. Your friendship means the world to me. And last, but certainly not least, I would like to thank my daughter Gracie. You constantly inspire me and continually light the darkness.

ABSTRACT

This is an autoethnographic account of the experience of living with chronic illness and a liminal status. This reflexive study is divided into three parts: 1) Lupus, the defining diagnosis, 2) Disease, identity and reevaluation 3) Dis-identification, chronic dis-ease, and liminality.

Throughout, music lyrics and my own poetry are used to represent my fluctuating identity.

Systemic lupus erythematosus (SLE) is a rare yet complex disease. The etiology is constantly questioned by doctors and not readily seen; it is both contested and invisible. Patients with this illness are highly stigmatized, and their psychological welfare can become neglected in a biomedical system that does not account for the overall well-being of patients. This case study addresses some potential consequences for an identity tarnished in this way. Misdiagnosis is sorely understudied throughout the literature and fails to account for the lived experience of the patient. This study seeks to fill these gaps.

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CHAPTER 1

LUPUS, THE DEFINING DIAGNOSIS

INTRODUCTION

This thesis is an autoethnographic layered account (Ronai 1995) that tracks the shifts in my cultural understanding of the medical system and the lived experience of chronic disease processes and their impact on the self. It is my hope that through writing this autoethnography, I will open up a dialogue with medical professionals, those who research the social aspects of chronic disease, those who are diagnosed with chronic illness, and loved ones and sympathetic others who live and learn with them. Autoethnography as a method allows me to draw on many resources to construct my account of living with chronic disease including my lived experiences, theories of self, theories of illness, poetry, song, and other relevant literatures. The layered account as a format serves to place myself within the social context of the medical experience, to understand my position as a researcher, and to keep check of my biases, beliefs and personal experiences of the patient-doctor relationship. Each layer of text is used to reveal levels of awareness that might otherwise remain experienced but hidden. Throughout this process I describe the experience of my medical journey, the emotional impact of the dis-ease process, and my reflexivity on the described experience. Asterisks (***) denote a shift in time, space, and voice. Poetry is *italicized* and centered on the page, and music is **bolded**, each representing a different voice within my identity.

I never wanted you or asked you to come

But you showed up invited

Like an unwanted pregnancy after a walk of shame
Doctors explained you to me and then gave you a name

PROLOGUE: DISEASE

I'm in pain most of the time. It feels like a fire has been set to the joints around my kneecaps. I have a difficult time walking when I get out of bed in the morning. I can't walk after getting off the couch. One foot in front of the other doesn't come easy; the pain is debilitating, and my bones hurt, everywhere. I don't understand the unexplained fevers, fatigue, digestive problems, and headaches. I'm still in my twenties, I shouldn't be feeling this bad. My general doctor is a little puzzled by the severity of my symptoms. He prescribes me pills to help me sleep, pills for the pain, and more pills for my anxiety; he then sends me to an orthopedic specialist. The Ortho doctor doesn't know the answer either but tells me that "he suspects an auto-immune disease." I don't know anything about auto-immune diseases, but I do know that the thoughts and questions are starting to spin out of control in my head. "What does this mean? I'm a little afraid. How do you know it's auto-immune? I've got to wait for the next doctor to tell me what the hell this is? Am I going to be okay?" And then I think, "I have children. This is wrong. You're wrong." The floor isn't open for much discussion, he's a very busy man and there are other patients waiting for him. He's sending me to a rheumatologist and then I am pleasantly dismissed. In turn, I dismiss his "suspected" diagnosis.

After ten vials of blood and an MRI, lupus is the name he gave it. Systemic lupus erythematosus (SLE) is the official name. I had already been diagnosed with fibromyalgia months earlier in the process and the doctor explained that this was really no surprise to him—they usually co-exist. I'm sitting on a blue pleather table in a little examining room. As he talks

to me, the doctor rolls himself around on a chair with wheels. The light in the room is bright and the space smells like Clorox. I'm hyper-sensitive to everything in the room—the smell burns the inside of my nose. He says “Lupus is a ‘son of a bitch’ because there’s no concrete explanation for a why a person gets it. It was most likely due to the annihilation of your immune system caused by the chemotherapy you had while fighting cancer a couple of years ago.” He explained that due to my medical history conjoined with that of both of my parents, he wasn’t going to give me a “rose colored glasses” prognosis. “The joint effort of both chronic illnesses—fibromyalgia and lupus—is the reason for all your pain and it will only increase with time,” he said, “but there are medications that can ‘manage’ this condition if you take them properly and follow my instructions.” I feel like I’ve just been kicked in my stomach as waves of nausea roll through my body. Cold sweat pops out on my forehead. My legs are dangling off the table; it’s too tall for my feet to touch the floor so one foot moves back and forth like it’s having a spasm. My hands are fidgeting with each other, they’re both cold and sweaty too. I think, “Why is it so bright in here? Why can’t I be as small as this room feels? I want to disappear.”

Sensing my extreme discomfort, the doctor moves me to his office for the remainder of my sentencing. His office is a large, beautiful, space with hardwood floors and a massive throw rug. Brown is the predominate color and it smells of leather, wood, and books. Bookshelves full of medical journals line one of the walls. His degrees and specialty certifications are in expensive frames on another wall—a testament to his success as a practitioner. The desk is a beautiful mahogany color, the centerpiece of the room. There is a large, plush, leather chair with metal grommets tracing the outline of the arms that occupies the space behind the desk—not pleather like in the examining rooms. Two identical leather chairs face his desk for the purposes of consultation. The list of what I “can’t do” and “shouldn’t do” followed. He explains, “Lupus is

an auto-immune disease, your immune system will continually be compromised.” He tells me about the medicinal regimen that needs to follow this new diagnosis. He says, “Under no uncertain terms are you to smoke, lupus attacks the organs, specifically, in many cases, the respiratory system.” When people die from this illness, “It never says lupus on the death certificate, it says things like pneumonia.” The room goes blurry, I am seeing everything through tunnel vision, everything except his lips which seem to be hyper-pronounced. I watch them with such concentration trying to absorb the words escaping from them—his voice becomes more and more muted.

“What did he just say about medicine”? “I can’t do what”? He continued to talk for several more minutes, maybe it was hours, but I can’t recall what he said until... “We can manage this condition, probably for a long time, but you need to take care of yourself.” Again, he reiterates, “With the medical history of both parents (my mother died at the age of 49), your case is a little more special. I’m sending you back to your primary doctor to manage you until he can’t anymore, at which point you’ll come back to me. You’ve already battled a round of cancer and considering the genetics, this isn’t the best news. I’m sorry.” I hear that with crystal clear clarity. I get up and walk out as the doctor gives me an affectionate squeeze on my shoulder. I’m numb and scared. I censor the tears that are trying to fall. I think to myself, “Don’t cry. Tears are a sign of weakness, an inward admission that you accept this. You are not weak. Let the anger take hold. It’s stronger. It will allow you to fight back.” I wipe my eyes and tell myself again, “Suck it up. Don’t be a baby.” Tears are a threat to my stability. I can’t wait to get in the car, a quiet place that belongs only to me, my own space where no doctors reside. All I want is music right now; the deep growl and pain in the voice of Melissa Etheridge. I don’t have a choice in anything that’s happened today, but I can still choose my music. I need to escape my head.

**I played the fool today
And I just dream of vanishing into the crowd
Longing for home again
But home is a feeling I buried in you
I'm alright, I'm alright
It only hurts when I breathe
And I can't ask for things to be still again....
My window through which nothing hides
And everything sees
I'm counting the signs
And cursing the miles in between
I'm alright, I'm alright, It only hurts when I breathe**

(Etheridge, Melissa 2002)

I want to be alone. My hands are trembling as I dig through my purse for a lighter. I light a cigarette in my first act of defiance. I realize that the doctor told me not to smoke “under no uncertain terms,” but now I’m going to smoke just because he told me not to! I inhale deeply and hold it in my lungs as long as I can. “He’s sorry”? I say out-loud to myself mockingly through a snarky little giggle. “No, I’m sorry that you’re such an asshole. My prognosis isn’t good because my genetics are shit? Fuck you. I don’t have time for this. I’m fine.” I need the anger to resolve my fear. I want to hit something, I need to scream. I’m so scared in this moment that I’m visibly shaking, and I feel utterly helpless. I call on my anger once more. “Stop being a baby! This is a lie, a cruel joke—it’s not real! “You’re sorry?? Yeah doc, me too. Me fucking too”! I have this conversation with myself in an attempt restore some type of balance to the turmoil I can’t get a

hold on... And I can't get a hold on it. I scan the I-pod for Melissa and turn the stereo up in my car as loud as I can stand it. I still refuse to cry. Instead, I scream the lyrics. The music is so loud it vibrates through my body. I recall seeing her on stage performing this very song. That was such a perfect night. I want to go back there. I just want to be lost in the music, in her voice, and feel nothing at all. I'm fine.

Music is an integral part of who I am. As a child, I sought out music for comfort when I couldn't handle the weight of what life would throw at me. I was blessed with a voice that was worthy of recognition except that I lacked the confidence to pursue it. Music is non-intrusive; it doesn't judge me for how I feel or my inability to cope with things that are, sometimes, bigger than me. The artists share in my pain, speak to my sadness, and occasionally, offer me hope; they speak when I can't. I turn on my playlist and sing myself to exhaustion or just scream if I want to, the musicians never care. I can tell a story through my music choices and have used this as a coping mechanism for many years. After I was diagnosed with lupus and the prologue of bullshit that followed, music remains my lifeline.

METHODS: AUTOETHNOGRAPHY

“Autoethnography is an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (Ellis, Adams, and Bochner 2011:1). It challenges the traditional methods in the way research is done and how it represents others (Spry 2001) and treats it as “a political, socially-just and socially conscious act” (Ellis et al. 2011:1). “A researcher uses tenets of

autobiography and ethnography to do and write autoethnography” rendering a method that is “both process and product” (Ellis et al. 2011:1).

Scholars from a wide range of disciplines have considered how social sciences would excel if research were closer to literature rather than physics, if stories were utilized rather than theory, and if research were “self-consciously value centered rather than pretending to be value free” (Ellis et al. 2011:2). Of particular interest, researchers “wanted to concentrate on ways of producing meaningful, accessible, and evocative research grounded in personal experience, research that would sensitize readers to issues of identity politics, to experiences shrouded in silence, and to forms of representation that deepen our capacity to empathize with people who are different from us” (Ellis et al. 2011:2).

I conducted a casual content analysis of 109 abstracts on autoethnography as methodology that were published between 1999 to 2017; 82 from articles, 25 from books and 2 book reviews. Approximately 36 disciplines use autoethnography including music, health care, psychology, athletics, government, business, human sciences, and communications (Rambo, Presson, Gaines and Barnes Forthcoming). Even though autoethnography is utilized for a myriad of disciplines, “there are some researchers that still assume research can be done from a neutral, impersonal, and objective stance (Atkinson 1997; Buzard 2003; Delamont 2009), though most now recognize that such an assumption is not tenable” (Ellis et al. 2011:2). In this vein, Ellis et al (2011) asserts that, “consequently, autoethnography is one of the approaches that acknowledges and accommodates subjectivity, emotionality, and the researcher's influence on research, rather than hiding from these matters or assuming they don't exist” (Ellis et al. 2011:2).

According to Ellis et al. (2011):

Layered accounts often focus on the author's experience alongside data, abstract analysis, and relevant literature. This form emphasizes the procedural nature of research. Similar to grounded theory, layered accounts illustrate how "data collection and analysis proceed simultaneously" (Charmaz 1983:110) and frame existing research as a "source of questions and comparisons" rather than a "measure of truth" (Ellis et al. 2011:117).

“Unlike grounded theory, layered accounts use vignettes, reflexivity, multiple voices, and introspection” (Ellis et al. 2011:5) in order “to ‘invoke’ readers to enter into the ‘emergent experience’ of doing and writing research” (Ronai 1992:123), “conceive of identity as an ‘emergent process’” (Rambo 2005:583), and “consider evocative, concrete texts to be as important as abstract analyses” (Ronai 1995; 1996:116).

