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CURRERE, ILLNESS, AND MOTHERHOOD: A DWELLING PLACE FOR EXAMINING
THE SELF

by

MICHELLE C. THOMPSON

(Under the Direction of Marla Morris)

ABSTRACT

This dissertation is a pathography, my experience as a mother dwelling with illness which began because of my son's illness. The purpose of this dissertation is two-fold: to examine my Self as a mother dwelling with illness so that I may begin to work through repressed emotions and to further complicate the conversation begun by Marla Morris (2008) by illuminating the ill person's voice as one which is underrepresented in the canon. This dissertation is written autobiographically and analyzed psychoanalytically. The subjects of chaos, the Self, and motherhood are examined as they apply to my illness. In addition to psychoanalysis, this dissertation draws from illness narratives, pathographies, and other stories of illness as a way to collaborate voices within the illness community.

INDEX WORDS: Curriculum studies, Pathography, Illness, Autobiography, Dwelling, Motherhood, Self, Chaos, Education, Memory, Other, Psychoanalysis, Good-enough, Currere

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B.S., Georgia Southern University, 2000

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A Dissertation Submitted to the Graduate Faculty of Georgia Southern University in
Partial Fulfillment of the Requirement for the Degree

DOCTOR OF EDUCATION

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2011

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CURRERE, ILLNESS, AND MOTHERHOOD: A DWELLING PLACE FOR EXAMINING
THE SELF

by

MICHELLE COX THOMPSON

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DEDICATION

To Alex and Tyler, whose unwavering love and encouragement has given me strength.

And to Bradley, who has opened my heart.

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CHAPTER 1

INTRODUCTION

The baby is a storm threatening to dissolve, break down, drown barriers...A baby threatens to open one's heart. (Eigen, 2005, p. 35)

[I]llness is an opportunity, though a dangerous one. To seize this opportunity I need to remain with illness a little longer and share what I have learned through it. (Frank, 1991, p. 1)

I have always been mystified by storms. Some of my fondest memories as a child were watching the imposing storms evolve as they made their way across the Atlantic Ocean. The porch of my grandparents' beach front condominium offered the prime vantage point to analyze the churning waters in the ocean's cauldron. I felt defeated as I watched the sand castle I had spent hours constructing earlier in the afternoon instantly crumble beneath the weight of the consuming waves. The bright summer sky above me slowly faded as the heavens steadily pulled the thick, black blanket of clouds over my head. The sheet of rain moved in a line, first across the water, then to the sand, across the parking lot, and finally to where I was standing, slicing sideways through the air as it pounded my face. I was fearful of the metal-like shards of rain as they ripped through the peaceful tranquility of my afternoon. I was forced to retreat behind the safety of the sliding glass door, but my face remained pressed against the glass as I longed for a time gone by. There I would sit, and wait, protected from the elements until the storm had passed, pondering how I would muster the strength to rebuild my demolished sandcastle.

Nature is the source of amazing storms---thunderstorms, tornadoes, hurricanes. By definition, a storm is a disturbance to the atmosphere accompanied by severe weather conditions; they scatter debris and mar the landscape. At times, there are visible signs that a storm is

brewing. Within seconds, the wind can change pattern and transform the sky to an eerie color. Individuals who have previously experienced a similar storm recognize the foreboding conditions and heed the warning. For example, those who have lived in the Midwest tell me that the sky turns an odd green-brown color when conditions are favorable for a tornado. Having never experienced a tornado, I would probably dismiss this obvious sign and be taken by surprise when I did not heed the tornado's warning to seek shelter. After all, the days preceding a storm may give no indication that a storm is on the horizon. The weather conditions during these days, often blue skies and moderate temperatures, encourage carefree merriment. This period of tranquility is referred to as the "calm before the storm." However, most storms share the commonality that they wreck havoc on the environment. Storms scatter debris and flood the terrain, crushing anything that stands in their path. Sometimes the changes to the landscape can result in better vegetation and improvements over time; however, the damage invoked by the storm makes a permanent mark on the landscape.

Though one may think of storms in only the physical realm of our world, storms are not only present in nature. Eigen (2005) speaks of "emotional storms" that occur within the Self. These "emotional storms" are not caused by some disease but are central components to the development of the Self. Emotional storms are caused by some sort of imbalance, or chaos in the system. However, these storms of chaos are necessary for survival because they provide an opportunity for redefining the Self. Similar to storms found in nature, these inner storms can cause a great disturbance to the Self's atmosphere and can scatter debris while destroying anything in their way. Although at first it may seem odd, Eigen (2005) encourages one's embracing of "emotional storms" and the accompanying chaos. It is through these "storms" that the most insight may be learned about the Self and then shared with others.

In another light, illnesses can create a type of “emotional storm.” And, similar to storms, illnesses are unique in the way that each manifests and changes the landscape of the Self. Whereas a large storm may destroy everything in its path, enduring illness in our lives may seem to obliterate everything emotional within us. In another view, the smaller storms of illness may chip and gradually erode us in particular ways. Perhaps one emotional difficulty may wear away at our sense of self image. When we experience something else of that nature, the adversity is compounded and gradual erosion can develop into a type of destruction. Childbirth can also be equated to a storm. Pangs that erode the body seem to destroy; yet, through a miracle, life appears. Clouds create low rumblings of thunder as they begin to assemble into an organized chaos; the dull, aching sensation signals the onset of labor. The whirling winds pick up the debris while the doctors, nurses, emotions sweep the mother in a tornado around and around and around. Lightning flashes across the sky as the flood lights illuminate the terrain that will soon be altered, scarred. The crashing of thunder and the pounding of rain indicates the power, strength, intensity of the storm’s arrival. The mother screams in anguish as the floodwaters break free from the barriers. The storm preparation seems to have taken an eternity, yet the storm subsides almost without notice. The severe weather conditions have diminished; however, a new storm is brewing—a baby has been born into the world.

A Heart is Broken

I could not fathom the magnificent storm brewing in my own womb. I was determined that Thursday, April 12 would be the most appropriate day for birth given the superstitious vibe of Friday the thirteenth. How I longed to see the sweet face of the little alien that had inhabited my womb, kicking my insides for almost 39 weeks. Without incident, Bradley Reed Thompson

entered my arms and heart forever at 11:53 p.m, minutes before midnight. I was blanketed in peaceful tranquility as I held my perfect angel in my arms for the first time, narrowly escaping the imposing deadline. His initial evaluation did not expose the congenital heart defect that remained undetected until his vital signs began to decline. Within hours after his seemingly perfect arrival, I saw the storm brewing, threatening to overtake me as the waves had destroyed my sandcastles as a child. I found that Bradley's only chance for survival was to have open heart surgery to correct the misplaced arteries. Less than twelve hours after arriving into this world, Bradley was taken from me, his fate in the hands of strangers. As I placed his broken body in the bassinet, I was fearful that the child I had yet to know may be taken away from me forever.

The days, weeks, and months that followed Bradley's birth were not at all what I had imagined in my mind. Many post-partum working mothers are given six weeks to physically recover from the storm of childbirth and to emotionally bond with her new bundle of joy. I was looking forward to holding my new baby close to my chest as I rocked him to sleep in the chair I had recently recovered to match his room's décor. I eagerly anticipated placing Bradley in his new stroller so that he and I could take leisurely walks around the neighborhood while I proudly introduced the newest addition to our family. I was not afforded these opportunities in the way that my mind had pre-meditated. Similar to the glass door that protected me from the elements of the storm so often as a child, I had become an expert at donning a façade to protect my emotions from the harmful effects of the ordeal. It was emotionally exhausting to remain strong throughout our twelve-day hospital stay. While my baby lay in the hospital bed surrounded by a chaos of tubes and wires, I felt helpless. As the days passed I was eager to put this time in my life behind me. Yet, I had only passed through the front wall of the hurricane. The four hour drive to our home in Savannah from the hospital in Atlanta was uneventful, although unsettling

at best. The eye of a hurricane is messy this way. It provides a false sense of calm. Nature slows down, almost stops moving for a moment. But this is all in preparation for the back wall of the hurricane, where the winds are the most violent, spinning in the opposite direction. Upon arriving home I was given an orientation of the medical equipment that had been delivered by the home health service. I felt trapped among the oxygen tanks, tubing, and feeding supplies that covered my bedroom. At this point, my glass-door façade became transparent as I collapsed into a hysterical fit of tears. I sat on the floor, back against the wall and head in my hands, sobbing. I did not sign up for this path in life; I wanted a healthy baby, not one with problems.

I have frequently used the term “ordeal” to define the storm of chaos that has encompassed my life since learning of Bradley’s heart defect. I am not sure why I first chose this word to sum up the experiences directly pertaining to and stemming from the moment I learned my child’s life was in jeopardy. Webster’s defines “ordeal” as “a severe trial or experience.” I believe this was my initial intent for the word. However, Webster’s provides a second definition: “a primitive means used to determine guilt or innocence by submitting the accused to dangerous or painful tests believed to be under supernatural control.” As I held Bradley’s violated body hooked up to a myriad of tubes and wires I kept whispering, *I’m sorry. I’m so sorry.* I am accused of causing Bradley’s heart defect, even if I am pointing fingers at myself. The doctors insisted that his heart defect was not something that could have been prevented. Still, I blame myself. I had been his sole provider for almost 39 weeks, and I failed him. I must be guilty. Some in my circle might suggest that a supernatural deity was trying to get my attention by allowing this “ordeal” to occur. I dismiss this thought while agreeing with Frank (1991) who insists that “[d]iseases are not messages from some god, nor is illness a test of faith” (p. 90). I believe the supernatural entity that is in control is that of chaos.

Illness, by nature, is chaotic. Medical professionals try to control illnesses with medication and treatments. Those who believe in superstitions, such as bad luck associated with Friday the 13th, thrive on control. I controlled my labor, as much as possible, determined for Bradley to be born before midnight to escape any bad luck that loomed ahead of him. But illness, specifically congenital heart defects, cannot be controlled.

Bradley's heart defect was chaotic; there is no explanation as to why something that should have happened during gestation did not. This non-occurrence affected Bradley's physical heart as well as my emotional heart, both of which are forever scarred. The heart is fragile and should be handled with caution. Doctors were once warned *noli me tangere*, Latin for "do not touch me," when contemplating altering the physicality of the heart. Operating on this delicate organ often requires the cessation of blood flow through its vessels. Blood must be rerouted outside of the body and through a machine where it acquires oxygen needed to sustain the remainder of the tissues. Bradley's body became a cyborg, if only temporarily, while his surgeons worked feverishly to transpose and reattach two minuscule blood vessels with diameters comparable to a piece of sewing thread. Similarly, I have become a cyborg in order to repair my emotional heart. My computer has absorbed my words, reorganized them to provide meaning, and allowed me to reabsorb what has been written so that my emotional heart may be repaired.

As Frank (1991) states, illness is a dangerous opportunity. Illness is not something to be taken lightly. Some illnesses, such as influenza, present in such a way that they can be identified and usually treated with appropriate medications and therapies which result in a favorable prognosis. Other illnesses, such as rheumatoid arthritis, are chronic; treatments may help ease the suffering but ultimately the individual must endure a life-long journey with the illness.

Illnesses, like cancer, can eventually lead to death. Still, I think the most dangerous illnesses are those that have no identified etiology, thereby making treatment almost impossible.