When addressing social problems, autoethnographies unveil the emotions, thoughts, collective experiences, and social processes of issues that may have otherwise remained hidden. As a form of participant observation, there is “complete engagement and immersion in the research setting” (Rambo et al. forthcoming). The authors further state that “science, in its clinical application, fails to regard the emotional well-being or life altering consequences of those who are directly affected by the results.” This omission of analysis can negatively impact the people it seeks to help. The authors assert that social problems like chronic illness, poverty, and war “are the products of a science that fails to reflect on how it feels to live in the worlds it creates or the social arrangements that put patients and populations in harm’s way” (Rambo et al. forthcoming). Ellis and Bochner (2006) posit that personal narratives can be a form of witnessing, noting that "the ability for participants and readers to observe and, consequently, better testify on behalf of an event, problem, or experience” (2006:6). In this way, autoethnographies allow a researcher to “identify other problems that are cloaked in secrecy such as the isolation a person may feel after being diagnosed with an illness” (2006:6). In witnessing, a negative dialogue may be the beginning of a positive dialogue; a transformation into an open,

on-going conversation rather than a continual absence of one (Frank 2015). Accordingly, Ellis and Bochner (2006) posit that “autoethnographers not only work with others to validate the meaning of their pain, but also allow participants and readers to feel validated and/or better able to cope with or want to change their circumstances” (2006:6).

Science and clinicians attempt to use biomedical models to explain how the social world affects and is affected by medicine and chronic illness. The biomedical model of illness and healing focuses on purely biological factors, and excludes psychological, environmental, and social influences. This model is the dominant, modern way for doctors to diagnose and treat a condition in most Western countries. Most doctors never ask for a psychological or social history of a patient; instead, they tend to analyze and look for biophysical or genetic malfunctions. The focus is on objective laboratory tests rather than the subjective feelings or history of the patient. This assumes that every race, nationality, and culture is the same. Consequently, according to Ellis et al. (2011) “autoethnography is one of the approaches that acknowledges and accommodates subjectivity, emotionality, and the researcher’s influence on research, rather than hiding from these matters or assuming they don’t exist” (2011:2). As Kleinman and Benson (2006) posit, “the moment when the human experience of illness or any other social problem is recast into technical categories, something critical is lost because it was never validated as an appropriate clinical concern” (2006:346). Ethnographies open doors for clinicians and researchers; cultivating lines of communication and conversation. This process sets their expert knowledge aside, not over and above, a person’s own explanation and viewpoint. This is how autoethnographies attempt to provide an ethic of care by resisting the norms of scientific explanation. It is a powerful tool which can help restore balance to the perspective of those who

not only research but also to the ones who stand to gain from the research provided when addressing social problems and injustice.

LITERATURE REVIEW: LUPUS THROUGH A MACRO-LEVEL SOCIAL SCIENCE LENS

SLE is often called “the disease of a thousand faces.” When the term “lupus” is used, it usually refers to SLE. Throughout this document, the term “lupus” is used to denote systemic lupus, since SLE constitutes the most common form of the disease. It is a relatively rare but complex disease. Its global burden — in terms of incidence and prevalence, differential impact on populations, economic costs and capacity to compromise health-related quality of life — remains underappreciated and poorly understood. Worldwide incidence and prevalence estimates of lupus vary substantially and are influenced by ethnic and geographic differences. Generally, patients of African ancestry and those from Asian, Hispanic and Aboriginal populations not only develop lupus earlier than do patients from white populations, but also tend to have a more acute disease onset, a greater number of (and more severe) clinical manifestations, higher disease activity and damage, and higher mortality (Auerbach, Beckerman, and Blanco 2013). Survival in patients with lupus is shorter in parts of Asia and the developing world than in North America and Europe, which indicates the potential additional importance of environmental and other socioeconomic factors in the prognosis of lupus. Studies provide evidence of the complexities of difference in lupus. For example, the manifestation and onset of illness, severity, duration, commonalities, and incidence change within different ethnic groups and according to geographical locations. This further supports the possibility that environmental and socioeconomic influences are important (Carter, Barr, and Clarke 2016). Poverty, low educational attainment, lack of health insurance, poor social support and poor treatment

compliance are all associated with unfavorable disease outcomes, both independent of, and in combination with, ethnic influences. The treatment of lupus incurs high direct costs, and sometimes even higher indirect costs; costs are influenced by disease severity and organ manifestations. Health-related quality of life is greatly compromised in patients with this illness.

Grounded in studies that have examined both genetic and socioeconomic factors in patients with lupus, some researchers propose that genetic factors are most important at disease onset, whereas socioeconomic factors become more important over time. In many countries, socioeconomic status is highly related to ethnicity, with non-white individuals generally having a lower socioeconomic status than white people. According to (Carter et al. 2016), low socioeconomic status has been associated with several adverse outcomes in patients with lupus, such as high disease activity, increased damage accrual, work disability and mortality (Carter et al. 2016).

Several large cohort studies have demonstrated that poverty is associated with higher disease activity, increased organ damage and higher mortality in patients with lupus of varying ethnic backgrounds, compared to patients with lupus of higher financial status. The Hopkins cohort, which began in 1987, was a study that included over 2,000 patients with lupus. The race of the patients in this study consisted of primarily whites and African Americans. These patients had been seen by one provider in the USA. They found that “patients with an annual household income below \$25,000 had an estimated 20-year survival of 70%, compared with 86% for those above this threshold” (Carter et al. 2016:610)

Generally, Hispanic and African American individuals in the United States have lower levels of education than their white counterparts. In addition, Hispanics may have limited

English language skills. These limitations can interfere with the ability of patients to understand practitioners and with the capacity of health workers to provide proper care (Carter et al. 2016).

Another factor related to financial status and education, which contributes to health disparities, is the lack of access to medical insurance and thus health care resources. Lack of health insurance, which disproportionately affects non-white populations in the United States, might delay or prevent access to specialist rheumatology care, and can limit the treatment options available to patients. In the United States, having private insurance has been linked to lower disease activity in patients with lupus of all ethnic groups, whereas public insurance, or lack of insurance, has been associated with increased disease activity, increased hospitalizations and increased mortality. Financial status, educational level and health insurance are likely to act in combined efforts, rather than independently, to influence outcomes in lupus (Auerbach et al. 2013).

Poor social support is associated with increased disease activity and impaired mental functioning. Lack of self-efficacy in disease management is associated with decreased mental and physical functioning. Adverse health perceptions and maladaptive illness-related behaviors worsen disease outcomes, medication beliefs and compliance (Thoits 2011). These effects are also adversely compounded by ethnicity (Carter et al. 2016).

“Lupus is widespread and affects 1.5 million Americans. It is more prevalent than Cerebral Palsy, Multiple Sclerosis, Sickle Cell Anemia, and Cystic Fibrosis” (Auerbach et al. 2013:606). These statistics do not take into account the rest of the world. Lupus has been understudied as a subject on the whole.

LITERATURE REVIEW: LUPUS THROUGH THE MEDICAL LENS

Lupus is a chronic autoimmune disease that affects multiple organs and is characterized by the presence of autoantibodies (Cordeiro and Andrade 2013). The immune system doesn't have the ability to recognize the difference between foreign bodies and healthy cells and tissues; without the ability of differentiating between self and foe, it attacks healthy tissues resulting in pain, inflammation, and possible irreversible organ damage (Miles 2011). Clinical manifestations of lupus are polymorphic in nature most frequently affect the lungs, kidneys, brain, skin, and joints; depression and psychosis are common neuropsychiatric surge complications (Cordeiro and Andrade 2013). Accompanying symptoms include chronic fatigue, weight imbalances, joint sensitivity, memory lapses, and muscle pain (Clauw 2003). The disease targets primarily women with a higher prevalence within the nonwhite population with peak onset occurring between 15–40 years, though it can present at any time. Lupus travels on a relapsing and remitting course that can be life threatening, physically debilitating, and mentally deteriorating (Cordeiro and Andrade 2013). In contrast, fibromyalgia, the disease I was first diagnosed with, is described as having chronic widespread pain and diffuse tenderness with “criteria of condition having 11 of 18 ‘tender points’ and a history of pain in all four quadrants of the body as well as the axial skeleton” (Clauw 2003:467). (It is worthy to note that lupus is considered a “mimicking disorder” and the symptoms of these two are very similar in nature. The *differentiation* between lupus and fibro are that the therapies are not the same). Common overlapping symptoms of fibro include chronic fatigue syndrome, tension and migraine headaches, multiple chemical sensitivity, irritable bowel syndrome, sleep difficulties, distortions in hearing and vision, weakness, and attention or memory lapses (Clauw 2003).

Further research states that, “lupus can be difficult to diagnose and the prevalence of misdiagnosis is high because its signs and symptoms often mimic those of other ailments” (Mayo Foundation for Medical Education and Research 2017). “Because the early symptoms of lupus can be vague and indeterminate, or resemble related conditions like rheumatoid arthritis or fibromyalgia, the diagnosis of lupus can be delayed in the United States. For example, women sometimes live in a liminal state for years, waiting for a diagnosis, often as their health deteriorates” (Mendelson 2009:391). In one autoethnography, “*It’s Like a Black Woman’s Charlie Brown Moment: An Autoethnography of being Diagnosed with Lupus,*” Ferdinand (2016) tells the story of how she was diagnosed with lupus but was later told that she did not have the illness. Due to changes in her insurance policy and the requirement of a new network doctor, she is diagnosed with lupus again. Her story does not end with a definitive answer; only the fear and confusion she now feels. She resides in a liminal space, waiting on an accurate diagnosis. The illness is both contested and invisible. By contested, I mean the etiology is constantly questioned and argued by doctors. The invisibility lies in the mask that lupus provides; an average person generally cannot readily *see* evidence of illness. Contested and invisible are key to understanding the experience.

You took refuge in my body and wreaked havoc in its rooms

Growing bigger than I can accommodate

You’re changing my existence and taking everything I need

As I become you and you become me

You drink up all my energy and deplete my soul

You rape my mind and leave behind the pieces

My pain is your joy and I can't compete with your wiles

My invisible tormentor hidden behind my smile

LIVING AND LOSS WITH LUPUS

I just woke up and it takes me ten minutes to stand up straight, my body jerking and twitching like a toddler learning to walk for the first time. When I can finally move, I take the few steps from the bed to the bathroom as 10,000 tiny little needles dig into the bottoms of my heels. I need help getting off the toilet. I slowly make my way into the kitchen where someone has been kind enough to make coffee. It seldom helps anymore but it is the one thing that feels consistently normal to me. I try to knock the fog off my brain; the fog from the impending migraine that I feel and the fog from all the medications that I took at bedtime the night before to *prevent* the migraine and to help me sleep. The migraine is still imminent nevertheless. I pace like I do so many mornings, re-training my body to walk until it cooperates, naturally. I'm aching all over, I'm hot to the touch. Feverish. I have the shakes like a person who's been in detox for a few days. This happens all the time. This has been my life for years now.

My memory also suffers. Studies have shown that patients with fibro have significantly less total gray matter volume and show 3.3 times greater decrease in gray matter than in healthy controls. "The longer the individual has had fibromyalgia, the greater the gray matter loss, with each year of fibromyalgia being equivalent to 9.5 times the loss in normal aging" (Kuchinad et al. 2007:1). With fibro, there is a heterogeneous series of disturbances throughout the autonomic, neuroendocrine, and neuropsychic systems that adversely affect a patient's quality of life, performance, and mood (Kuchinad et al. 2007). Research indicates that both lupus and fibromyalgia affect the memory. Through the years, I have found many instances where my mind is blurred between what is real and what I believed to be real. As time passes, I realize that some

of the most painful parts of my life are hidden from me. Is this a memory problem or my defenses guarding me? I often hear information but do not retain it. Is this the illness playing out its' divisive role in erasing my mind like the research would indicate? What is this fog? Have I just mastered the ability of rejecting my thoughts to protect myself? Is this all in my head? My mind feels raped, or violated, when I try to recount details of anything that matters to me; dates, names, occurrences, lectures, and memories are often lost in the shadows of my brain. I want to scream out "I'm not mental!" Am I? I don't sleep nearly as much as I should. My mind won't shut down. I hear all these questions in my head as vividly as a church congregation sending their prayers to God out loud, in unison. What's wrong with me?

All day starin' at the ceilin' makin' friends with shadows on my wall

All night hearing voices tellin' me that I should get some sleep

Because tomorrow might be good for somethin'

Hold on, feelin' like I'm headed for a breakdown

And I don't know why

But I'm not crazy, I'm just a little unwell

I know, right now you can't tell

But stay a while and maybe then you'll see

A different side of me

I'm not crazy, I'm just a little impaired

I know, right now you don't care

But soon enough you're gonna think of me

And how I used to be, me

(Matchbox 20 2002)

I find the Matchbox 20 CD and listen as Rob Thomas bellows this song. I'm glad someone else feels this way. It makes me feel better.

I didn't know how to come to terms with this – the pain, the 'crazy,' the seething anger—for years. I still don't know—I've stayed angry. I'm tired of being in pain. I hide it from most everyone; even the people closest to me don't understand and typically act as if it doesn't exist. I don't know why I expect more from them, I act the same way. Denial, anger, fear, sadness, repeat. Sometimes I like to swim in the river of denial. I can't possibly have this ugly disease ravaging my body. The doctors are wrong. Maybe if I act as if it doesn't exist then it simply, won't. Anger is the strong one—it feeds me. I'm angry with of all the restrictions this illness puts on me. I'm angry because I'm in pain all the time. I hate all the pills they keep trying to shove down my throat. I'm sick of explaining to people why I look fine one day and not the next—why do I constantly have to explain myself? I'm angry because I don't understand what's happening to me. I'm angry because of all the anger—it's changing me. I'm afraid of what I don't fully understand and can't change. I'm sad because of the fear of not seeing my children grow up. I am sad because I want life to be different but it's just not. This is the pattern. I chastise myself for being a bitch, for being weak, for feeling sorry for myself, for many things. I feel alone and afraid to feel what I feel.

*My disease is my child born of pain and regret
It tugs at my sleeve and screams for my attention
My body is a prison and I'm trapped in my mind
I am a mother of illness and the chains tightly bind*

My second marriage produced three beautiful children. He was in the Marine Corps when I met him, and I was quickly taken by his extremely good looks and northern mentality; different from the “still being coddled by mommy” southern men I had experienced. I didn’t know that behind that perfect smile was a rap sheet as long as my arm with a history of drug abuse that accompanied it. He was military—they take people like that? Fast forward to the divorce several years later.... We got joint custody of the children (reasonable visitation for him, split holidays, shared decisions) but I maintained “physical” custody. He moved back home to Ohio and I stayed here, in Mississippi. My children went to visit one summer and when I drove to Ohio to pick them up, he would not surrender my boys. I got my daughter because of my ex’s fucked up logic that “girls need their mothers, but boys are harder and need their dad.” He said, “I’m keeping them with me because you can’t handle them.” I had custody of all my children, but it didn’t matter. Ohio police did not recognize physical custody in that state and all they could do was keep the peace—not make him give me my boys. I had to leave, or we would both go to jail. I wasn’t given a choice. I had two other children at home. I drove away while my then 3-year-old ran behind my car, “Mommmy... wait...” and then he collapsed, wailing in the street. I watched it all in the rearview mirror. I had to pull the car over and vomit once I got out of sight. I’ve never been able to erase that image. Imagine the worst pain you’ve ever felt and then multiply that by one million. That’s where I was at. The image still torments me. Time to re-strategize, call my attorney, hire a hitman.... whatever I needed to do. Three weeks later I got a call from his sister informing me that my ex was using drugs again and that he’d left the boys with her after asking to borrow her car. He had been gone for five days. She said, “I’m scared he’s going to come get these kids and sell them for drugs, it’s that bad. I can’t stop him if he

shows up here.” I was 11 hours away, so we called Child Protective Services on three-way for immediate assistance. During this process, my ex-husband was arrested, and my boys ended up in the system.

Social services didn’t let the boys come home right away. Their daddy was labeled a habitual drug user so, in their eyes, mommy was probably a drug user too. This case stayed wrapped in the judicial process for 3 ½ years, my boys in Ohio, and me with their sister in Mississippi. I was subjected to multiple psychological tests and random drug screens, passing them all without a blink. I worked at the casino—made good money, had excellent benefits, even a 401k in place. Social workers came to my house and everything passed inspection. They were *finally* coming home. One hitch... I was sick. I had just finished a three-month round of chemo, just had a hysterectomy, and had just been diagnosed with Lupus. When my doctor would not clear me to fly on the last court date, the judge asked for my medical records. I willingly complied. The judge decided that, per doctor’s orders, it wasn’t necessary for a ten-day continuance. It was all semantics at this point, they could proceed without me. I blindly trusted that.

The court papers read as follows—First line: *“The court questions the integrity and morality of mother’s job at a bar and casino in Tunica, MS. We further question the true availability needed for the proper instruction of the boys and the value system set in place to ensure long-term productive, and caring citizens.”*

Second line: *“While the court empathizes with the physical condition of the mother, we are concerned with the overall fragility of the situation. Boys are often stubborn and strong-willed and we find that the mother’s condition may not allow for the proper care of the children. The mother’s health has been tenuous at best and we are concerned for the instability and long-*

term prognosis of this illness. Moreover, we are concerned about the emotional well-being of all parties concerned. For this reason, the court finds that [redacted] and [redacted] shall be placed in a home...”

Fuckers. GIVE. ME. MY. BABIES.

It is Christmas time—December 20, 2005. They’re never coming home. I want to die. Damn my illness. What else can it take from me? To say that I want to die is dramatic but that truth cuts to my soul. Losing them is like death, only worse. In death, there’s a conclusion that one can understand, come to terms with, and eventually find a way to carry on. I will always worry if they have blankets when they are cold, food when they are hungry, and if they think that I don’t love them. There is no closure and I will never come back from this. I didn’t blame the courts—the ones who judged and executed me for being sick. I blame the illness; a child that was not conceived in love, rather a darkness that is growing in my body and becoming part of everything I am. I could not be separate and apart from something that’s inside of me; the integration of this new identity held us equally accountable for the guilt and blame. Again, the self-loathing takes over and the anger begins to consume me once again. All I see is the illness when I look at myself. I’m my own worst enemy, destroying everything that means anything to me. Why was I not stronger? Why couldn’t I fight harder? The face of my illness is my own staring back at me in the mirror. I want to kill you, I want you to die. What have I done to deserve this sentence? I must be tainted. I hate you so much.

I waited a couple of years after the diagnosis to tell my daughter what was wrong with me to ensure that she was old enough to understand. She watches me struggle and knows something isn't right. Normal mommies don't look like this. I gloss over it and sugar coat most of it. I only tell her what I feel she *has* to know. I tell her that A LOT of people have lupus so it's a relatively common thing—doctors see it all the time. I tell her it's like having a cold—you feel bad for a couple of days, but the medicine makes it all better. I tell her that it doesn't hurt that bad, I just get a little tired sometimes. I tell her that there is nothing in this world bigger than my love for her so absolutely nothing can possibly be big enough to ever take me away from her. She's a smart girl and I see the fear in her eyes as I lie to her. She knows her brothers aren't here, but she doesn't know why. I can't explain it to her because I don't fully understand why. I hate myself in this moment and my heart completely shatters when I see the tears in her eyes. I hate this illness for the pain it causes her, and it laughs in my face. The anger and pain consume me and yet I smile because that's what she deserves. She needs a strong mommy even if it's all a lie. "I'll be fine, baby," I tell her, "I got this. I just don't want you to be afraid when you see me hurting sometimes." I hate myself even more.

LITERATURE REVIEW: SELF-STIGMA AND AUTOIMMUNE DISEASE

Stigmatization from society and often, one's closest inner circle, is traumatic. Studies were performed to investigate the beliefs about the causes of lupus among patients who have been diagnosed (Taieb, et al. 2010). One of the more common beliefs is that lupus is due to "autoimmunity with a notion of self-destruction" (Taieb et al. 2010:594). For example, one patient said, "it's a disease you create for yourself, when deep down you want to die." According to Taieb et al. (2010), "autoimmunity appeared to raise questions or strengthen pre-existing

questioning about psychological welfare and to contribute to generating psychological causal attributions” (2010:596). Autoimmunity is often broadly conceived as a self-destructive process. Nearly half of patients attributed a causal role to genes and heredity. More than a third of respondents classified lupus as a “contagious disease and/or classified as an infectious disease. The theme of impureness and being sullied was explicitly brought up in discourse” (Taieb et al. 2010:595). More than half of the patients interviewed referred to magico-religious causes such as God or witchcraft. Others believe it is a latent disease that was just “already there” waiting for the “right time” (Taieb et al. 2010:595). Still others searched past behavior and believed that their illness was brought on by questionable moral standards and wrong doing; this was the ultimate punishment for a life of bad decisions (Sutanto et al. 2013).

I walked away from the casino job a couple of years later. I was a cocktail waitress, a job that entailed carrying sometimes 40-pound trays in high heels for eight-hour shifts. The doctor told me that if I didn’t quit, I would be completely handicapped within five years; the job was too hard on my body and the lupus would not be kind. The doctors always know, right? Disheartened, I let it go.

I pull out my I-pod, again calling on Melissa Etheridge. She sings,

Each road that I walk down

Reminds me of you

This whole town is haunted

There'll never be anything new

Precious pain

Empty and cold but it keeps me alive

I gave it my soul so that I could survive

Keeping me safe in these chains

Precious pain

(Etheridge 1988)

I cry, I scream, I wail. I mourn for the loss of my boys. I cry for a job that I loved and left. I scream towards the sky in an uncontrollable rage.... “Fuck you if you’re up there! Fuck you for being so cruel. What did I ever do to you. To anybody.” Tears are pouring down my face. I kick the wall, hit the door, and scream like a small child throwing a tantrum. “I hate you. Let my body go or let me die. I don’t want this. I didn’t ask for this. Hello, asshole, are you there? You’re not there. You never were. Nobody is.” I collapse and sob for what feels like hours.

The day after one of these episodes will always bring shame. I tell myself to “stop being such a baby, there’s no time for a pity party.” See, the realization is that I have two other children to take care of. The thoughts of death are selfish because where the thought provides momentary peace, it would in turn cause severe pain to two people that I love more than life. They didn’t ask for this either. They deserve a mother that loves them, that will protect them and make them feel safe. My rational mind knows all of this, but my fear and sadness try to take the upper hand at times. My anger keeps me in check, otherwise I may give in to it. There’s a dichotomy in my soul—the child who succumbs to the pain and the warrior who fights it. I have good days along with the bad. On the good days, I war with this disease, determined that it will not win. It’s taking things from me that I love but I’m still standing and that has got to mean something—even if you feel empty inside.

*I feed you with anger and fear, the milk so sour it poisons us both
Your appetite so insatiable my legs falter from the strength you steal
Stress is my best friend and I thrive in confusion
Any hope of you ever leaving me is just a delusion*

There is an old Cherokee parable of unknown origin that goes like this: A grandfather is talking with his grandson and he says there are two wolves inside of us which are always at war with each other. One of them is a good wolf which represents things like kindness, bravery and love. The other is a bad wolf, which represents things like greed, hatred and fear. The grandson stops and thinks about it for a second then he looks up at his grandfather and says, “Grandfather, which one wins?” The grandfather quietly replies, “The one you feed”. Lupus is the Latin word for wolf which I learned early on in the first stages of diagnosis. The contrast between the parable and this fact has always resonated with me—a reminder that the “bad wolf” is the one I tend to feed. I’ve attempted to change this line of thought, so I got a tattoo on my arm that spoke to the wolf (lupus). It reads, “She slept with wolves without fear for the wolves knew a lion was among them.” The pain from the needle was a welcome release as I had my identity inscribed onto my arm. I want to be the lion. I am the lion. “Fuck you, wolf (lupus). You don’t win this round”!

As the years have gone by, the anger inside of me has silently, and not so silently, festered. Due to this illness, I lost another marriage. I was told, “You aren’t fun anymore since you’ve been sick.” I’ve learned not to trust anyone in this process except my doctors. Any relationship that followed came at arm’s length—never willing to completely give myself to anyone else. I’m always waiting on the other shoe to drop so to speak. The anger and mistrust

from one relationship carries to the next, growing larger every time. I set impossible standards that no one can reach. Ever. When it ends, I can blame them for not living up to my expectations. Set up to fail from the start so I'm never surprised. And then there's just simply the matter of "who wants to deal with this bullshit"? I don't want to be a burden on anyone else long term and if they did choose to stay, do they leave me at the end when I need them most? I cannot allow myself to be this dependent. I keep my doctor's visits to myself, carefully picking and choosing what I tell others, never affording anyone the opportunity to share any of this with me. In turn, I feel resentful and abandoned but in full realization that it's by my own doing. I push everyone away. The courts didn't judge me as fit for my own children and I can't take the continual rejection, if it even exists. This illness stays hidden from most of the world. I learned early in a "court of law" that the penalty is extremely high simply because it exists. Therefore, I treat everything else accordingly. I've learned how to smile when I'm in excruciating pain, how to lie with a straight face and no conscience. Never let anyone close enough to destroy you. I hide because I'm afraid. I no longer want to be stigmatized for another person's perceptions of what they think I have or the moral judgment of who they think I am. I already know who I am and it scares me. I don't want anyone else to see. Melissa sings again....