This dissertation discusses my emotional illness which has developed because of my son's physical illness. I am not really sure if the term "illness" is appropriate to describe what I have experienced during this time. I have not been to a doctor to seek medical advice. To most of those in my circle, I appear normal. But I think that it is the appearance of "normal" that is the most troubling. After all, my grandfather looked "normal" for months before there were indications that he had end-stage liver cancer. However, those closest to me know that something is unsettled deep within my Self. My dilemma is that what I am feeling has no definite etiology. I assume that my illness stems from the "Bradley ordeal." But by medical standards he is fixed, normal. Everything in my realm tells me that I should be thankful that he is still with me. And I am. But I do not feel that I am the same normal as I did before the ordeal began. My illness may be classified as a form of depression, but I do not feel depressed nor do I have faith that a handful of happy-pills will make my pain subside. I am not ill in the same way that one with cancer or AIDS is ill. But I do feel a sense of loss, possibly in a similar way that others who are ill experience.

Although I find difficulty determining the exact words to describe my illness, writing about my experiences has provided a source of healing no medicine could replicate. Frank (1991) encourages me to "seize this opportunity" and then to "share what I have learned through it" (p. 1). By this, he charges me to "experienc[e] it fully, then [let] go and mov[e] on" (p. 3). As distance separates me from the main events of the ordeal, it is becoming increasingly difficult for me to desire to stay with this opportunity any longer. I want to forget about what has happened, sweep it under the rug, move on. Most of the individuals who were involved

throughout the ordeal have moved on; why can't I? A part of me insists that the ordeal is over, but I know this statement is false. Illness is never over. Like a storm, the effects of illness are permanent even though the weather conditions/symptoms have waned. This storm may have passed, but there will be others to weather. Nothing is learned from the experience if I forget its effects and move forward prematurely. I do not take my charge lightly. Although difficult, I will "remain with illness a little longer" (Frank, 1991, p. 1) in hopes of learning more about my Self during this difficult time. In turn, it is my hope that my story may offer encouragement to another, as other's stories have encouraged me throughout my journey with illness.

Illness in Society and Education

Mathematical computer models measure storm intensity. The data obtained aids in predicting the severity of the forthcoming storm and possible destruction. Ultimately, these models are used as a means of categorizing storms. However, the ambiguity of the term "intensity" and its use in defining severity is troublesome. Some storms, such as tornadoes, are severe no matter what the intensity because they cause destruction to the terrain. When considering the terrain affected, a summer rain shower may drown freshly planted flowers and kill them. On the other hand, the mighty oak tree, which has weathered centuries of hurricanes, will not succumb to the most torrential downpour. Storms of differing intensities affect two distinctive terrains in unique manners. Similarly, illnesses of contradictory intensities will affect two individuals in different ways. An illness one person may endure with little setback could prove detrimental to another individual. Oftentimes, those who have experienced a similar illness will offer words of encouragement to the ailing; although well-intended, these words may serve to diminish the individual's emotional realm. While the etiology and treatment of similar

illnesses may be comparable, the affect on the individual is unique and should not be categorized. Categorizing illness can serve as a source of oppression. Paulo Freire (1970/2007) says that no one can speak for the oppressed, but through collaboration the community can speak with them. Therefore, the individual's story must be shared in order to form community among the ill.

Communities in society, generally speaking, do not accept the ill person into its sphere. Illness is discussed, but only on a superficial level. Questions such as "How are you doing?" are asked, but those inquiring entail little more response than "I'm doing okay." Time is not afforded to expose the complex emotions of anger, frustration, fear, loss. Even if time is allotted for the ill person to reveal these complexities, s/he risks appearing vulnerable and weak. In my experience, society has demanded that I appear strong, not weak, so that I can manage the curveballs life throws at me. I recall the numerous written accounts of concerned friends who were impressed with my "strength" throughout the Bradley ordeal. Although well-intended, their comments encouraged me to further repress my emotions. I often felt as if I needed to keep a tight lid on my bottled-up emotions in order to keep my anger, frustration, fear, loss from exploding all over the room.

The emotional complexities that accompany the ill person as s/he dwells with illness is an unwelcomed companion. Therefore, the body of illness can be viewed as taboo. This othering of illness has been my experience. Within my circle of friends and medical professionals, I have often felt as if I had to provide a quick answer to the questions asked pertaining to illness. I have been encouraged to reveal my emotional complexities to a professional who could afford the time needed to divulge my inner feelings. However, I am not comfortable partaking in such an intimate act with someone whom I have no relationship. Oftentimes, I have kept my feelings

repressed, shelved for a later time, although I know this is not healthy for the Self. Through this ordeal, my pink laptop computer has been my confidant, my unassuming listener, my ever-present help in need. She requires little more than a full power supply to absorb what I deposit in her and is willing to pick up from previous conversations no matter the time of day. Writing about illness has allowed me to work through the complexities of my illness. No time constraints, no interruptions, no biases. She and I are alone, trying to make sense of illness.

My experience with illness has allowed me to be more compassionate to others who are enduring difficult circumstances. In my classroom, I am often approached by students who are shouldering more than their share of burdens and are seeking someone who will listen to them for a moment. No teacherly advice, no self-help pamphlets. All that is asked of me is a moment of my time so they may disclose their concerns. Of course I understand the legal ramifications of counseling students outside my area of expertise. There are many instances in which a trained counselor is more appropriate to handle certain situations. However, similar to my reluctance of seeking professional help, students are hesitant to disclose information with someone whom they have little relationship.

Teachers are cautioned of becoming too personally involved with students because it may distort the educational realm. However, education must not limit its curriculum to that which is joyous; education has a responsibility to address the solemn curriculum as well. Paula Salvio (2007) identifies Sexton as an educator who shamelessly addressed the taboo subjects of depression, addiction, and suicide in the classroom. Although these are sensitive subjects, they are very real to many of the students I teach. Jonathan Silin (1995) is concerned that he has crossed the “invisible line” (p. 39) when speaking of death and illness to his students. He justifies his actions by asserting that these taboo topics are not exclusive to members of the adult

world. Students are neglected when educators assume that they are not mature enough to be concerned with such issues. Illness knows no age, gender, race, time, or place. Each individual is vulnerable to the effects of illness. Are we, student and teacher, not the same within and outside of the classroom? If I do not seize opportunities to facilitate the complicated conversation within my classroom then I am missing the chance to educate my students. Illness is a part of currere and holds a rightful place in the curriculum.

I feel it is my obligation to incorporate illness into the complicated conversation. When speaking about the subject of illness, many in my circle insist that one cannot dwell on it. No, one cannot dwell “on” illness because illness is not an object; illness is a part of the individual that one dwells in, not some other entity apart from the body. Illness is a dwelling place. Heidegger (1971) discusses the relationship between the terms “building” and “dwelling place.” He identifies that a building can be a dwelling place, although it does not have to be. Buildings can provide shelter, similar to the way my grandparents’ condominium provided shelter during the violent summer thunderstorms. But illness is not the type of dwelling place that provides shelter. Illness exposes, rather than protects, the individual. One cannot rest in the comforts of illness and wait for the passing storm. Illness is the storm and one must holdfast so not to be carried away by the turbulent wind. As Heidegger (1971) identifies, a dwelling place is not a place of stagnation:

When we speak of dwelling we usually think of an activity that man performs alongside many other activities. We work here and we dwell there. We do not merely dwell—that would be virtual inactivity—we practice a profession, we do business, we travel and lodge on the way, now here, now there. (p. 145)

As I engage in the other activities that are required as wife, mother, daughter, sister, teacher, church member, friend, illness travels with me. Illness is not an object that I can leave at home to wait for my return, like the dishes piled high in the kitchen sink. Nor is illness an object that I can discard and purchase anew, like a pair of shoes. Illness dwells alongside, oftentimes as an unwelcomed companion, traveling with me on life's journey.

Drawing from the Stories of Others

The purpose of my dissertation is to investigate the effect dwelling with illness has made on my Self as a mother and an educator. When Bradley was in my womb, he was a part of me. Once his umbilical cord was severed, and further when he was taken to a hospital in another city, he became apart from me. Apart but a part. His heart defect was a part of him. But Bradley's illness also became a part of me. His illness was separate from my body but simultaneously consumed my body. Similarly yet differently, his illness became my illness. Yet, Bradley became an othered part of me, some thing I needed to compartmentalize in order to work through the emotional complexities. Although, he was more than just an illness that I could cast off for another time; Bradley was my child who needed my attention and affection. How difficult to love something that also is the source of pain! The troublesome yet intriguing duel of the Self/Other has played a major role throughout my experience with illness. Reading others' accounts of illness has helped me to make some sense of the non-sensical attributes of illness. As I attempt to flesh out the role of the Self/Other dualism in my experience with illness, I hope to encourage others who may also be traveling similar journeys.

There are two key authors who I credit with sparking my interest in my dissertation topic. As I read Arthur Frank's (1991) *At the Will of the Body*, I found myself engrossed in his story,

his words, and the meanings that they held for me. Was it possible that he knew about my struggles? Was he with me when I had my emotional breakdown? How did a person whom I had just met, and only in the literary sense, know so much about me? I turned the pages of his book fluidly while I bathed in its waters, finding comfort within the confines of this shelter. Frank (1991) states, “My own experiences are in no sense a recipe for what others can expect or should experience” (p. 5); however, there are some commonalities among the stories told by ill persons. The plot is different and the characters are not the same, but there are common threads that weave throughout stories of illness. Doll (1995) asks, “Writing is a kind of knitting, isn’t it?” (p. vii) I suppose it is. Jewel tones of green, red, blue, and gold threads woven in intricate patterns represent the times of rejoicing, such as the pride felt after the birth of a baby. Muted tones of drab and gray and black represent the dark times: finding out my child had a congenital heart defect and the overwhelming fear that I may lose him. Just as knitting a large blanket takes time and must be worked on in sections, so I also took time to compose the various aspects of myself. When viewed separately one may wonder how all of the pieces will fit together. Drab? Why would anyone choose that color? But unlike physical knitting, the yarn used to knit one’s life story is not always chosen by the knitter, but instead is chosen for her/him. As the knitter uses needles to stitch together the blanket, so do the medical professionals stitch together the ill body, using both jewel and muted threads. The artwork on the cover of Doll’s (1995) *To the Lighthouse and Back* is of interesting significance. The artist, Jason Smith, explains:

Like a beacon in a sea of words, this lighthouse is built Mother (the Madonna of Fra Angelico’s San Domenico alterpiece) upon mother (the author’s). One shields her eyes from the other but cannot turn away. Rays (from Virginia Woolf’s *To the Lighthouse*) pierce the ignorance. The light is harsh but the only guide we have. (inside cover)

Here, the artist represents the duality of the Self and the Other. While writing a story of illness, one faces parts of the Self that are strange, grotesque even. One cannot disown this part of the Self, the Other; instead the Self turns away, but accepts the fact that the Other is part of her. This recognition is painful but necessary if restoration is to occur. These painful experiences are intricately woven among the joyous events within the blanket of one's life story.