The lies upon your lips

The anger in your hair

Nuclear fingertips

Annihilating stare

It seems wherever you go you can't help but to explode

And your demon's screaming out of control

Say good-bye to the enemy

Go find another master

Say good-bye to the best of me and

Call it a disaster

Call it a disaster

Call it a catastrophe

Your intention is clear

It's set to self-destruct

(Etheridge 2012)

Yeah Melissa, I understand all too well...

LITERATURE REVIEW: STIGMA, CHRONIC ILLNESS, AND CHRONIC STRAIN

Although stigma may be experienced in multiple ways, it is particularly important to understand the extent to which people living with chronic illnesses *anticipate* stigma and internalize it. To quote Goffman (1963) concerning the discreditable individual, he states:

However, when his differentness is not immediately apparent, and is not known before hand, when in fact his is a discreditable, not a discredited person, then the second main possibility in his life is to be found. The issue is not that of managing tension generated during social contacts, but rather that of managing information about his failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case for whom, how, when, and where (1963:42).

Why do we hide? Studies reveal that patients will deny or hide physical symptoms and pain for fear of rejection or abandonment; some to maintain a “normal” identity (Sutanto et al. 2013:1760). The goal of passing is to become part of the “normal” group, but this management strategy creates stress because of worry about the risk of discovery and the embarrassment of being caught (Goffman 1963). “People with invisible illnesses are frequently questioned and left with the impression that others see them as malingerers or faking their symptoms”

(Armentor 2017:469). There is a clear lack of understanding that follows chronic illness—yesterday that person was fine, non-symptomatic, functioning to full capacity—today is different. Doubts from others were described as emotionally painful and “hope breaking” (Armentor 2017:468).

According to the literature, many people living with chronic illness experience various forms of *enacted* stigma (Earnshaw et al. 2012). Miles (2011) states that “because of a general lack of biomedical knowledge, any mention that one suffers from problems related to the immune system brings forth the specter of AIDS in the minds of many whose only reference to immune problems is that disease” (2011:661). Further, she adds that “AIDS is not a morally neutral illness and those suffering from it often are stigmatized as immoral and marginalized because of fears of contagion” (2011:661). In Ecuador, several women reported that after being diagnosed with lupus, friends and neighbors stopped associating with them (Miles 2011). Additional reports reveal refusal of eating from the same dishes of the “infected” for fear of contagion, or the woman in Mexico who worked in a small restaurant and feared she would lose her customers if they “heard the word ‘immune’ disorder” (2011:661). Moreover, women worry about their moral character being called into question due to the illness. Studies find that it is not unusual that chronic illness provokes moral reflections as the patient and those around her seek explanations for an illness that is so obscure (Morris 1991). As Sontag (1990) posits:

Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious. Thus, a surprisingly large number of people with cancer find themselves being shunned by relatives and friends and are the objects of practices of decontamination by members of their household, as if cancer, like TB, were an infectious disease (1990:6).

Lupus is no different.

Because the etiology of lupus is unknown, so closely linked with fibromyalgia, and difficult to diagnose, (Armentor 2017), disbelief is one the largest stigmas documented in the literature. Words such as “hypochondriac” or “attention seeker” precedes phrases like “they think I’m crazy” and “Oh it’s all in your head” (Armentor 2017). This is an invisible illness that often shows no physical signs of its presence; looking healthy can undermine credibility with family, friends, colleagues, and even health practitioners. In seven studies (Sutanto et al. 2013), patients described a “disrupted identity” in terms of their illness when explaining the experiences encountered due to erratic symptoms that were incorrectly diagnosed. They were continually accused of being hypochondriacs. Further, anticipated stigma may have a “substantial impact on the health of people living with stigmatized identities, in part, because it is a chronic strain” (Earnshaw et al. 2012:272). They further that, unlike enacted stigma, “which is a discrete event and therefore an acute strain” anticipated stigma has the potential to be “perpetually present and constantly weighing on one’s mind” (2012:272). Research suggests that chronic strains have a substantial impact on both physical and mental health, the impact being far greater than that of acute strains (Thoits 2011). In other words, the suffering caused by stigma can have more of a negative impact on an individual than the illness itself (Ablon 2002). What ultimately happens to such a tarnished identity?

I pray to a God I don't believe in for relief that never comes

My pushers feed me pills with a glass of bullshit on the side

The kush, your only sitter, the only way I can be free

From this little assassin that's breaking me

TREATING LUPUS: THE LIVED EXPERIENCE

They give me pills. So many pills. It started with high doses of Lyrica-Cymbalta cocktails and moved onward to Lortab and Oxycontin for pain. They feed me Toradol/Thorazine soup for the migraines and any lingering pain I might have. Lupus is generally treated with steroids but since I am allergic, alternate routes have been required. I've been unable to handle most medications well. They keep dealing them out. Understand that nothing touches the pain—the pills just fuck me up to the point that I'm too high to care. What do pharmaceutical reps offer them for pushing this shit down their patients' throats, anyway? I have no tolerance for codeine-based drugs and severe reactions to most other pain killers. After several rounds of Botox in my head (32 shots a round) for treatment of the migraines, my eyelid started to droop and my vision began to fail me. The treatments were stopped and replaced with a daily high dosage of Tramadol. Not only were the Botox treatments traumatizing but the end result left me frustrated and angry. Again.

Medicines have always been a trial and error process at the expense of my sanity and exacerbated symptoms. It's all bullshit. When did I become this person? I'm already a mess without the smorgasbord of poison they keep trying to feed me. Some pills make me mean. Others make me want to die. Still others just allow me to melt into the couch where I'm available for no one. Lights on, nobody home. Who am I right now? I turned to medical marijuana for pain relief and peace of mind—it's not evil like the prescribed drugs are. I function without pain, I smile and rest; and still I would be villainized over and above any doctor for my choices. Just one more thing to be judged for.

And I can't reconcile the hatred when we're standing face to face

Because when I look at you all I see is me

And I'm supposed to love myself but that could never be true

Because when I look at me all I see is you

EPILOGUE: LUPUS

This illness has caused me to face many demons, truths about myself that are hard to reconcile. It is a part of who I am. It has taken me years to restructure my identity in a space that makes sense for me. The mere fact that it is here has caused a type of pain that can never be undone. They say time heals all wounds but I'm proof that that is a lie. This has cost my livelihood, relationships, and most importantly, my children. The mirror is the hardest surface to look at. Lupus is a beast and it is my child. I have fed and nurtured it like most mothers would, but I want to suffocate it and kill it like some mothers have. The anger throughout the years has grown so much that it has overshadowed and taken control of who I was before the diagnosis. Fibromyalgia alone is a painful little monster but one that can be controlled without the emotional toll that lupus entails. Lupus is autoimmune... and I'm a "special case" ... so it's never been "if" for me, but "when." When is it going to present itself to a point that it completely takes over and I'm gone? Do I get to see my daughter get married? Will she be okay without me? I've always protected her and the thought of her feeling alone terrifies me. Do I get the chance to tell my boys what really happened, that I didn't leave them, that I've always loved them? Hell, if I could just touch their face, smell their hair, anything... do I get that chance? I just want to tell them that I love them. I need to tell them that I'm sorry for any pain that my absence caused them knowing that it will never be enough. Even now, as I'm writing this, my

heart is beating faster and I'm starting to shake. The wolf is at the door and my anger and sadness are being released in waves. My whole existence changed because of this and I've had to re-route my life, always feeling like it's a race against time to get everything done that is important to me. Because of this illness, I have been the architect of my own destruction in every relationship. The thing is, you can't love anyone else, truly love another until you love yourself—and I don't. It's extremely hard to admit this but I judge everyone else so harshly because I can't deal with my own shit. I'm alone and I'm afraid and I have done it to myself. There's no separation between me and this disease—we are one.

In the face of my demons, I call on Melissa one more time.....

Walking on the edge of rage and understanding

Between the black and the white

This child is so angry

Alone here tonight

Alarming desperation

Leads me to believe

With all my shields and protection

It's only me I deceive

Dance without sleeping

Dance without fear

Dance without senses no message I hear

Dance without sleeping

Dance till I'm numb

Dance till I think I can overcome

(Etheridge 1992)

I collapse on the floor and cover my head with my arms as I sob. I hate who I've become.

CHAPTER 2

DIS-EASE, IDENTITY, AND REEVALUATION

PROLOGUE: DIS-EASE

Throughout this autoethnographic process, some things became abundantly clear to me. Fibromyalgia is my child—all the characteristics are there and each one manifests itself daily. As I further my research into lupus, however, I am starting to question a few things.

I note again that the disease focuses primarily on women with higher prevalence within the nonwhite population with peak incidence showing between 15–40 years, though it can present at any time. Lupus travels on a relapsing and remitting course that can be life threatening, physically debilitating, and mentally deteriorating (Cordeiro and Andrade 2013; Sutanto et al. 2013; Taieb et al. 2010). I am a white female. This disease has never been “relapsing and remitting” but more, the obvious explanation for the progression of every other ailment according to my doctors. Further, according to Jennifer Robinson, MD (2016), “a tell-tale sign of lupus is a butterfly-shaped rash across the cheeks and bridge of the nose” (2016:3). Other common skin problems include sensitivity to the sun with flaky, red spots or a scaly, purple rash on various parts of the body, including the face, neck, and arms. Some people also develop mouth sores (Robinson 2016). I’ve never had any of these symptoms. The doctors warned me against the sun and told me about the possibility of the rashes but in all these years, nothing like this has ever presented itself. I’ve pushed those boundaries; overexposure to the sun and tanning beds. Nothing. I reread, “Lupus can be difficult to diagnose because its signs and symptoms often mimic those of other ailments” (Mayo Foundation for Medical Education and Research 2017). Where one diagnosis is seen (lupus), it is common to see the other (fibro). I reread, “Because the early symptoms of lupus can be vague and indeterminate, or resemble related

conditions like rheumatoid arthritis or fibromyalgia, the diagnosis of lupus can be delayed in the United States, for example, women sometimes live in a liminal state for years, waiting for a diagnosis, often as their health deteriorates” (Miles 2011:652). I reread Ferdinand’s (2016) autoethnography where she tells the story of how she was diagnosed with lupus, and later told she didn’t have the illness, and ultimately told she has it after all. Some things are not making sense.

I need to see my doctor.

REEVALUATION

This is the first time that he has ever sat and listened, really listened, to what I have to say. I explain the research that I’m doing and tell him that I am concerned about the discrepancies of where lupus fits and doesn’t fit in my particular case. As tears roll down my face, I explain that I need answers; my entire identity has been defined by this thing that doesn’t necessarily fit or make complete sense to me any longer. They pull vials of blood just like they did all those years ago when I was first diagnosed. I feel the same fear and numbness as before, however, nothing is muted this time. The anger makes me strong.

The doctor’s office calls me four days later with my results. The antibody titers are negative; I don’t have lupus. I was misdiagnosed. This disease, my child, that has shaped me, changed me, guided me, and become me, is not real. It does not exist. What the fuck? I trusted them; while shutting everyone else out of my life for years, I trusted my doctor above all. This call comes right before I walk into class. I am forced to suppress. I’m dying inside. I want to scream and break things and cry. I feel a thousand emotions and I can’t structure any of them. Who am I? It has been suffocated and killed just like I wanted. But it was mine and they just

took it away. My child, the thing that has grown in me for years, an undeniable part of who I am. They took it. I am a walking contradiction of emotions and my identity is shattered. I feel hollow. What has happened to my identity?

LITERATURE REVIEW: ILLNESS IDENTITY

I go back to the literature for answers. Sue Estroff (1989) brilliantly targets the process by which an illness becomes an identity. "Each person locates their illness in relation to the self, along a continuum of subjectness; that is, how closely linked to one's self or separated as distinct from one's self the illness is considered" (1989:190). She further notes that, "the fact that chronic pain is not considered 'real' in the sense that chronic disease is considered to be "real" has a strong impact on the process of identity formation" (Estroff 1989:192). A patient can spend years waiting for a diagnosis and subsequent relief of chronic pain. Even in the midst of ambiguity, "the chronically ill attempt to form their new identities according to the type and degree of their illness, its timing, the meanings attached to it, and their own self-expectations" (Honkasalo 2001:322). This is sometimes problematic for those who are trapped in an ambiguous illness without a legitimizing diagnosis.

Leder (1990) writes of pain as a manner of "being-in-the-world." Pain re-organizes our lived space and time, our relations with others. It results in what he refers to as "spatio-temporal constriction," intentional disruption, and an alien presence that exerts upon us a telic demand. "Intentional disruption refers to how pain breaks off the body's openness toward the world, resulting in the objectifying of the painful body" (1990:74). Pain exerts an "alien presence" in the body because it is felt as something that is "a not-me," and the consequent emotion feels very wrong.

The social science literature provides many definitions of self; anthropologists have noted the nature of the self as being culturally variable (Ewing 1990). The self is something that is connected and open to the social world. The construction of self is dictated through the social and political worlds; it is relational, shaped and reconstructed through discourse and ongoing interactions. The self is not ready-born; it is something that develops and has a history. From this point of view, I am sympathetic with sociologists Goffman (1963) and Mead (1934), who argue that the self is thoroughly relational and dialogical. Mead's main point is that the self is reflexive, that it has the capacity to be an object for itself. For Mead, "the self is essentially a social structure: it arises in social experience" (1934:140). According to Giddens (1991), "reflexivity refers to concepts of personhood—to the capacity to use 'I' in shifting contexts" (1991:53). What about the notion of the self's intersubjectivity? Jackson (1998) posits that "the self is reciprocal to other selves, and it arises and is shaped by social interactions and dialogues. 'I' and 'you' are correlative, and the 'self' exists by virtue of the existence of 'others'" (1998:24). According to postmodern theories of split subjectivity, "the self is regarded as a process that, from the beginning, includes an 'Other' and thus, is not whole but split" (Jackson 1998:27). Finally, regarding embodiment, Honkasalo (2001) asserts that "the self is an inner experience of subjectivity that is both constructed through cultural processes and inherent within the world" (2001:327). The self is embodied, which means that, at the pre-reflexive level, the body and the self are one. Following this line of thought, we do not possess a body or a self, but rather, a "me." During chronic illness this embodiment is fractured, hence producing "the split" that Jackson (1998) asserts. This fracture—or disruption—disrupts lived temporality, spatiality, intentionality, and being-in-the-world (Kleinman 1992). Illness is frequently experienced as

disturbance and chaos, as a threat to the whole experience of "being me." Illness necessitates transformation; a process that begins by incorporating the disruption and threat into a new self.

In this vein, the relationships between the self and pain are often personified and defined in terms of social relationships. In a study performed in Finland (Honkasalo 2001), data was collected by interviewing chronic pain patients between the ages of 35-65. Interviewees often described their pain in constructs according to familiar concepts. One person noted:

I have learned to talk to it, because if it is the pain that throws me around, then I can't decide anything for myself. So, I always say to my pain: "Hi, should I do this, or should I not?" We sometimes have negotiations about what we will do and what we won't do. And then sometimes I say to my pain: "Listen, I do not give my consent"... There are some things I do not accept because I know it gives the pain power (2001:332).

In this example, she speaks of her pain as if it were a close friend or advisor. As the conversation progressed, she spoke of a sudden attack of pain during the holidays that forced her to stay in bed. Again, she states:

Then I started to think that this was clever, actually. I remember I was so tired and exhausted when I came. It was rest I needed, so I got it because I got that pain. Then I thought, "OK, it is more clever than me. It really put me to bed because I needed it; it took care of me, in a way. So, let's have a rest" (2001:332).

However, within the same narrative, her relationship with pain turns hostile when she starts to discuss her struggle for autonomy: "It is something that I have learned—who rules over whom...Who has the power in my life. I think I'm writing the script for my own life" (2001:333).

Even though some people describe their pain as a friend, for most it is cold and hostile. It is experienced as an intruder, or thief, that takes away the most precious things in one's life. Pain stops stories, interrupts life projects, interferes with one's plans. It confuses one's thoughts, concentration, and sleep. It does not allow one to rest. Some patients want to kill their pain with medicines, "to choke it, to render it obsolete," or, finally, if nothing else will work, to kill

themselves along with their pain. This was a common wish among the interviewees. Another described it as a balance of terror. What is interesting in the above comments is that the relationship between the self and pain is personified and defined in terms of social relationships. One splits into two and “I” becomes “we.”

This brings me to the importance of mind-body dualism. (Kirmayer 1988) states that:

...mind-body dualism is so basic to Western culture that holistic or psychosomatic medical approaches are assimilated to it rather than resulting in any reform of practice. Distress is dichotomized into physical and mental, real and imaginary, accident and moral choice. The duality of mind and body expresses a tension between the unlimited world of thought and the finitude of bodily life. It provides a metaphoric basis of thinking about social responsibility and individual will (1988:83).

His analysis of the pervasiveness and tenacity of mind-body dualism brings one closer to the understanding of why chronic pain is stigmatized because of its liminality. Chronic pain is a mystery that straddles the mind-body boundary; the more a bearer of chronic pain lacks a clear-cut diagnosis, the more ambiguous the patient becomes with respect to this boundary. Corbett (1986) found in her study of a comprehensive pain center that staff resisted the possibility of such boundary straddling. For them, "pain, it seems, was either physical or mental, biological or psycho-social never both nor something not quite—either" (Scheper-Hughes and Lock 1987:10). When a patient is made accountable for their illness, it neutralizes the threat to biomedical authority when a sickness cannot be controlled or explained. As Kirmayer (1988) states, "Patients are then either rational but morally suspect in choosing to be sick or irrational and thus morally blameless but mentally incompetent" (1988:83). Chronic pain sufferers share the same stigmatization as those who are physically disabled; a marginality caused by possession of an imperfect body. The physically disabled are indeed stigmatized; they have again been "reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman 1963:3).

They are viewed as less than normal by society and only problematically entitled to the sick role. Though many disabled people challenge the expectations and values of society, it does not change the prevailing attitudes. Chronic pain sufferers also occupy another kind of liminal space, for “their problem relates in complicated and poorly understood ways to mind-body borderlands” (Jackson 2005:345). In biomedicine, the entire mind can be spoken of as a liminal state. With respect to “the unlimited world of thought and the finitude of bodily life, biomedicine is unmistakably clear that the only good state is the physical state.” (Kirmayer 1988:83). Sullivan goes so far as to argue that speaking of “Cartesian dualism” is incorrect, for Rene Descartes arrived “at a full—fledged ontological dualism which opposes mental and physical substance absolutely ... [whereas] modern medicine refuses to acknowledge anything like a separate or separable mental substance” (Sullivan 1986:343). To attempt to articulate between chronic pain and a disability status is complex and dynamic, but clearly, chronic pain sufferers see the processes that stigmatize them to involve their mind.

As Estroff (1989) posits, an “I am illness” is one that overtakes and redefines the identity of the person living with that illness. An illness becomes more than an illness that one has, rather something one is or may become. Like Schizophrenia, lupus “includes not only the experience of profound cognitive and emotional upheaval; it results in a transformation of self as known inwardly, and of person or identity as known outwardly by others” (Estroff 1989:189), supporting Jackson’s (2005) dualism and the chronically pained self.

Among the above interviewees, some were still waiting for a diagnosis, while others had received one after waiting five or six years. How many encounters did they have with biomedical professionals before getting their diagnoses? The fact that chronic pain is not considered to be

"real" in the sense that chronic disease is considered "real" has a strong impact on the process of identity formation. Imagine being in this state for years.

Liminality is the quality of ambiguity or disorientation that occurs in the middle stage of rites, when participants no longer hold their pre-ritual status but have not yet begun the transition to the status they will hold when the rite is complete. During a rite's liminal stage, participants "stand at the threshold" between their previous way of structuring their identity, time, or social status, and a new way, which the rite establishes (Turner 1967:110). Liminality, according to Turner (1967), consists of "neither one thing nor another, or maybe both, neither here nor there, or maybe even nowhere (in terms of any cultural topography), and at the very least 'betwixt and between' all the recognized fixed points in the space-time of cultural classification" (1967: 96).

What the literature suggests is that to make sense of their illness and their self, people are engaged in a continuous back-and-forth between reconciling themselves with, and distancing themselves from, their pain. According to research, chronic pain, as measured along a continuum of subjectness, and is constituted by this ambiguous movement. What is important is that in the same narrative pain and the "self" occupy positions that go back and forth between extreme subjectivity and extreme objectivity. The traffic along the continuum of subjectness implies dimensions that employ both the lived body and the embodied self. What is taking place involves a disruptive process whereby the body exists not only as something pre-reflexively lived, but also as an alien object to be controlled. So, as Jackson (2005) would posit, "the experience of "being an ill 'we'—of fusing one's self and one's pain—is subsumed within a question of mastery" (2005:340). The studies further suggest that the relationship between the self and pain is influenced by the biomedical framing of chronic pain as a liminal state. Within this liminality, including the shifting boundaries and shattered categories, one can't help but ask questions of

morality. The ending result is that stigma and shame are attached to one's personae, and as a consequence, isolates and devalues the person who suffers (Estroff 1993).

*My disease was my child born of pain and regret
It still tugs at my sleeve and screams for attention
My body is still a prison where I am trapped in my mind
Yet this baby is dead, it was never alive
What did I feed with my anger and fear?
How did you leave when you were never here?
There is still so much grief and massive confusion
Your mere existence was just a delusion*

EPILOGUE: LOSING ANOTHER BABY

Throughout the years, I've had to reshape my identity multiple times trying to figure out where I fit in all of this. I have no capacity to understand why any of this ever happened. Almost everything has been lost to this illness. After years of rage and pain, I found myself in a place of concession. Except, none if it was true. The only thing that made sense to me was that I had lupus—it was mine. It grew in my body and became a part of everything that is me; the one thing left after so many other things have been taken. It became personified in my life; this illness serving as a mental representation or an object. It is inscribed on my body as a reminder that I am strong. The doctors took it. There were no apologies, no explanations, no realm of understanding the extent of damage this misdiagnosis has inflicted on my life. I have been judged by myself and others; forced to reconstruct my identity on the premise that lupus existed. I am still

grieving. I grieve because lupus (my child) is gone. In my mind, it validated judgments that have placed on me. It validated my anger. I found a place where it made sense even if that place was ugly. Now, nothing makes sense. The onslaught of medication doesn't make sense. The anger was for nothing. I lost everything... for nothing. It never existed. Do the doctors even care? They never asked what the diagnosis of lupus meant to me. They never asked if I was okay. They never noticed the extent to which I was spiraling out of control for all those years. I'm still spiraling. I am so confused. Is there no accountability?

CHAPTER 3

DIS-IDENTIFICATION AND CHRONIC DIS-EASE

PROLOGUE: LIVING WITH LIMINALITY

My doctor has referred me to a new rheumatologist. By the time I finally get in to see her, I will have waited a year. There are no available appointments until then. I believe Miles (2011) when she stated that,

Because the early symptoms of lupus can be vague and indeterminate, or resemble related conditions, the diagnosis of lupus can be delayed in the United States, for example, women sometimes live in a liminal state for years, waiting for a diagnosis, often as their health deteriorates (2011:652)

I have to wait to find out whether or not I have this illness? This is bullshit. Will the new doctors even know if I have lupus? How do I ever believe anything they tell me? On a recent visit to my primary physician, I was informed that his office had finally obtained my records from my diagnosing rheumatologist. The results of my lab work stated, "most suspicious for" and in another "most consistent with" lupus. Much like the day I was diagnosed with lupus, I'm muted. Angry. Confused. Shattered. This is not a definitive diagnosis. From the beginning, this specialist *never knew for sure* though all my medical records are inundated with this incorrect diagnosis.