Equally influential in shaping the context of my dissertation is Marla Morris' (2008) *Teaching through the Ill Body*. Her pathography validated my feelings of vulnerability as I allowed those in my public world admittance into my private realm. I am fortunate to have studied extensively under Marla Morris. She first introduced me to the field of psychoanalysis and the genre of pathography. She encouraged me to write for myself, not for others, because it is when you write for yourself that the most meaning is obtained. She taught me how to be a genuine educator and that separating my personal from my professional life was inauthentic. She also prompted me to read a lot, especially pathographies because “[w]e understand our own struggles mostly in light of studying the struggles of others” (Morris, 2008, p. 112). Morris' (2008) contribution of her pathography is pioneering in the field of curriculum studies. I find it ironic that a subject, such as illness, that literally affects every person in some way or another has been omitted from the canon. It is my hope that my work further advances this novel area of the field.

Like Morris (2008), I use psychoanalysis to analyze my pathography. For me, writing autobiographically is naturally analyzed through psychoanalysis. I agree with Connelly and Clandinin (1988) who suggest, “There is no better way to study curriculum than to study ourselves” (p. 31). Curriculum encompasses the lived experience. Therefore, illness is a part of the *lebenswelt*. There have been numerous accounts written about individuals working through

illness. Many accounts have been written about people dwelling with illness in their own body, such as cancer or other chronic illnesses. This is the case with both Frank's (1991) and Morris' (2008) written accounts. Other stories speak of illness in a third person view. A loved one may be dwelling with Alzheimer's disease or AIDS and the author describes the personal effects of traveling alongside the ill person. However, I contest that my work is different. My son's illness has not just affected me; his illness begat my illness. What is troublesome is that my son's illness has been fixed by medical standards. Yet, the effects of the ordeal constantly plague my thoughts. I still carry guilt that I was somehow responsible for his heart defect. I carry guilt that I did not properly bond with him during those first few precious months of his life. This guilt affects my relationship with my son, my relationship with others, as well as the relations within my Self. It is my desire that this dissertation will further advance the novel area of the field pioneered by Marla Morris by adding a new dimension to the curricular conversation: the discussion of an illness within an illness.

Curriculum Studies and Pathography

I have heard some claim that their profession is their life's calling. My sister, for example, knew at a very young age that she wanted to be a math teacher. I, on the other hand, stumbled into the education profession, and moreover the field of curriculum studies. However, in hindsight, I cannot imagine my life in any other capacity. Call it destiny, fate, providence, or a natural order of the cosmos. At minimum, my life has been a collection of apparently random happenings that have organized themselves into a more significant meaning.

At a young age I aspired to enter the medical field to make caring for others my life's work. On the surface, this mission for my life may appear to others as being benevolent;

however, I gained a sense of self-satisfaction in knowing that I could help someone during times of need. My undergraduate degree in exercise science led me to a career as a medical assistant in a cardiology office. While I enjoyed my work, my duties did not allow me the time to forge relationships with my patients in a way that I felt they deserved. I was cautious of spending too much time with one patient for fear of getting my attending physician out of rotation. On one occasion, after explaining a heart procedure to a patient, she looked at me and asked if I had thought of becoming a teacher, suggesting that I had a knack for explaining things in a non-threatening manner. I credit this woman, this nameless and faceless individual in my memory, for encouraging me to become an educator. It is in the classroom with my students that I am able to forge the relationships that I lacked with my patients yet still care for them in times of need. I strive to instill a sense of individuality among my students while encouraging open communication. However, on more than one occasion I have been called to the principal's office and reprimanded for my personal teaching methods. Salvio (2007) paints a portrait of Anne Sexton who "rarely hesitated to make herself open and available to her students, showing them her worksheets, discussing her own problems and processes in writing, and holding conferences with them in her living room" (p. 8). While I am not Anne Sexton, I can identify with this portrait of openness that Sexton had with her students. I am not an expert in my classroom. I feel that my students and I are on an educational journey together as students of curriculum, learning from each other as we travel these winding roads through life. Together, we jump through the necessary hoops required by the institution while infusing opportunities to engage in meaningful dialogue.

My teaching philosophy is simple: Students will not care what you know unless they know that you care. I cannot claim this statement as original, although I have no recollection as

to the source that impressed its meaning on me. Since the beginning days of my teaching career, I have held fast to this philosophy. Education encompasses more than what is assessed on a standardized test, contrary to what is often publicly highlighted as being of utmost significance. Education is about relationships and, more importantly, meaning derived from those relationships. Because so much time is mandated for purposes of addressing standards and helping students achieve passing test scores, much of what is of importance to students is omitted from the curriculum.

The field of curriculum studies strives to address that which is left out of the canon while valuing the *lebenswelt*, or lived experience, of the individual. Pinar (1972) suggests that one should “work from within” (p. 10) when interpreting the meaning of curriculum. Heeding Pinar’s suggestion, I continuously search myself through autobiographical inquiry as a means of “[working] from within.” Autobiography as a form of curriculum inquiry has roots reaching back to the beginning of the Reconceptualization. The foundation of curriculum studies lies in the concept of *currere*, which in Latin means “to run the course.” With some illnesses, especially those of viral nature, a patient is often told by the doctor to let the illness “run its course.” This can be a disturbing recommendation to a patient who is seeking immediate relief. However, inducing a quick fix with medication instead of letting the body take control of the healing process robs the body of the opportunity to fight adversity. I question how some educators can expect a quick fix in areas such as student behavior, curriculum, or test scores. Pinar (2004) insists,

The method of *currere*...promises no quick fixes. On the contrary, this autobiographical method asks us to slow down, to remember even re-enter the past, and to meditatively imagine the future. Then, slowly and in one’s own terms, one analyzes one’s experience

of the past and fantasies of the future in order to understand more fully, with more complexity and subtlety, one's submergence in the present. (p. 4)

Of course, not all educational concerns can be permitted to "run their course" through the institution's hallways. Some situations, such as school violence, must be dealt with immediately. Similarly, some illnesses, such as cancer, cannot be permitted to "run its course" through the body without some medical intervention. However, a definitive treatment plan or prognosis is not always a possibility, especially when dealing with complex illnesses or illnesses with no definite etiology. Sometimes the outcome is unclear. Treatment may work, or it may not. The future is unknown.

Throughout my study in the field of curriculum studies, I have learned that the end of the journey is not of utmost importance. In fact, the end of the journey may be unknown. While I value this concept, for someone who is of a controlling nature this uncertainty can be bothersome. When I first settled on my dissertation topic, I grappled with the notion that a good story had to have a beginning, middle, and an end. I can identify the beginning(s) of my illness. Although the middle of my story is jumbled, at best, I am beginning to make some sense of what has taken place. But the end.....what end? Wikan (2000) describes her story of illness:

It is a story with a definite beginning (or two), a moderately clear middle, and a muddled, unfinished end. Who says that narrative begins with an end, with knowing how it all went? I shall argue the contrary. What marks my illness narrative, as well as the narratives of many people I know, is the absolute certainty of the beginning. The reason is evident: the beginning is the turning point—the end is simply what happened or how it all went. Life goes on, and so I don't know how it all went; the ending is not yet clear. I

wish I knew, wish I could say, this is where it ended, here is a new beginning. But I can't. (p. 215-216)

I remember writing my last post in the online journal I kept during the first few months of Bradley's arrival into the world. It had been six weeks since the Bradley ordeal began. His supplemental oxygen had been discontinued, his feeding tube removed, and the frequent doctor visits had been weaned. And so, my journal ended. This seemed logical. But then, is illness logical? It is true that this chapter of Bradley's illness (my illness) had come to a close, but I was a long way from writing the final pages of my story. I longed to go back to my journal, to update those who had followed our story so closely with Bradley's current status. But I wondered who would pay this any mind? The wedge of time creates a large gap, distancing my readers from their emotions tied to the Bradley ordeal. I forced myself to have an end to my story, to have a concise, happy, Pollyanna ending. Square peg, round hole: This forced ending did not close up the gaping hole inside of me. I desperately wanted my story to end, or to at least know how it all would end. But Wikan (2000) states, "Life goes on, and my illness story is caught up in life" (p. 216). Life, the lived experience, *lebenswelt*. Pinar (1975) reminds me that life is not linear but is filled with chaotic happenings all which enhance the *lebenswelt*. Frank (1991) says, "Writing creates an illusion of order, but in life experiences overlap" (p. 42). Therefore, I should not force my story to have a clear beginning, middle, and end because it is through these interminglings that my life story is genuine.

The field of curriculum studies strives to give value to the individual's life story. Pathography situates nicely within the field because it attempts to value the experience of the ill person. Pathography as defined by Hawkins (1999) is "a form of autobiography or biography that describes personal experiences of illness, treatment, and sometimes death" (p. 1). I feel that

educational curriculum is more concerned with test scores, lesson plans, and methodology than with the student as an individual. In this regard, education is similar to the field of medicine. The representation of the ill person's narrative pales in comparison to the plethora of laboratory results, dictation notes, and prescription records that plague the medical chart just as the student's individual experience fades in light of test scores. Flipping through a medical chart, one would find a vast amount of information regarding the patient's illness but little about the ill person. What is recorded allows doctors to draw commonalities among those who are ill as a means of categorizing. Pathographies value the patient as a person, rather than a medical case. Collaboration, through the use of pathographies, allows those who are ill to unite in community while honoring the individual. This omission belittles the ill person's experience and serves to oppress the individual. Pathography provides the avenue for individuals to express their story, either verbally or textually, so that meaning may be derived from what is shared (or not shared?).

Introduction to the Chapters

In Chapter 2, Writing for Pleasure, Writing through Pain: The Value of Pathography, I highlight pathography as a form of autobiographical inquiry. I explore my own pathography through Arthur Frank's (1995) restitution, chaos, and quest forms of personal narrative. While using William Pinar's (1975) *Method of Currere* as support, I examine my pathography regressively, progressively, analytically, and synthetically. Describing the ambiguity of illness can be troublesome when there is little in the literature to serve as a guide. Drawing from Susan Sontag (1978/1989), Anatole Broyard (1992), and Anne Hunsaker Hawkins (1999), myth and metaphor will be discussed as a literary devices which can serve to define illness. I also examine how place, time, and voice shape the ill person's story. Finally, I highlight specific literary

works that have been of influence to me during my journey with illness and have encouraged me to write my pathography, suggesting a sort of community among the ill.

In Chapter 3, *Order of Disorder: Finding Meaning in a System of Increasing Entropy*, I compare illness to chaotic and complex systems. Knowing that there is order in chaotic and complex systems, I search for the order and meaning in my own illness. I begin the chapter by comparing a chaotic, broken life to a mosaic as described by Terry Tempest Williams (2008). Drawing from scientific literature (Lorenz, 1993; Gleick, 2008; Prigogine and Stengers, 1984) and curriculum studies literature (Trueit, 2008; Fleener, 2008; Davis, 2008), I discuss how chaos and complexity theories apply to illness. I employ Lewis Carroll's (2000) *Alice in Wonderland* as a metaphor for the black hole of chaos one can sink into while dwelling with illness. Using Jung's (1969) notion of "synchronicity" and the concept of "synch," I question the hidden order of illness that is masked by extraneous noise. Finally, I seek to understand stability of chaotic and complex systems by using Prigogine and Stengers' (1984) example of the chemical clock reaction as well as Boym's (2001) notion of nostalgia as ways in which systems seek stability during chaos.