I think about how being misdiagnosed with lupus has redirected so many aspects of my life. I think about the massive amounts of poison I've been fed. I was hospitalized for a severe allergic reaction to steroids; the one medication that is indicated as the primary manager of lupus. I think about the pain killers that have never touched the pain; pills that only made me unaware that life was still moving around me. I think about all the antidepressants to treat the symptoms of being told that I have an illness that is going

to ravage my body though I never had clear understanding of what that meant. I ruminate on the doctor's words from so long ago when he told me that he wasn't going to give me a "rose colored glasses" prognosis. Because of the combination of other medicines, my eyesight is failing me at an increased rate. Lupus has always been the obvious explanation for the progression of every other ailment according to my doctors. Except that I don't have lupus. At this point, I only engage in natural remedies to help the pain. All the pills have stopped. The symptoms that took me to the doctor all those years ago are still prevalent. I have no idea what's wrong with me. There are other medical situations that can no longer be attributed to lupus, yet they are still present. I guess lupus was the easy answer for all these years. Except, they never knew for sure what it was in the first place. What now?

I think about the ramifications of having this particular illness narrative throughout my medical records. I was denied life insurance for my children. Lupus is right next to cancer on the list of illnesses that are sure fire payouts for insurance companies.

Mostly, I think about my boys. Would that have been different if the courts didn't have access to my medical files? More to the point, would it have been a different outcome if my records weren't inundated with untruths? Tears roll down my face as I write this.

My family doesn't know what to say—they say nothing. It's like lupus was snatched from me in the middle of the night and it took everything with it. There is an uncomfortable quiet—a silence so loud it feels like my ears are bleeding. Not having lupus is arguably a good thing, however, I've paid an extremely high price for the belief

of its mere existence. How do you get all those years back? How do you right the wrongs? How does anyone *say* anything that will make it better?

These are the questions that now keep me up at night. The brain doesn't stop. I would almost rather have lupus than to know that there is no validation for anything that has happened to me. I stay in this place of liminality waiting for a legitimizing diagnosis—one that won't come for months yet. I am scared and feel more displaced than I ever have. How do I believe a doctor ever again? Do the doctors know the damage they have caused? **THEY NEVER HAD A CONCRETE DIAGNOSIS.** I cannot articulate the disorienting confusion that I currently feel, nor do I know how to explain this to anyone. It's numbing. In a system that is designed to help and heal, do they know what they've done to me? Do they care? Is there no accountability? Again, I look to the literature for answers.

LITERATURE REVIEW: REDEFINING MISDIAGNOSIS AS MISTAKES

William Nolen (1971), a surgeon, writes: "Patients like to believe that doctors are infallible they like to think errors can only happen to other doctors, not theirs. Unfortunately, that's not the case. Not some, not most, but all doctors, at one time or another, make errors. That is the nature of medicine; it isn't an exact science" (1971:1). Here the doctor explicitly states the dichotomy between the patient and doctor views about the occurrence of mistakes. Do doctors even recognize the "mistakes" they make and more pointedly, what is their definition of "medical mistakes"?

A study was developed examining the evolution of professional language during specialist medical training (Stelling and Bucher 1973). The data from their study makes a strong

point and the authors state: "The very concepts of mistake and failure are lay concepts; in the process of professional socialization they fade away or become redefined during the acquisition of perspectives which place emphasis upon the process of doing the work rather than the outcome of the work" (1973:5).

They also comment:

One of the striking things is how many of these articulate people suddenly become inarticulate when confronted with words like 'failure' and 'mistake.' Before defining these words, they translated them into their own frame of reference. To these physicians, a mistake was "a wrong behavior when any well-trained person ought to know better." Mistakes were about matters of *procedure* and *process*. Mistakes were never determined by outcomes (1973:6).

The researchers further comment with the old adage that "the operation was successful, but the patient died" to expressly illustrate the difference between the patient and doctor perspectives. "The layman is concerned with the results; the professional is focused upon the work itself" (Stelling and Bucher 1973:7). In research conducted by Bates (1980), she states that:

10% of the specialist consultants and 50% of the general practitioners said they did not understand the question, "What does it mean when one talks of a mistake in medical practice?" After probing, some of these doctors went on to say that the selection of medical students, or government interference in medical practice, was a mistake (1980:106).

Research shows a distinct and carefully constructed type of medical vocabulary used by doctors. "Doing one's best" is the language used and defined by the doctor as "feeling no guilt towards their patient if they feel that they have done their best for him/her, even if the patient dies because of or in spite of treatment, it is not regarded as a failure" (Bates 1980:106). As one physician states in this study, "What they (patients) fail to realize is that my work has to do not so much with the results but has to do with the process." Included in the vocabulary of "doing one's best," the concept of "acceptable errors of judgment" is intertwined within the definition. According to Bates (1980), this means that decisions made in the process of treatment may, later,

turn out to have been the wrong ones, but if a well-trained person could justify them at the time, it not seen as culpable (1980:106). "A mistake usually becomes a mistake in retrospect," said one of her respondents, and another said, "You rarely notice a mistake when you are doing it." Bates adds that this is, of course, "similar to lay concepts of a mistake, in that most of us would not make mistakes if we regarded them as mistakes at the time, but where medical vocabularies differ is that while laypersons do regard mistakes as blameworthy in retrospect, doctors do not" (1980:107).

This difference is illustrated by a further series of discriminations made by doctors when talking about mistakes. Bates' (1980) study shows that,

there is distinct differentiation between "normal" mistakes, which all physicians accept as being a risk factor and a necessary part of working as a doctor, and "deviant" or "glaring" or "unforgivable" mistakes, which are condemned in other doctors, are regarded as shameful by the individual committing them, and are usually the subject of attempts to cover up (1980:107).

Freidson (1976) describes this distinction in his research. He shows "that physicians will freely admit to having made mistaken diagnoses and mistaken decisions about treatment. They will even admit to mistakes due to inexperience by the doctor that are fatal to the patient" (1976:9).

Thus, Freidson's physicians discussed mistakes that are made due to ambiguity of evidence at the time or unusual cases which were not recognized for what they really were, all ascribed to the inexperience of the doctor who saw the patient (1976:9). What about these "mistakes" from a seasoned physician? The literature does not provide an answer. In Bates' (1980) research, one of her subjects, a senior resident, said:

A mistake is a death where the person should not have died You treat them wrongly because of inexperience or lack of qualification, but the whole profession of medicine allows for it, and no one particularly criticizes it. Other doctors don't condemn you for making a mistake Unfortunately, nowadays people are becoming more suing-minded and you can't afford to make so many mistakes (sic). You might get into trouble for it, but none of your peers will hold it up to

you—it's a mistake, but that's inexperience and one just has to accept that (1980:107).

This is obviously a point where physician and patient definitions diverge sharply. As Bates (1980) claims, “it is clear that this doctor has learned to consider mistakes solely from the doctor's point of view, and not the patient's, since patients and their relatives would probably be less likely to accept with calm resignation that inexperience by the doctor has cost the patient's life” (1980:107).

Further, interviewees from this study (1980) also distinguished between "honest" mistakes and "bad" or "glaring" mistakes. "Honest" mistakes, according to doctors, were defined as “misjudgments of the situation that go with the job—every doctor makes them, but good doctors were said never to make the same mistake twice. Thus, a repeated "honest" mistake would be a "bad" mistake, as this would amount to carelessness or neglect” (1980:107). Freidson's (1976) respondents made a similar distinction, but talked of "glaring mistakes," which were seen as actions which violated an accepted rule of medical practice. Such a rule, for example, is “When in doubt, suspect illness and continue to try to diagnose and perhaps treat” (1976:108). A doctor who ceases to investigate further, when in doubt of a situation, would be guilty of a glaring mistake (Friedson 1976).

Is this where I fall? A glaring mistake? Some things were indicative of lupus but even as a lay person doing her own research, the symptoms that were not indicative of lupus are glaring. Why did he not investigate further?

Throughout her study, Bates (1980) noted that “glaring,” “deviant,” or “unforgiveable” were the consistent terms cited by doctors as being the result of carelessness or ignorance in

matters that well-trained doctors should know. Conversely, “understandable” mistakes, according to doctors, are the result of pressures from work or the state of medical knowledge. Accordingly, Nolen (1971) says “such mistakes are no reflection on the competence or on the conscientiousness of the doctor, but glaring mistakes imply ignorance due to poor training or failure to keep abreast of modern knowledge, or, even worse, neglect of the patient which is unforgivable” (1971:108).

There was a continual emphasis by physicians on the word "judgment." Judgment, according to the doctors, “is the ability to make correct judgments which distinguishes the competent from the incompetent physician” (Bates 1980:108). The word "judgment" isn't defined on any universal, verifiable characteristic but instead, is used as a multi-layered category for several different kinds of judgment. Throughout the study, physicians described themselves as using different kinds of judgment for different cases. Thus, Nolen (1971) describes a particular stage in the training of a physician during which he is overconfident. He says that all doctors go through this stage, but most will outgrow it. “Knowing one's limits, therefore, is a part of judgment” (1971:108). There is a further distinction between "routine judgment" and "fresh judgment." “From a nonmedical point of view,” according to one consultant in Freidson's (1976) sample, "everything a doctor sees involves fresh thought and judgment" (1976:110). The doctor's perspective is a bit different however.

"If I'm treating a certain type of small, limited carcinoma of the skin, that's a routinized treatment therapeutically. It doesn't require fresh judgment ... But should that lesion be a larger one, and its behavior much more malignant, then it requires fresh judgment, so that's the difference. A great deal of work starts off by falling into a pretty clear category. Fresh judgment involves the exception ... I would say where fresh judgment is involved, there is no error... It's where fresh judgment would be involved but was not exercised and routine followed instead. That would be the greatest error” (Freidson 1976:111).

Clearly, then, physicians believe that gross or glaring mistakes can only occur if an unusual situation is mistaken for a routine one. As Nolen (1971) documents, "if a physician commits an error while using 'fresh judgment' that error is normal, excusable, and therefore not an error at all" (1971:113). These "normal mistakes" were even called "so-called mistakes" by physicians in Freidson's (1976) research. They regarded such normal mistakes as "unavoidable events"; "these are not so much committed by the doctor as they are suffered or risked and doesn't reflect on a physician's competence so much as on his luck. Thus, one should not judge or criticize a colleague's apparent mistakes because 'there, but for the grace of God, go I'" (Friedson 1976:120). He further notes a final but crucial distinction between normal and deviant mistakes: "physicians have a general idea of what every competent physician should know and should be able to do successfully" (1976:113) But, physicians say regretfully, "Laymen are inclined to expect more knowledge, skill and predictable performance from medical work than are physicians, and so are unlikely to subscribe to the notion of normal, excusable mistakes" (Friedson 1976:115).

In consequence of this view of "acceptable errors of judgment," Bates (1980) posits that,

mistakes made in all but the most routine medical activities are viewed as excusable by the medical profession and are not criticized by peers; nor is any penalty exacted by the system unless the patient discovers the error and sues. And indeed, *it is only the recent upsurge in litigation* that has made the medical profession fully aware of the fact that for the patient, outcome is the most relevant variable, and that the patient who is dead, disabled, or disfigured because of an "acceptable" and "uncriticizable" error, is not likely to agree with the calm professional assessment of the situation (1980:109).

Where are the consequences for the social and psychological damage imposed on those patients who blindly trusted the diagnosis of these doctors?

In a line of work that involves high risk and serious consequences for failure, the medical profession has developed certain strategies for coping with mistakes that cause the least amount

of disruption to themselves. The first strategy is the “covering-up” of mistakes and there is a considerable amount of this deceit in medicine; a fact that is freely admitted by the various physicians interviewed throughout the course of social research (Bates 1980). "If a wrong drug is given, or a diagnosis missed, these are usually hushed up" (1980:109) said one doctor in Bates's interviews. Another said, "You are covered a lot in hospital practice in terms of mistakes in treatment, because no one really finds out unless there is a coroner's inquest" (1980:109). A third doctor said, "It's wrong to flaunt colleagues' mistakes when you might make one tomorrow, because then they might do the same to you. The patient has a different perspective, a personal point of view—what's happened to them—whereas the doctor has treated 300 other people" (1980:110). Similarly, Nolen (1971) describes the process in which cases are selected for presentations at surgical case conferences in hospitals. These case conferences are meant (supposed) to be learning experiences for all concerned. "There were many things to consider [when he was selecting a case]. Number one—in my book anyway—was to avoid presenting some case I had really screwed up. I didn't hide my mistakes, but I didn't advertise them either" (1971:14). He then goes further to describe how to ensure that no one ever discussed his real failures. Marcia Millman (1976), during her two-year observation of the Medical Mortality Review conferences in hospitals, came to the conclusion that “doctors systematically ignore errors, treating them as if they were inconsequential” (1976:15). By their definition of mistakes as "normal events," and by claiming, as physicians often do, that each case is unique and different, she posits that,

doctors are able to believe that most mistakes are unavoidable and are just a normal part of medical practice. By judging each other's work by the criteria of “correctness of procedure,” i.e., what the doctor did during the treatment, doctors have ensured that no real evaluation of treatment can occur, since by the time another practitioner sees the patient, the first doctor can always say, "But you

didn't see the patient when I did, and at the time I saw him, the situation seemed different . . .” (1976:15).