Pinar (1985) draws from Foucault's (1970) "Archeology of the Self" when questioning the "authentic self." Drawing from the notion of the "authentic self," Chapter 4, *Private Matters in a Public Arena: A Self-Examination*, discusses one's need for maintaining a façade in the public arena so as not to appear weak or out of control. I examine the dichotomy of the Self and the Other and discuss their interrelatedness. Although writing about my illness dwelling experience exposed the nakedness of my soul, it has helped to bridge the public and private aspects of illness while adding another dimension of conversation to the field of curriculum studies. Drawing from Freud's (1925) essay "A note upon the 'Mystic Writing Pad'" and Toni

Morrison's (1987) *Beloved*, I flesh out the connection between memory and my lived experience as one dwelling with illness. Finally, using Jungian psychology and Balint's (1968) notion of the "unthought known," I investigate the role of the unconscious as it relates to illness.

Chapter 5, Defining 'Good Enough: The Mommy Dilemma, draws from Winnicott's (1971/2005) notion of the "good-enough mother" and the impossibility of upholding the characteristics outlined by Winnicott. Expanding on Doll's (1995) comparison of the Home and the Self, I draw connections between the Home and the Mother in both a figurative and literal sense. Exploring Thurer's (1994) *Myths of Motherhood*, I discuss the multiple roles mothers must play, specifically from my own vantage point as a Southern, white, middle-class woman, and the pressures induced by society for the mother to remain "good-enough." Drawing from psychoanalysis (Rich, 1986; Atwell-Vasey, 1998; Kristeva, 1986, 2005; Chodorow, 1978) I examine "maternal legacies" and the mother's requirement for providing "potential space" for her children to gain independence. My illness dwelling has been accompanied with much grief as I grieve for the time I have lost with my child as well as the guilt I harbor regarding the unknown etiology of his defect. To partially examine the complex emotional dimension of motherhood, I draw from Hodgson and Krahn (2004) and Kubler-Ross and Kessler (1969; 2005) as I way to begin working through my repressed emotions of grief and guilt. Finally, I draw strength from mothers (and others) who are ahead of me on this journey of illness with a child who does not fit society's "norm."

In the final chapter, *Illness, Motherhood, and Education: Redefining 'Normal'*, I examine three illness which have been prevalent throughout my pathography: Bradley's congenital heart defect and it's a/effects, my illness which has developed because of Bradley's illness, and society's illness of excluding the ill person's voice from the conversation. I

investigate the institutions of illness, motherhood, and education in effort to examine ways in which to “denormalize” each of these systems. Using Foucault (1994), Porter (1997), and Charon (2006) as support, I argue that the societal system of the patriarch and the economic system of capitalism have had a significant influence on generating the institution of illness. While using Adrienne Rich’s (1986) *Of Woman Born*, I continue the conversation begun in the previous chapter to investigate the institution of motherhood as it is perpetuated by the systems of the patriarch and capitalism. To examine the institution of education, I draw from Dewey’s (1915/2001) *The School and Society* as a way to show the continual gap between traditional educational curriculum and the lived experience. Additionally, curriculum theorists Reynolds (2003) and Schubert (1991) are highlighted as two influential educators who have complicated the conversation within their own classrooms. Next, I examine my Self as I struggle with the overwhelming desires to be “normal” or to find wholeness after illness. Using Mark Epstein’s (1995) notion of the “broken cup,” I begin to view illness in a different light: not as a way of defining a body’s brokenness but as a characteristic of an already broken body. Finally, I conclude my pathography recognizing that this is not the end of my Self examination, but rather an end to my beginning of understanding the effects of my illness dwelling.

CHAPTER 2

WRITING FOR PLEASURE, WRITING THROUGH PAIN:

THE VALUE OF PATHOGRAPHY

The process of putting one's strong emotional experiences into writing gives voice to fears, dreams, and disappointments. Through writing, we can see the experience more holistically, reflect on it, and connect it to other experiences in our lives and those around us. (Luce-Kapler, 2004, p. 81)

I am persuaded that I have finally done enough fieldwork—writing is not only possible but now actually seems necessary. (Taylor, 2009, p. 13)

My mother always told me that I had a knack for writing. I recall an assignment from early elementary school in which I was required to blend the week's spelling words in a poem. Given only a week to finish the assignment, I eagerly completed the task the first night, as if something within me was hungering for the openness offered by the blank piece of paper and the opportunity to fill its lines with sincerity. The self-fulfillment I achieved by organizing a set of unrelated, chaotic expressions into significant meaning was exhilarating. Although it was only a simple poem, there was a peace, an order within the honesty of accomplishing an entry that portrayed such nakedness of the soul. I felt timid allowing my teacher to pore over my poem, an intimate part of my Self that I was offering for public viewing. What if she rejected my words, diminishing the meaning that I had hoped to convey? When considering written accounts, the acceptance of others is not required; self-satisfaction is of utmost importance. However, when written accounts are acknowledged private convictions that have been made public can feel validated. My teacher's approval was deeply received, suggesting a connectedness that acknowledged a shared response as we read the simple verses imprinted in blue ink on the white

page. This acceptance further enhanced self-satisfaction of creating something orderly and significant from something chaotic.

The connectedness I felt with my teacher when she read my simple poem encouraged me to be vulnerable with others, allowing my writing to serve as a window to my soul. I filled a little white paperback book with my poetry and zealously shared my masterpieces with anyone who would listen. At this young age, I was naïve in believing that all would acknowledge my writing in the same positive manner as my teacher. As years passed, I became more cautious of whom I permitted to read my work. The hormonal and somewhat tumultuous teenage years were filled with uncertainty; I was unsure whom or what I could trust, including my own intimate thoughts. Writing provided an outlet to expel intimacy that would have otherwise remained locked away in the innermost portion of my soul, hidden from view from even the conscious part of my Self. I continued to use poetry as a way of drawing meaning from chaos. However, unlike the poems in my little white paperback book, these poems were primarily for my personal viewing.

I do not recall a specific event in which I began to draw the curtains on my soul's windows, selectively choosing those who were privy to my intimate thoughts. It is possible that the natural chaos which accompanies the teenage years made me suspicious of how others would view my most personal and private feelings. In addition to writing poetry, I used blue ink to expunge repressed emotions onto reams of notebook paper, cleansing my soul as I bathed in the waters of the writing process. I privately termed this genre my "stories about nothing and everything;" if an outsider were to read my accounts, the words would make little logical sense. But nothingness and chaos can give birth to wholeness and order. As Luce-Kapler (2004) suggests, my written accounts, despite their nonsense, created a holistic view of my experiences,

allowing for a broader perspective to digest the difficulties I was encountering. Occasionally I would reflect on my writing which allowed me to recognize the connectedness between present and past experiences. I found that I was drawn to this time of reflection specifically when I was searching for words to describe my current feelings of loneliness and confusion. More often, after initial creation the chaotic groupings of crumpled notebook paper filled with blue ink were stashed carelessly under my bed without consideration until my mother forced me to throw all of the “trash” away. Much of what I wrote described painful experiences, ones in which I did not want to relive time and time again. I wonder if stashing these pages of pain under my bed, hidden from view, was a symbolic way to repress emotions that I did not want to work through. At first glance it may appear as if I had addressed these chaotic feelings by writing them out; yet, on the surface, I believe I had had only paid them enough attention to satisfy their immediate need, allowing me to repress them under my bed until they demanded my attention once more. Even still, the attention they were finally afforded classified them as “trash,” suggesting they be discarded from my life. But I am not convinced that I could throw my emotions into the trash in the same manner I threw away the notebook paper that contained the textualized descriptions of my intimate thoughts. Emotions linger, stuck under the bed in the spot that you can see but your arm is sometimes just short of reaching.

While I have worked through some of my repressed emotions, I have come to appreciate the opportunity writing has given to search my Self for meaning on a deeper level. Reading the stories of others who share similar experiences has been equally beneficial. I wish reading had been a lifelong pleasure of mine the way that writing has been. Truthfully, I hated to read when I was in school. I did not have difficulty with my reading skills. It was more that I resented being told what to read and having a time frame in which I must finish the work. I respect the place

that required reading holds in the educational arena. However, I cannot remember being encouraged to delve into a particular subject that I could read at leisure. It was not until much later in my educational journey, specifically during the later portion of my doctoral program, I found subject matter which engrossed me in such a way that I felt malnourished without its provisions. During one of my doctoral courses, Marla Morris introduced me to pathography, a genre of literature that connected my medical interests with personal reflection. One book that captivated my attention like no other was Arthur Frank's (1991) *At the Will of the Body*. As I read his story of illness, I felt as if I were reading my own words. Perhaps the similarities between both of our experiences drew me to his story. Or, perhaps the timing was just right and I was ready to bring the repressed emotions into the light in order to begin the healing process. Whatever the case, I credit reading Frank's (1991) narrative as the pivotal point in both my doctoral coursework and, more significantly, working through my illness.

The more I read about illness, the more I am able to write. Reading is the prescription for healing my broken Self whereas writing is the remedy. Frank (1991) assures me that medicine has the ability to heal the broken body, but not necessarily the broken life. He states:

What happens when my body breaks down happens not just to that body but also to my life, which is lived in that body. When the body breaks down, so does the life...Medicine can diagnose and treat the breakdown, but sometimes so much fear and frustration have been aroused in the ill person that fixing the breakdown does not quiet them. At those times the experience of illness goes beyond the limits of medicine. (Frank, 1991, p. 8)

Bradley's broken body created a break down in my life. Although Bradley's heart could be fixed with medicine, a prescription was not available to assemble my life's broken pieces. I did not seek medical advice for suggestions on how to work through my emotions. I was not

comfortable sharing the details of my story with someone whom I have no relationship. I know that some ill persons take medication to help them “get through” difficult times. I am sure that such medication is beneficial in many instances. However, I felt that taking happy-pills to help me deal with the chaos in my life would only allow me to further repress the emotions I was already striving to ignore. I was in a condition of consuming chaos, having little control over what was happening in my life. Perhaps I unconsciously believed that taking medication or seeking therapy would further remove control from my grasp. The medical treatment for my illness was one of the only aspects of my life that I could control.

Another way I felt able to control the chaos was through writing. After being introduced to the genre of pathography, I began using my remaining doctoral courses as an opportunity for Self inquiry. Writing from an autobiographical viewpoint, I analyzed my experience with illness through psychoanalysis to search for a deeper personal meaning. Writing about my dwelling with illness has forced me to analyze my relationships to others and to my environment, serving as a sort of therapy during this difficult time in my life. The act of writing, especially about illness, may be the prescription that the doctor ordered. Swallowing medicine can make one vomit. Writing about illness can make one’s soul vomit. But the body needs to rid itself of the poison in order to become well again. Dwelling with illness can be paved with chaos as the ill person tries to sort out the broken body and spirit. Autobiographical inquiry allows the ill person to find her/his way through the chaotic maze as s/he strives to understand the affects of illness.

Pathography as Autobiographical Inquiry

Autobiography as a form of understanding curriculum has roots reaching back to the beginning of the Reconceptualization. Madeline Grumet defines autobiography as “a medium

for both teaching and research because each entry expresses the particular peace its author has made between the individuality of his or her subjectivity and the intersubjective and public character of meaning” (as cited in Pinar, Reynolds, Slattery, & Taubman, 2004, p. 515). Autobiographical inquiry strives to make meaning out of lived experience. However, autobiography as a form of inquiry has been met with criticism. Within the field of curriculum studies, Marxists have considered autobiography to be self-centered and isolated from community relations. Janet Miller’s (1990) *Creating Spaces and Finding Voices* is significant in establishing autobiographical inquiry as a source for collaboration. Although her work centers on teacher collaboration, her work may be applied to those dwelling in the illness community. She stresses the importance of collaboration “in order to take into account the complex constraints of those who want to uncover as yet unrecognized forms of oppression” (Miller, 1990, p. 153). Oppression is detected within the context of the illness community when the sharing of commonalities and identification of differences are conveyed. The writing and sharing of pathographies helps to unite those in the illness community so that the poison of oppression may be recognized and a suitable antidote administered.

Those who write from an autobiographical viewpoint are often criticized for attempting to tell what some would view as the “real” story, when the telling of a “real” story is almost impossible to reproduce. As time and distance separates the author from events, factual information becomes blurry. Additionally, the unfolding of life experiences is not linear but overlaps, turning this way and that way. The author can have difficulty recalling specific events and the order they occurred. When the author writes her/his autobiography, the events are organized in a logical, cohesive manner for ease of both writing and reading the story. Even though autobiographies are traditionally classified as non-fiction, there is most definitely some

aspect of fiction with the pages of the text. Nevertheless, the author arranges her/his story in such a way that it reflects meaning from the experience, making the “process of autobiographical recollection...part self-discovery and part self-creation” (Hawkins, 1999, p. 15).

I was once determined to retell my story exactly as it happened, as if exact factual information made my story somehow more legitimate. I felt I had an advantage over others who attempt to retell a story because I had kept detailed written accounts as the events were unfolding. As I tried to assimilate the factual information from these written accounts into a cohesive and comprehensible story, I found myself tripping over pertinent information that needed to be included, but it did not make sense to include it at this moment, but if I included it later in the story it would not be placed exactly where it occurred in “real” life....Oh, the trouble! My thoughts began to blur and I almost gave up writing my story altogether. It occurred to me that even my written accounts that were constructed during the ordeal contained fiction. I recall one journal entry written by my husband, who was walking alongside me through the entire ordeal. Reading his version of the account I thought, *That is not what happened!* At first, I assumed that he had fictionalized the events. But it was possible that the same event had impressed our memories differently. I concluded that it is not the construction of the story that is of importance; the meaning that is derived from the story is most significant. However, the way in which the author constructs her/his story can illuminate the way in which the author has made meaning from the story.

The genre of autobiography encompasses many different forms of writing including stories, narratives, and pathographies. In my close reading of the literature discussing the personal side of illness, these three terms have been used both interchangeably and in distinction. At the risk of oversimplifying the previous terms, I view stories as conveying a clear beginning,

middle, and end, whereas narratives are personal accounts shared so that an unbiased party can draw meaning from what is revealed. For me, pathography encompasses the recursive element that Pinar (1975) stresses when he suggests personal reflection of the lived experience. Because of my primary emphasis of self-exploration throughout this study and for the sake of clarity, I will henceforth refer to my work as a pathography. By employing autobiographical inquiry, specifically in line with pathography, I seek to understand my experiences of dwelling with illness as it has affected (is affecting) my Self.

Most of the pathographies I read are what Hawkins (1999) would classify as testimonial pathographies which explore the author's feelings about illness and whose purpose is to help others deal with illness. This type of pathography also recognizes the positive role medicine plays in overcoming illness. Hawkins (1999) identifies two additional categories of pathographies: angry pathographies, which illuminate the dehumanizing of American medicine and "pathographies advocating alternative modes of treatment," (p. 4) suggesting the ill body seek other means of healing beyond what is suggested by orthodox medicine. I have some trouble classifying my own pathography into one of these categories. At first glance, I assume my pathography could be categorized as testimonial. My writing takes the reader through my experience with illness and encourages the reader to draw personal meaning that may encourage her/him throughout her/his dwelling with illness. Hawkins (1999) suggests that testimonial pathographies serve as reflections of illness to those who absorb their meaning. I can appreciate this point; after all, this is precisely how I felt reading Frank's (1991) pathography. Yet, I do not feel that my pathography is exclusively testimonial in nature. Aside from my desire for first myself and then for others to gain meaning from my experience with illness, I also hope to further the conversation that some aspects of the personal side of illness are largely ignored. I

feel that many aspects of American medicine have become institutionalized, largely due to the demands of our capitalistic society. Because of the overwhelming emphasis placed on monetary value in a capitalistic economy, the personal side of caregiving may be diminished. Listening to patients' fears and inhibitions regarding illness could be viewed as squandering time, when one could be scheduling tests and procedures that could potentially raise revenue. This notion disturbs me greatly. I feel that the medical realm can be productive while simultaneously providing adequate attention to the personal side of illness.

When I mention the subject of my dissertation work to those in my circle, the term "pathography" is often received with a puzzled look. However, the origin of the word is simple. Webster's defines the Greek root word "pathos" to mean "feeling or suffering." Thus, a pathography is an account written by the ill person or about an ill person that attempts to capture the feeling and suffering associated with dwelling alongside illness. Hawkins (1999) further elaborates on the meaning of the term:

Pathographies are important as human documents not only because they record a traumatic crisis that may occur to all of us but because they represent—in their very writing as well as their content—the ways these crises may be overcome, survived, and understood. Pathography describes a profoundly destructive experience; at the same time it testifies to the capacity to transform that experience in ways that heal. (p. xix)

Writing my pathography has allowed me to digest the events of my ordeal in hopes that I may gain some sort of meaning, and possibly healing, from this time of Self inquiry. Through this process, I have been forced to slow down, absorb both the beautiful and grotesque parts of my ill body, and assemble order from disorder. If I had not embraced the opportunity to write this pathography, I question my outcome from the ordeal. Perhaps I would have continued to repress

my emotions, ignoring them until they reared their ugly heads while simultaneously burning bridges that could never be repaired. I desire to share my pathography with other ill persons who may be able to gain meaning from my experience and apply it to a specific situation their lives. I hope to return the favor of those who have gone before me, sharing their stories of illness. I have felt some sort of strangeness yet oneness in reading others' pathographies. The strangeness keeps the story at arm's length as I recognize the otherness of the illness. Yet, the familiarity of the emotional context of illness draws me in, encourages me to visit with the author a little longer as we compare and contrast our ill bodies. The oneness I feel with others who are ill is what keeps me grounded, validates my feelings, and encourages me to keep trudging onward.

Personal Narrative and Pathography

Auto/biography as a form of gathering information meanders across many areas of education. Connelly and Clandinin (1991) are significant contributors to the field of narrative inquiry and use the "storied experience" (p. 121) as a means of conducting empirical research. However, they reserve the term "narrative" to describe the inquiry method and the term "story" to indicate lived experience. Wikan (2000) has a similar opinion on these two terms. She says:

Writing a narrative, you are in control; telling a story, much less so. Indeed, one of the advantages of using the experience-near 'story' rather than the experience-distant 'narrative' is that 'story' rings with the connotations 'told to.' One usually tells a story *to* someone, whereas with narrative...? Since I don't even have the word in my language, I really don't know. But I suspect that narrative has a more textual bent. (p. 231)

Rita Charon (2006) helps to define the term "narrative," particularly in the medical sense. She specifically reserves the term "narrative medicine" to mean "medicine practiced with these

narrative skills of recognizing, absorbing, interpreting, and being moved by stories of illness” (p. 4). A close examination of the terms story, narrative, and pathography has helped me to organize my thoughts about how my work should be situated within the field. I have always enjoyed writing and storytelling, but these seem to compete with my scientific training. Scientific writing encourages the author to write from a neutral viewpoint without interjecting personal bias into the written account. Scientific writing subscribes to an outline the author must follow. Additionally, scientific writing is concerned with deriving meaning from facts and figures rather than personal experience. The home of pathography is a natural fit for me because it is “the dream of a novelist and a scientist combined” (Sacks in Luria, 1972, p. xii). When writing a pathography I am able to use my scientific knowledge of facts and figures while deriving meaning from my experience with illness. Similar to scientific inquiry, I ask the “why” and “how” questions as they pertain to understanding my Self. However, instead of directing these questions toward what I am observing outside of myself, I am interested in answering these questions as they relate to my experience with illness.

Pathographies are often clustered with a group of literary works known as “illness narratives.” The manner in which these narratives are constructed can give insight into the meaning that can possibly be derived from the illness experience. Frank (1995) states, “People tell their own stories, but they compose these stories by adapting and combining narrative types that cultures make available” (p. 75). He highlights three ways to describe an illness narrative. The restitution narrative describes one's journey from health, into the land of the sick, and toward the future of restoration. Phrases such as “no big deal” are often used to downplay the gravity of the situation. The emphasis here is on returning to the land of health. The opposite of restitution narratives are chaos narratives. The ill person does not see a way out of sickness. There is

nothing to be learned, nothing to be gained from the experience. There will not be a day of restoration. Finally, quest narratives seek to find ways to use adversity for good. They strive to make meaning out of an unfortunate situation while viewing illness as a journey.

Frank (1995) suggests that it is possible for each of these narrative types to be present at some point throughout the narration. He equates the shift in narrative modes to the alternating colorful patterns viewed through a kaleidoscope. One colorful image is vibrantly created, only to be rearranged with the slightest rotation of the tube. I agree with Frank (1995) when he says, “At the bedside, the kaleidoscope turns much more quickly than in print” (p. 77). During my experience with illness it seems my kaleidoscope has been in constant motion. While my mind remembers my own narrative varying among these three descriptions, it is difficult for my hand to textualize the shifts due to the constant overlapping of narrative styles. My controlling nature endeavors to categorize my illness experiences, showing how my dwelling with illness has neatly varied from one style of narrative to the next. I humor myself in times when I attempt to make life experiences appear linear!

While it would be virtually impossible to chronicle the exact shift and overlapping among narrative styles, I am able to identify specific events throughout my experience that correspond to each of Frank’s three descriptions. At the initial onset of the ordeal, my account is representative of the restitution narrative. As I placed my faith in a supreme being, ultimately subscribing to the notion that Bradley’s illness was predetermined, I looked toward a brighter day when health would be restored. My religious background has guided me to believe that God is in control of all situations and that He works grave situations for His good. I possibly subscribed to the restitution narrative because this is the narrative style most accepted by my support circle. What a testimony for God’s kingdom to be able to share how He delivered

Bradley from the clutches of death and, moreover, to emphasize the enduring lessons of faith and perseverance attained while going through this trial!