The only way to reconcile this situation, for the critic, is that two or three doctors would need to see the patient simultaneously and agree on a course of action. Millman (1976) points out that,

physicians have made very few rules about what actually does constitute good practice. This omission permits the existence of large grey areas where judgment needs to be exercised, thus ensuring that any mistakes that cannot be covered up can be defined as normal and excusable mistakes (1976:15).

Upon further research, misdiagnosis accounts for more malpractice claims than any other medical misstep (Lippman and Davenport 2010). In a survey conducted of US adults by Isabel Healthcare in 2006, “55% of respondents cited misdiagnosis as their greatest concern when they see a doctor in an outpatient setting” (2010:498). In a Harris Poll conducted by National Patient Safety Foundation (Golodner 1997) several years earlier, one in six adults reported having a condition that was misdiagnosed.

Overconfidence by the doctors was cited as one of the major components that contribute to this problem. Further, in 45 percent of the cases, failure to create a proper follow-up plan was noted as the most common problem in the diagnostic process (Lippman and Davenport 2010).

It is human nature to see things in terms of what you are familiar with. For example, a doctor who has been treating a patient with migraine headaches for years is apt to assume that when the patient says, “This is the worst migraine I’ve ever had,” it is more of the same. Similarly, a clinician who has identified a disorder that matches several of a patient’s symptoms may dismiss or overlook signs and symptoms that do not fit that explanation or diagnosis. Safety advocates refer to this phenomenon as “premature

closure” (Lippman and Davenport 2010). It may also be a function of overconfidence. One example of physician overconfidence comes from a study conducted by the Agency for Healthcare Research and Quality (2005). Experienced dermatologists were asked to examine lesions and diagnose melanoma. The study found that “although the specialists confidently diagnosed melanoma in more than 50% of the test cases, 30% of their decisions were later found to be incorrect” (Lippman and Davenport 2010:506).

CRITIQUE: CULTURAL, RESEARCH, PERSONAL

There are glaring problems within the medical culture in attempting to understand and resolve patient issues that are related to mistakes. There is an obvious bias within the medical field in their ability, or responsibility, in defining what a mistake is. Throughout the aforementioned studies, the fact that doctors never seemed to own the word “misdiagnosis” but deflected to the lesser word, “mistake,” is problematic; especially considering misdiagnosis is the most prevalent cause for lawsuits. Every physician takes the Hypocratic Oath, where one line reads: “I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice.” Sadly, the lines seemed blurred to the understanding of who this oath was intended for. How can a doctor understand what constitutes a mistake when the only point of view is his own? This is why autoethnographies are imperative; they are important, useful tools to pull doctors out of their own perspectives. It is problematic that the literature only addresses how the doctor frames his or her mistakes. How does a patient trust a person who is set up in a system that is designed to negate the existence of a mistake; one that removes all culpability from the doctor and leaves the patient in the hands of so-called judgment? A patient doctor relationship requires both the patient and the doctor. If research

continues to only gauge the success or failure of medicine based on one person's point of view—that of the doctor—then it continually fails to recognize the problem.

There is only one article in current research I found that addresses the issues of “mistakes” or misdiagnosis from the perception of the patient who has lived inside the consequences of a medical nightmare (Ferdinand 2016). Due to the prevalence of “mistakes” in the medical field, one would think that the literature would be more robust. Research is antiquated, from last century. What exists shows a flagrant neglect and disregard in medical culture for the patient's entire well-being on a whole. Doctors are giving the wrong answers to questions even when they're asked by patients in the hopes of self-preservation. The studies on this subject appear to show that doctors take no responsibility for the patients they are responsible for.

We see clearly from the literature how structural violence is reflected in how lupus is addressed throughout the globe. People, and especially women, suffer health consequences due to structural positioning and no power. The inability to work, or the mere fact that there are no jobs, profoundly affects both the individual and society. Although lupus currently cannot be cured, survival and life expectancy have increased over the past few decades due to improvements in diagnosis and treatment. However, lupus can still cause considerable organ damage, potentially leading to high morbidity and mortality. As such, “...the direct costs of the disease can be substantial, reaching up to \$55,334.00 per patient per year” (Carter et al. 2016:613). How do people in impoverished societies pay for healthcare? Beyond the financial burden, intangible losses should also be considered, as lupus contributes to decreased health related quality of life via a wide range of adverse psychosocial factors. This measurement of a patient's physical and functional health also provides a view of their social environment and

psychological beliefs, which influences their response to illness. Patients with lupus experience a lower health related quality of life than do the general population, and the reductions are akin to, or even exceed, those for other chronic diseases (Carter et al. 2016)

This lower quality of life is compounded when caught in the middle of an illness that is so contested and invisible. Those living with a chronic illness are constantly shifting their identity to live up to the expectations of a society who has constructed the meaning of their illness. The control of information oftentimes becomes the main focus of an individual over and above the illness itself. They find themselves “betwixt” and “between”—two warring ideals—of who they are and who they’re supposed to be; the dichotomy of Leder’s (1990) “not me” to Estroff’s (1989) “I am.”

As someone who has been diagnosed with lupus, then told I was misdiagnosed but need further testing, and now find myself in a liminal space, I finally understand. I imagine this is how most people living with chronic illness feel. Standing outside of myself, making “me” the object, I know what people thought. I know some were genuinely worried about my coping abilities. I was diagnosed with a horrible illness and lived in horrible pain—sometimes. I felt fine one day but not the next. I didn’t deal with that well because I didn’t understand the nature of the illness; nor did I even have the right diagnosis to point me in the direction of a better treatment. What is the “right” way to cope? Others just thought I was unstable, lending credence to the doctor’s prior decision to put me on antidepressants. I realized that most of what I was facing was a direct result of that decision and knew fully that the parameters of that decision had no play in the current context; however, the lines became blurred and I began to internalize how I perceived others to see me. I have ascribed meaning to what other people think or my perceptions of their

thoughts, and in turn, learned to hide my identity from many. I struggled between what was “normal” and the expectations of everyone else. There were so many “me’s” wrapped up with the thoughts, expectations, and perceptions of other people that “I” would get lost in all the discursive elements that surrounded me. I remember feeling crazy—a person with multiple personalities—never knowing which one to engage at the right moment but duly influenced by them all. Because of this capacity to move from subject to object according to Mead (1934) “...humans not only better develop the ability to control and monitor their own behavior, but of more importance, the development of the self becomes more pronounced” (Hewitt 2000:5). My “self” has been reconstructed continually until I found a space that made sense to me—one that accepted who I am regardless of how ugly that looks from the outside—and within. “I am” my disease and “we” are one.

Recently, I was told that I don’t have lupus, that the doctors got it wrong and I have been misdiagnosed. The “me’s” that have been present for so long are now either nonexistent or have fundamentally changed. No one knows what to say. The discourse has stopped. “I” am trapped between who I was, who I am now, and who I am supposed to be. I am carefully balancing myself in this threshold of liminality; I don’t want to fall through this space and lose myself again. The tattoo inscribed on my arm serves as a constant reminder of the moment that I accepted who I was with lupus—the moment “we” morphed into one. It was all a lie. Or is it? What will the next set of test results show? Will the doctors perform their due diligence this time? How can I trust any diagnosis ever again? My next appointment isn’t for months. I think back to Turner’s (1967) work where he states that. “the attributes of liminality...are necessarily ambiguous, since this condition and the persons elude or slip through the network of classification that normally locate states and positions in cultural space” (1967:95). I have lost

my identity as a healthy person but now have no validation that comes with a correct medical diagnosis. I know I'm not who I was but the work of reconstructing my identity within the context of a chronic illness is pending a legitimizing diagnosis. I live in a space that is betwixt and between, neither one thing nor the other. Everything is ambiguous.

DIALOGING WITH MEDICAL PROFESSIONALS, SOCIAL RESEARCHERS, SURVIVORS OF CHRONIC ILLNESS, AND THOSE WHO CARE ABOUT THEM

These things and more are what patients can't tell their doctors. These are the things they don't have the *opportunity* to tell their doctors. Biomedicine generally allows room for the physical manifestations of illness and nothing more. Open dialogue between the patient and physician are necessary for the promotion of holistic treatment. How long can it possibly take to ask a few questions? There needs to be a different approach to medicine; one that promotes holistic treatment. What if the doctors integrated an interview technique that seeks to understand how the social world both affects and is affected by illness? Kleinman and Benson (2006) were right when they stated, "the moment when the *human experience of illness* or any other social problem is recast into technical categories, something critical is lost because it was never validated as an appropriate clinical concern" (2006:346). Studies could be performed with a small number of medical facilities to test the efficacy of "mini-ethnographies" (Kleinman and Benson 2006). A small interview process, or "mini-ethnographies" would open the conversation between patients and doctors, treating the viewpoints of the patient as valid data. With this approach, doctors can perform mini-ethnographies that would assist in the holistic treatment of a patient. In this way, the doctor/patient relationship is co-constructed, trust may be established, and the dehumanization of the patient is minimized.

Doctors rarely ask questions concerning ethnic identity, how it matters to the patient, and how ethnicity informs the patient's sense of self. To acknowledge and affirm ethnic differences in patients is crucial to understanding a patient's experience of ethnicity and illness. This is an indicator of how life is lived—how people define themselves and their place within family, work, and social spaces. Ethnicity is not an abstract identity. What is at stake for the patient and their family as they face this illness? Whether it's life, religion, close relationships, and material resources, the question brings perspective to the moral lives of patients.

Questions aimed at acquiring an understanding of the meaning of illness helps a patient reconstruct their illness narrative. This process not only opens the doctor to cultural differences, but helps the patient recognize that doctors do not fit a categorical stereotype any more than the patient does. It also opens the conversation to cultural meanings and how those meanings may hold serious implications for care.

Further, physicians should also consider the ongoing stresses and social supports that frame the patient's life. What are the principle psychosocial problems surrounding the patient? Are there tensions within family, work, financial problems, personal anxiety? These factors will help a physician navigate how illness and treatment might be affected (Kleinman and Benson 2006).

Much like autoethnographies, to form mini-ethnographies would go a long way in opening dialogue, validating patient concerns, avoiding miscommunications, and opening doors that provide holistic interventions. My doctor never asked me any of these questions. In fact, my doctor never saw *me* at all. I was merely a number. I wonder how things might have been different if I had ever been asked any of these questions. Social science research should be aimed at social and political change. More qualitative research with survivors of chronic illness and

misdiagnosis is called for. Current studies have largely failed to contribute to bringing change in society, especially because they seem to be leveraged on the side of the medical culture.

Interviews and longitudinal studies could be utilized to inform the medical culture and invoke change. Perceptions cannot be changed and hearts can never be moved if stories are never told.

This research does not address the way in which patients are often stereotyped. Indeed, stereotypical versions of all ethnic groups exist within the larger society. This is what Ferdinand (2016) feared when she was struggling through a misdiagnosis. As hooks (1995) writes, “Stereotypes are created to serve as substitutions, standing in for what is real” (1995:38). In this way, stereotypes are dangerous when visiting a physician as the doctor may only see the stereotype, not the real person. They are also dangerous as they “do not merely tell us how a culture ‘sees’ a group of people; they also tell us how a culture controls that group, how it bullies them into submitting to or evading the representations that haunt them” (Morgan and Bennett 2006:490). This research does not address gender biases. Though women are twice as likely to suffer from chronic pain as men, studies show women's reports of pain are more likely to be dismissed (Powell and Pawlowski 2018). It is too easy for a doctor to pin a woman’s symptoms on stress or anxiety; antidepressants and anxiety medicines are defaulted to as a cure all. How many women are subjected to the consequences of this on a daily basis? I know I’ve encountered it a time or two. Adding these variables to this study would be an interesting twist on how the medical culture is leveraged against its patients. It would also reveal more of the patient/doctor relationship.