Frank (1995) insists that restitution narratives are not favored only by my religious community: “The restitution story, whether told by television commercials, sociology, or medicine, is the culturally preferred narrative” (p. 83). Wanting to be accepted by those who listened to my account, I held fast to the notion of restitution until the vision of gravity to glory failed. It is possible that I ran out of patience as I waited on God to redeem me from the turmoil of the ordeal. The restitution narrative promises a restoration of the ill body. When I first learned of Bradley’s heart defect, I was assured that after surgery Bradley would be fixed, good as new. Perhaps I believed that after Bradley’s surgery my own anxieties would be relieved and my psyche would be restored to the euphoria I felt when I initially held Bradley in my arms. Frank (1995) identifies this mindset as a mechanistic view in which the body, like a machine, is broken and in need of “fixing.” Supposedly, Bradley’s broken heart was fixed after undergoing surgery. However, the remedy for his brokenness created an entirely new and unexpected set of broken parts that also required a mechanic’s attention. Feeding difficulties, elevated pressure in the arteries, and speech delays are broken areas in Bradley’s body. The corrections made to some areas (feeding difficulties) have been sufficient and restored this part of his body back to normal; however, other areas (arterial pressure and speech delays) have yet to find the proper tools needed for repair. What if Bradley’s body is unable to be fixed? In a similar light I consider my own illness. I know that some part of my Self is broken, yet I cannot put my finger on exactly what needs to be fixed. Restitution narrative is no longer valid if a remedy is not identified.

Restitution narratives can be very powerful in terms of encouraging others who are dwelling with illness. The retelling of the illness experience depicts how the ill body has overcome adversity. But when the body cannot be fixed, chaos becomes heir to the throne. “Chaos is the opposite of restitution: its plot imagines life never getting better” (Frank, 1995, p. 97). Whereas restitution narratives follow a prescribed outline, chaos narratives depict the life experience in disarray. Although chaos narratives are more representative of one’s dwelling with illness, the disconnectedness of events discourages listeners. Chaos narratives are the anti-thesis of the pretty package with a bow on top metaphor that I have often applied when discussing illness. Unlike restitution narratives, chaos does not promise hope for a brighter tomorrow. These narratives of illness are depressing and threaten to push away those who are willing to listen to the ill person’s account of dwelling with illness.

An ill person living in chaos cannot verbalize, or textualize, what s/he is experiencing. The ill person is in the abyss, incapable of finding direction. Chaos does not subscribe to order; ideas, thoughts, feelings are jumbled. To put experience into words, there must be some sort of ordered thinking. Deriving meaning from chaos can only be done through reflection. With this consideration, Frank (1995) states chaos narratives cannot be disclosed, only lived. To live in a state of chaos is terrifying. Order is necessary for the body to preserve homeostasis. However, a state of chaos denounces order. How can one begin to make sense of illness when there is no system for classification?

Traditionally, a narrative follows a logical order to draw the listener close. Chaos narratives do not have order, making the act of drawing meaning problematic. The narrator details the lived experience without pause or reflection for either the ill person or the listener. This method of narration is difficult, at best, to comprehend and discourages listeners from

absorbing the narrative's meaning. Frank (1995) explains the dilemma for listeners of chaos stories:

Hearing is difficult not only because listeners have trouble facing what is being said as a possibility or a reality in their own lives. Hearing is also difficult because the chaos narrative is probably the most embodied form of story. If chaos stories are told on the edges of a wound, they are also told on the edges of speech. Ultimately, chaos is told in the silences that speech cannot penetrate or illuminate. (p. 101)

Chaos affects every facet of the individual—not only the ill body, but also every aspect of life that the ill body comes in contact with. Many times throughout my dwelling with illness, I have felt the domino effects of chaos. I recall feeling out of control, as if someone or something else was dictating my every move. For someone who has a controlling personality, this is the worst nightmare turned reality. One part of my life becomes unsettled and before I can make the necessary adjustments, every aspect of my world has become out of balance. Chaos takes the ill person down, down into the abyss. No rope is long enough to pull the ill body from the depths of despair. Some may try to help the ill person by demanding s/he reach for the rope (therapy) in order to save her/himself. While living a life void of chaos is desired, forcing the ill person to accept assistance denies the chaotic lived experience.

Restitution narratives promise the ill body's return to normalcy after being fixed and glorify the medical treatments used to restore the body to health; conversely, chaos narratives are born out of despair, masking the voice of the ill person. Frank's (1995) final narrative classification, quest narratives, "accept illness and seek to *use* it" (p. 115). While restitution narratives may be the most verbalized and accepted by the listener, quest narratives could be considered the most interesting to read. These are classic stories of a hero conquering adversity

as he seeks the boon in hopes of returning to the masses to share what he has learned. The ill person is determined to gain something of value at journey's end, although the object worth seeking may be unidentified. However, "[t]he meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking" (Frank, 1995, p. 117). The current state of my pathography could be described as a quest narrative. The purpose of my dissertation work has been to reflect on my journey with illness so that I may draw meaning from what I have experienced. Although my initial journey with illness has not come to an end, I am reflecting on what I have experienced in hopes of bringing the boon back to all who will listen to my account. Frank (1995) further defines quest narratives into three categories: memoir, manifesto, and automythology. I have trouble placing my pathography in any of these categories. Perhaps this is where I distinguish between narrative and pathography. For me, a narrative is used primarily to classify a personal account; although, meaning can certainly be obtained from a narrative. I consider the sole/soul purpose of pathography to be a much deeper, spiritual inquiry into the Self, whose meaning is most greatly derived reflexively. I still feel the overwhelming drive to return the boon, "the ability to mourn not only for [myself], but for others," (Frank, 1995, p. 136) to the masses.

Pathography and the Method of Currere

Dwelling with illness is indeed an active process. The effects of illness are ever-present, a constant reminder of life's fragility. Illness is a journey, not a mere trip from point A to point B. When one receives the call to journey with illness, s/he is committing to a lifetime experience. In this way, journeying with illness is similar to my journey in the field of curriculum studies. The effects of my time spent dwelling in the field's literature, complicating

the conversation as I have journeyed alongside others of like mind, are nourishment to my scholarship. When this leg of my journey is complete, I will not have reached my final destination of “point B.” There are an infinite number of destinations to which I must travel. However, it is not the destination that is of utmost importance, but the meaning gained from the experiences along the way.

As a student of curriculum studies, I have been encouraged to run along the journey’s path. However, “to run” does not suggest that I hurry, rushing down the paths in haste. Subscribing to a method of *currere* encourages me to move forward, always yearning for a deeper understanding of the curriculum. While journeying with illness, I have had times when I did not want to run or move forward. When you are ill, you are too exhausted to run, unless you are trying to run away. Oftentimes I find myself wanting to move backward, back to a time before illness met up with me on the journey. But returning to places I have previously traveled is not on my itinerary. I have already acquired the passport stamp for the place where illness became my traveling companion. Thus, I must take the cumulative knowledge I have learned and press onward.

Pinar (2004) suggests employing *currere* as “a strategy for students of curriculum to study the relations between academic knowledge and life history in the interest of self-understanding and social reconstruction” (p. 35). It is through this method of *currere* that curriculum becomes “an extraordinarily complicated conversation” (Pinar et. al., 2004, p. 848). Throughout my doctoral coursework, I am fortunate to have been among professors who have been willing to share parts of their life story so that I may find meaning and apply it to my own life. “Complicated conversation” challenges my belief system and makes me a stronger individual; previously held ideals are not necessarily changed but at least challenged so that I

may attain a more holistic view of curriculum. If conversation among individuals is revered within the context of curriculum studies, can it also be within the medical and educational communities? My students are comprised of more than test scores and demographics; they are individuals with distinctive ideas and goals. Should not these same characteristics be recognized for those who are ill?

In an essay titled “Method of Currere,” Pinar (1975) suggests that curriculum should be addressed regressively, progressively, analytically, and synthetically. Pinar later referred to these as the four “movements,” believing that the term “method” was too rigid to allow for the psychoanalytical work that was taking place. Through these movements, one may come to appreciate the relationship between the sequential and the theoretical aspects of the life story. To embrace currere, one must strive to understand the lived experience. I believe this approach can also be beneficial when writing one’s pathography. Pinar (1975) encourages a regression from the present to the past life, “to capture it as it was, and as it hovers over the present” (p. 21). It is the total lived experience that is valued here, not just what is currently in the present, because the past inhabits the present. My past constantly resides with me, like a shadow. The present’s sun shines on me and casts a shadow on the ground. I try to step away from the shadow, but it follows me. If I stand in such a way to orient the sun to illuminate my face my shadow falls behind me, out of sight to the others in my presence. However, I find myself in a constant dizzying dance with the sun, trying to keep it in front of me so as to hide my shadow. Sometimes I feel that I am “not really living in the present but [am] dwelling not only on but also in the past; more precisely, I [am] living the present by reliving the past...as if I had then known the future” (Taylor, 2009, p. 45). The memory of Friday, April 13th haunts my mind. Each year I recall the time and place of one, two, three....years before when I was given the diagnosis that

caused my life to turn topsy-turvy. For me, springtime is a paradox of joyous and solemn emotions. Spring welcomes new life. Spring also has its share of rain. I rejoice as I celebrate another year of Bradley's life, reflecting on the blessings he has brought to me. Yet, instead of fully embracing the merriment, the rainclouds envelop me as I remember the events of the ordeal.

Each year on April 13th, I am presently living in the past. Indeed, the past inhabits the present. However, the future interferes with my recollection of the ordeal. I imagine how the events would have played out, given my enlightenment. *I should have known something was wrong with Bradley when he would not feed properly. Would I still have this feeling of guilt if I had been more attentive to Bradley while he was in the hospital?* "Where I once was, I once again shall be" (Taylor, 2009, p. 46). I do not ever want to fully experience the ordeal again. I am not sure if my psyche could handle another diagnosis of this magnitude. However, as I continue to dwell with illness, the recursive memories of the ordeal force me to be with the events time and time again.

Pinar (2004) encourages one to free-associate while looking toward the future in the progressive movement of currere. "[O]ne looks toward what is not yet the case, what is not yet present. Like the past, I suggested, the future inhabits the present. Meditatively, the student of currere imagines possible futures" (Pinar, 2004, p. 36). While Bradley was in the hospital I imagined what our life would be like on the other side of sterility. My free-association led me down a road of fantasy where I imagined that everything would be as I had always planned. Imagine my disappointment when life's pharmacy would not fill the prescription that I had written. I think about my students who have gotten pregnant while in high school. Many label their pregnancy as an "accident." Is it really an accident, or just not what they envisioned when

they imagined their future? Could the same be said for illness? I am not suggesting that illness is dictated in some master plan for one's life. I recall a conversation my sister and I had as we stood beside Bradley's hospital bassinet. She commented that between the two of us I was the one that was better prepared to handle a child with a medical condition, given my previous experience in the medical field. She continued by suggesting that God would not give me something that I could not handle. I began to subscribe to the notion that this "trial" was designed by some supreme being. My extensive knowledge in cardiology would provide a sense of comfort during this chaotic time. Pausch (2008) reminds me, "We cannot change the cards that are dealt, just how we play the hand" (p. 17). I began to cling to the notions that this was a "God thing" and that I could learn a valuable life lesson from this experience. These thoughts may have helped me initially overcome my adversity but I believe they enabled the repression of my true feelings.

Pinar asks, "How is the future present in the past, the past in the future, and the present in both?" (quoted in Pinar et. al., 2004, p. 520) What is this analysis anyway? Is this what doctors are doing when recording the patient history? Is this what educators do when analyzing test scores? How does a student's current test score compare to previous results and what might that say about her/his future? The field of curriculum studies values the lived experience; however, I question how the medical community responds to this concept. With the incessant focus on statistics, lab reports, and test results, little room is left in the medical chart to record the patient's history. Undoubtedly, medical test results have significance in the accurate treatment of the patient's condition, just as some educational assessments can provide insight into a student's deficiencies. Without diagnostic testing, many conditions would go undetected. The issue comes, however, when the patient/doctor relationship is reduced to a set of normed

measurements. The patient's illness is more than what is written in the medical charts (diagnosis, signs, symptoms, prognosis, treatment); it is also what is not written about the patient (thoughts, feelings, dreams, previous experiences). Autobiography in the form of pathography can allow "lived experience to be revealed and expressed, unlike mainstream educational research which in its obsession with measurement obliterates subjectivity" (Pinar et. al., 2004, p. 549). Analysis should encompass the total lived experience: past, present, and future.

It is not healthy for one to remain in the past, nor fantasize about the future, for too long. One must come back to reality, to "[re-enter] the lived present" (Pinar, 2004, p. 37). In this final movement, synthesis, Pinar (1975) encourages a unity, or wholeness, between the past and future as to better understand the present. But to be "whole" means to be able to accept all parts of the Self: past, present, and future. Frank (1991) says, "It is proper to meditate on how you have lived so that you can become the person you want to be" (p. 87). But it is sometimes difficult to think about the past. I am reminded of a picture I took of Bradley the day that the cardiologist discontinued his oxygen. He was wearing a shirt that said *I won't remember any of this*. As he lay there in his bassinet, sleeping peacefully, I cried silently and thought *Thank God. I do not want to remember any part of the ordeal either*. Events are too painful to want to remember. But Frank (1991) reminds me that "when all is forgotten, nothing is learned" (p. 131). Although the thought troubles me at times, my past shapes my present and my future. Morris (1996) explains:

I am embedded in my own complex past, my own personal history, and that past shapes my present, and writes and re-writes my future. At each and every moment I appropriate that past into my present and this affects my possibilities....The direction my life might take is riddled with uncertainty. (p. 412)

The uncertainty of life's direction is unsettling to my controlling nature. My tendency is to want to know the ending, speed ahead to the destination. But I am reminded that I must slow down, for it is the meaning of the journey that is of utmost importance.

Metaphors and Myths in Illness

When I first arrived at the hospital where Bradley and I were to take up residence for the days prior to and following his heart surgery, I was given a red hardback journal in which I could document what I deemed important. I remember staring at the journal, not knowing what to write. In truth, I really did not want to write anything in it because imprinting my thoughts and feelings onto the pages would encourage me to remember the events of the ordeal. Not that I feel that I can ever completely forget the trauma of what I have experienced. But something within me longed for a way to make sense of what was happening. I needed a way to organize my thoughts, a way to work through the engulfing chaos.

A patient's father in the CICU waiting room introduced me to an online webpage where I could keep friends and family abreast of Bradley's status. Writing my thoughts on a webpage seemed much less threatening than writing in a journal. With a click of a button, what had been written on the screen could instantly vanish as if it had never been recorded. To conceal ink marks in a journal, one must expend great effort by either scratching through the words or ripping the page out of the book. In either case, the reader can easily see that something has been deliberately purged. Likewise, the author has a constant reminder of thoughts that tried to make their presence known, only to be cast aside because they did not fit into the organized scheme.

Writing daily, and sometimes hourly, entries in the online journal constructed a sense of order to the chaos of Bradley's illness. Although I appreciated the organization provided by the online website, I find it ironic that I openly allowed others to read some of my most raw and intimate thoughts. I was creating online entries, a blog if you will, at a rapid pace. Oftentimes, I recorded events as they were happening; I am sure that much of what was recorded was characteristic to Frank's (1995) chaos narrative: "...and then and then and then" (p. 99). However, the computer allowed me to censor what I was allowing others to read. For the most part, I was able to wrap my story in a nice little package before it was presented to my audience. It was in the CICU waiting room, sitting in a small purple chair pulled close to the computer monitor, that the first words of my pathography were written. Broyard (1992) states that "[a]lways in emergencies we invent narratives" (p. 19). Like Broyard, writing about my experience with illness helped to make sense out of the chaos created by Bradley's life-threatening emergency. Allowing the computer to aid in organizing my thoughts helped me to gain a superficial control over a situation in which I felt entirely helpless.

Like the jumbled thoughts I deleted from my computer screen, I have tried to delete the effects of illness from my physical appearance. Although my past illnesses may not be externally portrayed, the antibodies created to interpret the illness, should it present itself again, are stored in my memory. Broyard (1992) equates the written accounts of lived experience to "antibodies for illness and pain" (p. 20) as they strive to create organization from chaos. Expressing these lived experiences, whether verbally or textually, can aid in one's understanding of the curriculum. Curriculum is not what is confined to the segregation of the classroom; curriculum encompasses the totality of the lived experience. Therefore, the ill person's experience should also be noted as a part of the curriculum. However, "curriculum is not merely

the presentation of knowledge. It is a process of interpretation” (Grumet, 1989, p. 235). Interpreting the ill person’s curriculum can be relayed through storytelling. The seemingly simple act of relating personal accounts can be messy. When trying to interpret meaning from personal accounts the audience searches for elements with which s/he can identify on a personal level. Personal accounts, both written and spoken, help to connect the speaker with the audience. But Morris (1996) reminds that “[t]he text is constantly reinterpreted, the signified/signifier have no connection, meanings are ambiguous” (p. 414). Literature embodies a multitude of experiences, yet literature that personifies the experiences of the ill person is scarce. Woolf (2002) identifies that, “English, which can express the thoughts of Hamlet and the tragedy of Lear, has no words for the shiver and the headache” (p. 6). Do some view illness, especially those illnesses that do not fall into the conventional diagnoses, as a form of Otherness because there is little in the literature in which to aid one in describing it? Morris (2004) states, “If the world is truly text then our personal encounters are textual” (p. 85). Thus, personal encounters with illness are also textual. However, putting illness and emotions associated with such into words is challenging when concrete examples are lacking in the literature and society.

Frank (1995) contends that “[t]he body is not mute, but it is inarticulate; it does not use speech, yet begets it. The speech that the body begets includes illness stories; the problem of hearing these stories is to hear the body speaking in them” (p. 27). Here, Frank identifies the “mind/body dilemma” (Descartes, 1996). The body relies on the mind to conjure up the words in which the body wants to say. However, I suspect that there is often a miscommunication between the body and mind. Bertrand Russell (1998) discusses this dilemma of trying to articulate that which is wordless. He states, “The things one says are all unsuccessful attempts to say something else—something that perhaps by its very nature cannot be said” (p. 320). He uses

examples of music, the sea, and sunsets as entities that are difficult, at best, to describe. I know I have experienced sunrises from the porch of my grandparents' beachfront condominium that cannot be put into words, only experienced. And even still, the same experience will have different meanings for different individuals. How troublesome it is to write about illness when the very meaning of the word is ambiguous!

Literary devices such as metaphors and myths are oftentimes used to make the ambiguous more concrete. Metaphors can serve to symbolically represent that which cannot be put into words. Charon (2006) contends that metaphors can provide insight into the deeper plot of the ill person's story: "All thinking...including scientific and mathematical as well as poetic, is metaphorical, because metaphor is how the human brain travels" (p. 119). While metaphors can be used to help make sense out of ambiguous terms, such as illness, they can also mystify and distort the term. Susan Sontag's (1978/1989) *Illness as Metaphor* and *AIDS and its Metaphors* describes the danger in equating illness to anything other than what it is—illness. She exposes that certain illnesses, such as tuberculosis, cancer, and AIDS, carry an attached stigma that could exaggerate the ill person's suffering, turning the illness into a game of "blame the victim."

I appreciate Sontag's analysis, for it has made me give pause to how I respond to others when I learn of their diagnosis. However, I would like to spin the table around on Sontag's discussion. After being diagnosed with cancer, Sontag became angry at how others spoke about the dreaded "C," as if the diagnosis came with a coffin. Cancer, tuberculosis, and AIDS are viewed as grave illnesses, ones of serious nature. But the diagnosis of Bradley's illness, a congenital heart defect, was met with favorable prognosis. True, the defect itself was life-threatening if not corrected. However, I recall one of the nurses telling me that if Bradley was to

be born with a heart defect, transposition of the great vessels was the defect of choice. I question how this superimposed “positive thinking” has affected me as I have dealt with Bradley’s (as well as my own) illness. Because, metaphorically speaking, Bradley’s defect was not as detrimental as another defect, or another illness such as cancer, I feel that I have been required to put on a happy face, convincing me to be relieved that he *only* had this particular heart defect. The thought that his defect was *not that bad* in the grand scheme of things lingers in the back of my mind. When I start to become upset about Bradley’s illness, I am reminded, both from others and from my own thoughts, that the circumstances could have been much worse. I quickly repress my feelings of anxiety, guilty for feeling momentarily ungrateful for Bradley’s life. Therefore, in a similar yet opposite manner as exaggerating illness, downplaying the effect of illness can be equally distorting to how the ill person combats suffering.

Sontag (1978/1989) illuminates how metaphorical use can distort the meaning of illness. However, Anatole Broyard (1992) critiques Sontag, suggesting that she is disregarding the value metaphor can give to an ambiguous term such as illness. Broyard (1992) equates metaphorical use to “literary aspirin...a relief from medical terminology...[expressing] the bafflement, the panic combined with beatitude, of the threatened person” (p. 18). Metaphors can soothe and comfort the ill person. For me, it is troublesome when I find difficulty verbalizing or textualizing my thoughts and feelings. When I can equate my experience to something familiar, the chaotic becomes more concrete. Sometimes there is no other way for me to describe my experience than through the use of metaphor.

Broyard (1992) began to make sense of his cancer when he likened dwelling with his illness to visiting a distant country, or having a love affair with a demanding woman, or giving a lecture of unknown subject matter. Living with Bradley’s (and my own) illness has been

somewhat like my favorite reality television show, *The Amazing Race* (Bruckheimer and van Munster, 2011). Teams of two members must race around the world, collecting clues and completing tasks while avoiding elimination at each leg of the race. The team that crosses the finish line after successfully completing all tasks will be awarded one million dollars. Bradley and I are a two-member team vying for our chance at the grand prize. But for us, our prize is a life free from illness. What troubles is that I am not sure if our prize is authentic or fictitious. Are we striving for something that does not exist? Nevertheless, we collect clues and complete the tasks outlined by the doctors and speech therapists in hopes of avoiding elimination. Contestants on *The Amazing Race* travel by airplane from one city to the next. Our race began on April 13th when I signed the paperwork consenting for Bradley to be transported by airplane to a hospital in a distant city that could meet his medical needs. Since that time, Bradley and I have been a team, racing through the obstacles that have been placed in our path. Oftentimes we have a difference of opinions, as team members on *The Amazing Race* often display. However, like it or not, we are on this journey together, racing against the clock in hopes of achieving our prize.