Dr. Hunter Patch Adams once said, “You treat a disease, you win, you lose. You treat a person, I guarantee you, you'll win, no matter what the outcome” (Anon. 2014). This is how Dr. Adams treats his patients. These are the types of questions that he asks. If only this were the

current philosophy throughout the culture of medicine. The doctor's job is to treat the whole person, not just the disease they are facing. When you treat a disease, you will be successful some of the time, but when you take the time to really care for a person on an individual level, you will always win. Medicine nor patients are a "one size fits all" scenario and mini-ethnographies could be one technique to pave the way for better care all around.

EPILOGUE: CONCLUSION

Misdiagnosis is sorely understudied throughout the literature. There are glaring problems within the medical culture in attempting to understand and resolve patient issues that are related to these "mistakes". There is an obvious bias within the medical field in their ability, or responsibility, of defining what a mistake is. Throughout the literature, the fact that doctors never seemed to own the word "misdiagnosis" but deflected to the lesser word, "mistakes," is problematic; especially considering misdiagnosis is the most prevalent cause for lawsuits. How can a doctor understand what constitutes a mistake when the only point of view is his own? It is problematic that the literature only addresses how the doctor frames his or her mistakes. How does a patient trust a person who is set up in a system that is designed to negate the existence of a mistake; one that removes all culpability from the doctor and leaves the patient in the hands of so-called judgment? Recalling the literature, my situation can be referred to as an instance of "premature closure" (Lippman and Davenport 2010) Because some of my symptoms fit, other signs and symptoms were glaringly dismissed that never fit my diagnosis. Further, in 45 percent of the cases, failure to create a proper follow-up plan was noted as the most common problem in the diagnostic process (Lippman and Davenport 2010). In my case, no follow-up was ever

planned. Instead, I was simply deferred back to my primary until I was no longer able to be “managed.” In full agreement with the literature, my specialist was supremely overconfident.

I don’t know that the doctor ever saw *me* at all. In hindsight I wonder if he was judging me as the courts did; as a person whose integrity and morality was in question due to my job at a casino. As he sat in his plush leather chair, behind his beautiful mahogany desk, with all his success framed on the walls, was I perceived as a lesser class than the very same, obscenely educated doctor, because of where I worked and what he may have perceived as my life choices? Did the doctor who held my life in his hands perceive me as an individual human with a unique story and situation or was I stereotyped the way Ferdinand (2016) feared she might be at her visit? Was I discounted by the doctor’s personal views of whom he should deem worthy of his full attention? Again, I think back to the literature when it states that stereotypes “do not merely tell us how a culture ‘sees’ a group of people; they also tell us how a culture controls that group, how it bullies them into submitting to or evading the representations that haunt them” (Morgan and Bennett 2006: 490). How much did perceived class dictate certain decisions? Judge. Doctor. Cocktail server. These titles do not hold the same cultural capital. Based on my socioeconomic status entwined with his perception of who I was, I was dismissed as just a blip in his day; a patient unworthy of his time and attention. The courts would judge me through this same lens years later.

Further, the literature asserts that unfavorable disease outcomes are linked to, among many factors, a lack of resources (Carter et al 2016). Arguably, and in my case, a lack of resources exists when there are no appointments available. At the time of my next appointment, I will have waited a full year to be seen by the new specialist. A lack of resources existed when I was dismissed all those years ago with the wrong diagnosis. This is not acceptable.

The literature on liminality is robust. It helped me put into words what has been felt but at the time, could not be articulated. I revisit Turner (1967) again to make sense of this space I remain in. Liminality is the quality of ambiguity or disorientation that occurs in the middle stage of rites, when participants no longer hold their pre-ritual status but have not yet begun the transition to the status they will hold when the rite is complete. During a rite's liminal stage, participants "stand at the threshold" between their previous way of structuring their identity, time, or social status, and a new way, which the rite establishes (Turner 1967:110). Liminality, according to Turner (1967), consists of "neither one thing nor another, or maybe both, neither here nor there, or maybe even nowhere, and at the very least 'betwixt and between' all the recognized fixed points in the space-time of cultural classification" (1967:96). I will "stand at the threshold" until I have a legitimizing diagnosis. I am not crazy. This is a normal process for one that lives with an ambiguous illness sometimes. I am glad I understand this now. It helps me understand others as well.

I again consider the literature when it asserts that poor social support is associated with increased disease activity and impaired mental functioning (Thoits 2011). This autoethnography has opened a door of communication in my personal life. For years, I kept everyone at arm's length. The guilt, anger, and shame that I felt would never allow anyone to get close to me and I resented them for that. It was never them. This process has challenged me to take an honest inventory of my life. The relationships that I have in my life, including the one with myself, are being renegotiated. When there is no communication, healing cannot take place. I am no longer closed off. Ties are stronger because I am allowing people in. Because of this autoethnography, questions have been answered for those closest to me. They have learned right beside me throughout this process. We are communicating and connecting. I will no longer allow others to

reside in a liminal space, always questioning where they fit in my life. This is what my doctors did to me. This writing process has given me clarity. I realize that I do not have to be alone. It is empowering.

It takes collaboration for anything to work. A patient doctor relationship requires both the patient and the doctor. If research continues to only gauge the success or failure of medicine based on one person's point of view—that of the doctor—then it continually fails to recognize the problem. Autoethnography creates a platform from which a patient can speak. There is nowhere else in the medical system where she is “authorized” to speak. If they don't ask the right questions, they will never know the whole story. Perception only changes when the whole story is known. Due to the prevalence of “mistakes” in the medical field, one would think that the literature would be more robust. Research is antiquated, from last century. What exists shows a flagrant neglect and disregard in medical culture for the patient's entire well-being on a whole. Literature, the little that does exist, typically fails to take into account the lived experience of the patient. This study starts to fill that gap.

There is *one* article that addresses the issues of misdiagnosis from the perception of the patient who has lived inside the consequences of a misdiagnosis. Ferdinand's (2016) story plays through my head on repeat. She too felt lost, confused, and scared. Her story provided me with a companion who made me feel less alone in my sense of what has happened to me during this illness. She made me feel less crazy for feeling the things I've felt though our insecurities are different. Her story helped validate something that I still have problems believing. Her autoethnography created the opportunity for connection and made me part of a community defined by suffering at the hands of a medical culture that often does not practice its due diligence or ethic of care.

This is what autoethnography does. It “[breaks] the silence around understudied, hidden, and sensitive topics” (Adams and Holman Jones 2008:377). If not for this process, I never would have known that I had been misdiagnosed. “Most consistent with” and “most suspicious for” is never a concrete diagnosis. It is okay to ask to see your lab results. I want you to know that because I never did—until now. Your medical records are always *your* business. Know that too.

I would like to emphasize the point that I am not villainizing doctors. With special emphasis towards my primary physician, he has given me the time and care above what most doctors would. When I made it important for him to listen, he did. He heard *me*. He told me that our conversation gave him clarity about a few other patients—that he finally understood what they were trying to tell him. It took us 12 years to get to this point. The connection between me and my doctor provided healing for us both. I am not the same person. He is not the same doctor. I believe that most doctors would operate in this fashion if they just knew how. I do not believe that the specialist treated me with malicious intent. I think back to the literature when it said, “doctors, when in doubt, suspect illness and continue to try to diagnose and perhaps treat” (Friedson 1976:108). A doctor who ceases to investigate further, when in doubt of a situation, would be guilty of a glaring mistake (Friedson 1976). I was definitely the subject of a glaring mistake. He was certainly overconfident. Careless. Cavalier. Wrong.

I believe that he is caught up in a biomedical system that trains them to treat the illness but not necessarily the patient. These systems are designed to heal but oftentimes they only exacerbate existing problems by ignoring the patient. The medical culture needs a shift in their focus. Without the personal stories, the lived experience of the patient, there will never be a real understanding of the psychological damage a doctor can inflict; damage that can supersede any diagnosis that could ever be given—especially when illness is all the doctor sees.

This facet of research is what the literature does not address; it is virtually non-existent. The perceptions of the patient, specifically the identities of patients living through the nightmare of misdiagnosis, is rendered invisible. This is my contribution to the existing gap in the literature.

This has been an autoethnographic account of the experience of living with chronic illness and a liminal status. It is not an attempt to place all doctors in a bad light nor a platform for disparaging the intentions of the entire medical community. Rather, it is privileged access to my experience of being misdiagnosed with an ambiguous illness. In this way, “we can best understand what it means to live with chronic illness by listening carefully to the stories that participants share” (Telford, Kralik, and Koch 2006:458). I wanted you to feel what it was like in the moment of diagnosis and to be there with me in my darkest moments as I struggled with my identity and pain, in hopes of “exploring emotive topics and those which are conventionally kept private” (Chang 2008:50). Autoethnography creates the platform from which a patient can speak. As Frank (2015) asserts, “In the cycle of witnessing, telling the story of one negative dialogue can be the beginning of a positive dialogue. That is what witnesses do; they transform absence of dialogue into open, on-going dialogue” (2015:13). I hope this autoethnography opens an on-going dialogue. I hope you never feel alone.

The aim of this study was to open up a dialogue with medical professionals, those who research the social aspects of chronic disease, those who are diagnosed with chronic illness, and loved ones and sympathetic others who live and learn with them. I feel confident that I have done that. I have also investigated, through my own personal narrative, the potential ramifications of a tarnished identity when the individual has been ultimately misdiagnosed. There is nowhere in the medical system I have ever been “authorized” to speak in this way.

I have spent a great deal of time trying to figure out how to wrap this up. There are no profound statements and no easy answers. It is difficult to end because there is no end to my story yet. I still wait for diagnosis, whatever that means. I continue to reside in a liminal space waiting for an identity that fits. Whatever the identity, the new diagnosis will not define me. This autoethnography has forced me to look at myself in a different light, caused me to face my demons, healed certain parts of me, and equipped me with knowledge. Imagine how much more autoethnographies could inform a medical system that is so broken. No matter the diagnosis, I will fight different this time. I am no longer the person who will take anything at face value again. Knowledge is more powerful than trust.

Lupus is devastating when it is diagnosed—diagnosis is extremely difficult when/if it ever comes. The disease itself is completely ambiguous as is the identity that lives inside it. It ravishes the body and makes it final assault on the identity of the bearer. How does one ever really reconcile that? I'm still a work in progress.

I came here to let you know

The letting go has taken place

I have held the winter's son

Become one set my pace

Isn't that what we wanted all along

Freedom like a stone, maybe we were wrong

But I can say goodbye

Now that the passion's died

Still it comes so slow

The letting go

Piece by piece I take apart

This complicated heart and I hope to find

Something I can prove is real

I can feel is truth, I can say is mine

That's all I ever wanted to be

The closer that I've got, the further I could see.....

(Etheridge 1991)

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APPENDICIES
APPENDIX A
IRB DETERMINATION

irb@memphis.edu

Fri 8/24, 8:49 AM

Brandi Michelle Barnes (bmbarnes);

Carol A Rambo (crronai)



Institutional Review Board
Office of Sponsored Programs
University of Memphis
315 Admin Bldg
Memphis, TN 38152-3370

August 24, 2018

PI Name: Brandi Barnes

Co-Investigators:

Advisor and/or Co-PI: Carol Rambo

Submission Type: Admin Withdrawal

Title: "Defining Diagnosis: A Reflexive Account of a Chronic Dis-ease Process"

IRB ID: PRO-FY2019-95

From the information provided on your determination review request for ""Defining Diagnosis: A Reflexive Account of a Chronic Dis-ease Process"", the IRB has determined that your activity does not meet the Office of Human Subjects Research Protections definition of human subjects research and 45 CFR part 46 does not apply.

This study does not require IRB approval nor review. Your determination will be administratively withdrawn from Cayuse IRB and you will receive an email similar to this correspondence from irb@memphis.edu. This submission will be archived in Cayuse IRB.

THANKS,

IRB Administrator

Research Compliance

Division of Research & Sponsored Programs

The University of Memphis

[315 Administration Building](#)

[Memphis, TN 38152-3370](#)

P: 901.678.2705

F: 901.678.4409

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