Like Broyard (1992), thinking about Bradley's (and my own) illness metaphorically has helped me to stay focused during this chaotic time in my life. I am not sure that Sontag (1978/1989) would approve of my use of metaphor. Then again, each person digests illness differently; suggesting that one should refrain from using metaphors to work through illness devalues the ill person's lived experience. Similar to metaphorical use, ill persons can employ myths to work through illness. Myth, as defined by Dundes (1984), is "a sacred narrative explaining how the world and man came to be in their present form" (p. 1). For centuries, myths have been used cross-culturally to interpret the likes of creation, the fall of man, and the after-

life. Similarly, myth can also be used to give meaning to illness. Hawkins (1999) states, “Mythic thinking of all kinds becomes apparent in that delicate autobiographical transition from ‘actual’ experience to written narrative, since this transition is one that constructs necessary fictions out of the building blocks of metaphor, image, archetype, and myth” (p. 18). In her book *Reconstructing Illness*, Hawkins (1999) investigates the relationship between mythic thinking—specifically the myths of rebirth, the battle, the journey, and “healthy-mindedness”—to pathography. Pathography is an interpretation of the ill person’s experience rather than a factual account of what really happened. Myths can aid in interpreting the ambiguous and serve to organize chaotic happenings.

The first myth Hawkins (1999) considers is that of rebirth, equating pathographies to autobiographies of religious conversions that suggest a death of the old self and a resurrection of the new self. Given my religious background, I am very familiar with this image of renewal: “Therefore we are buried with him by baptism into death: that like as Christ was raised up from the dead by the glory of the Father, even so we also should walk in newness of life” (Romans 6:4). Likewise, illness can baptize the ill person, creating a “newness of life.” I have known many ill persons who have overcome seemingly impossible circumstances. These persons appear to have won the battle with the Grim Reaper. They have a new outlook, grateful for the second chance at life. However, sometimes the ill body is submerged in water and the spirit drowns. The Grim Reaper has not captured the ill person’s body but the spirit is in the abyss.

The myth of rebirth encourages an attitude of immortality; if the old self can be made new again, the ill person can eliminate the fear of death. In this light, the myth of rebirth can be connected to Frank’s (1995) restitution narrative. The ill person is assured a cure, a remedy for the illness. The idea of rebirth may encourage the ill person to trudge on, staying positive while

seeking a better tomorrow. While restoration from the illness is possible, it is not the general rule for most serious illnesses.

When I hear an ill person speak of personal illness, especially life-threatening ones such as cancer, s/he often describes it as her/his “battle with” illness. I believe that much of the American culture has encouraged ill persons to feel that they are in a war against an outside force that is trying to storm the castle walls. This mindset may encourage the ill person to seek medical ammunition needed to fend off the enemy. However, I believe employing the myth of the battle paints the illusion that illness is apart from instead of a part of the body. Illness becomes an enemy that must be fought, taken down, and destroyed, rather than an entity that cohabitates with the individual. As Hawkins (1999) identifies, the battle myth has deep historical roots. Greek and Christian mythology is abundant with stories of good versus evil. But when considering illness, the battle is much more involved than just some outside force trying to take control. The body becomes ill because something in the body has failed.

Oftentimes, the body’s broken part lies within the failed immune system. A pathogen “invades” (to use medical terminology) a cell and begins to destroy from within. Bradley’s illness cannot be viewed in this light. His heart defect was caused because something that should have happened during gestation failed to occur. Bradley’s body was not invaded by some foreign object; his castle walls were not built strong enough to withstand normal wear and tear and began to crumble under their own weight. Considering my own illness, I do not feel that I am in a battle at all. What would I be fighting? Chaos is the only thing that has come into my life. Unfortunately, I do not believe there is any medical ammunition that could fend off this enemy. It is possible that I could be fighting myself, a war within the castle walls. If this is true, my ill body has become a sort of ying yang—good and evil intertwined.

The myth of the battle often intertwines with the myth of the journey. Many times, I have employed the myth of the journey as a stage for understanding my experiences as a curriculum studies doctoral student. The field of curriculum studies emphasizes the concept of the journey, and moreover, the meaning gained from the journey. Possibly the most notable depiction of the journey myth is Joseph Campbell's (1949/2008) *The Hero with a Thousand Faces* which chronicles the hero's journey through three phases: departure, initiation, and return. When I first began to work through my illness, I desperately tried to mirror my experience to that of the hero's quest. Campbell (1949/2008) describes how the hero must answer a call to begin his journey and battle with numerous forces which try to prohibit him from returning the boon to the masses. The call came when I was encouraged by Marla Morris to write my pathography for my dissertation. I had known for some time that I needed work through the repressed feelings I harbored during the Bradley ordeal. But, for whatever reason, the timing never seemed appropriate to embark on what has become a deep Self inquiry.

After answering the call, the battles with my repressed emotions, with loved ones, and with my Self became more hostile. I had definitely encountered conflict prior to answering the call; however, the battles had not been as magnified as they now were. I likened this phase of "initiation" to what my pastor says about temptation by Satan: Satan does not waste time tempting someone who is out of the God's will. Yet, when the person begins to draw near to God, Satan unleashes his most enticing temptations to lure the person away from righteousness. As I have spent time in self-exploration, fleshing through my complex emotions pertaining to my illness dwelling, I have felt intense anxieties that threaten to lure me from this time spent engaged in "soul work" (Morris 2008). Although I am still on guard in case other battles arise, I feel I am teetering more on the edge of return. On one hand, it is difficult for me to draw this leg

of my journey to a close. My time spent in self inquiry has been difficult, but simultaneously fulfilling. I have learned a great deal about my Self and wish I could tarry longer in hopes of learning more. However, I have a responsibility to return to the masses to share what I have learned.

Campbell's (1949/2008) Hero Quest and Hawkins' (1999) myth of the journey are similar to Frank's (1995) quest narrative description of illness. When the ill person is first presented with the call, s/he may choose to ignore it. Minor symptoms can be temporarily ignored and attributed to fatigue, muscle strain, or the like. Eventually, the symptoms manifest in such a way that they can no longer be ignored. The call must be answered. The following days, weeks, months entail what Campbell (1949/2008) refers to as a "road of trials": medical tests, laboratory cultures, diagnoses, treatments. If the ill person survives the trials, both physically and psychologically, s/he has the opportunity to return home with a newfound meaning of the lived experience.

There are several problems with using the myth of the journey as a metaphor for illness. The myth assumes that the hero survives the battles, conquers the enemy. What if the ill person is not able to overcome illness? If the ill person is swallowed up, physically and/or psychologically, by illness, then good has not triumphed over evil. When applying the journey myth as a metaphor for illness, illness becomes evil, something to be conquered. I argue that illness is a part of the body and I do not believe that the body is evil, or good for that matter. The body just is, period. Illness just happens, period. But what the ill body learns from dwelling with illness can be used for good and evil purposes. As previously mentioned, overcoming adversity brought on by illness can create a renewed spirit which illuminates the ill body.

However, illness can also cause one to become full of bitterness and hatred, casting a shadow on the ill body and its surroundings.

The myth of the journey, and therefore the hero quest, portrays a masculine view of illness. I am not the fighter of battles that is suggested by the myth. The masculine role of the hero denies my inhibitions about battling my illness, my emotions, my world. Sometimes I do not want to fight; I want to cry, or run away, or reason with adversity. The battle in Campbell's (1949/2008) depiction is between hero and foe. The hero has some thing that must be fought. But illness is not some thing or some entity outside of the self. Illness is a part of, not apart from, the self. In illness, there is no thing to be fought; there is only some thing to try to understand if I am not psychologically worn down when the battle is over. The myth of the journey encourages me to wrap my illness in a pretty little package with a bow on top, containing it in such a way that it is manageable. Whenever I am faced with uncertainty, this packaging becomes my defense mechanism. Illness cannot be neatly packaged in this way; illness cannot be compartmentalized. However, this is exactly how I tend to treat things that I struggle to endure. I find it much easier to package these emotions so that they may be shelved for a later day rather than to deal with them in the present.

I do not suggest that using the myth of the journey to interpret illness is wrong. I think that any device that allows one to cope with illness can be beneficial for the ill person. For me, employing parts of this myth as a way of describing the indescribable has allowed me to cope. I only raise my concerns about applying this myth to illness because I feel that this myth generalizes many aspects of the ill person's experience. I feel that I am indeed on a journey and if I make it out on the other side, I will have learned something along the way that I may be able to share with others. I suspect there are those who view illness as a journey into the abyss,

especially those with chronic illnesses who struggle to make it through each day. Hawkins (1999) states that the myths of the battle and the journey “help turn an experience where one is primarily acted upon into one where one can act—precisely by giving it meaning” (p. 89). The institution of illness can create a passive experience for the ill person. The ill body is often a thing to be worked on because it needs fixing. I imagine the broken body similar to my car when I take it in to be serviced. I tell the mechanic the symptoms my car is experiencing, but ultimately the tweaking of the car’s mechanical parts is under the direction of the mechanic. Likewise, when the ill body is turned over to the physician to be repaired, especially if the ill person is under anesthesia, the owner of the vehicle is at the mercy of the mechanic’s hands. Utilizing the myths of the battle and journey remove the tools from the mechanic’s hands and place them in the hands of the ill person. The experience becomes much more active because the ill person is now in the driver’s seat.

Another way the ill person has become more of an active participant in dwelling with illness is through what Hawkins (1999) refers to as the myth of “healthy-mindedness.” Borrowing the term from William James (1958), “healthy-mindedness” refers to “an attitude characterized by the sense that nature is inherently and absolutely good, the relegation of evil and sin to the status of illusory constructs, and a relentless optimism” (Hawkins, 1999, p. 127). This myth is troubling because the “healthy-mindedness” attitude is a distortion of reality for the ill person. Living in a one-dimensional world where everything is as it should be denies the affects of illness. Some individuals in my circle insist that ill persons employ an optimistic, “glass is half full” view when discussing illness. This idea bothers me greatly because I once was victim to a distorted view of illness which I feel caused me to further repress my feelings about dwelling with illness.

Persons who subscribe to the attitude of “healthy-mindedness” do not rely on orthodox medicine to dictate the journey will illness; instead, the ill person is in the driver’s seat, often utilizing alternative medicinal treatments. There is something for me to learn from the “healthy-minded” person. I am too quick to rely on orthodox medicine when I am ill, possibly because I have always had an interest in the medical field and the doctor/patient relationship. Instead, I should be more open to alternative medicine that focuses on treating the holistic individual instead of focusing on the complaint of the day. After all, ill persons of centuries ago were not privy to the technological medical advances of today; remedies for illness were derived from nature.

While I believe that alternative medicinal treatments can be equally as beneficial as orthodox medicinal therapies, I cannot be naïve in believing that alternative medicine could remedy all illness. For example, Bradley’s heart defect could have only been corrected through surgery. Personally, alternative treatments for illness include using myths and metaphors as a way to work through illness. Similar to illness narratives, differing forms of myth and metaphor overlap throughout the ill person’s experience. Using myths as a metaphor for illness can distort the reality of the ill persons lived experience. They create a prescribed order that conflicts with the chaotic nature of illness. Frank (1995) says that using generalized myths and metaphors can be dangerous because it denies the mourning that is ever-present in illness. However, these literary devices can be equally beneficial in helping the ill person organize the chaos that accompanies illness. Utilizing myths and metaphors to work through my illness has granted a sense of control in an otherwise chaotic situation, allowing me to become an active participant in the meaning-making of my lived experience.

A Place and Time for Pathography

The strangeness I feel when reading another's account of dwelling with illness could be attributed to our differences in where we are coming from, our difference in *place*. Kincheloe and Pinar (1991) state that “[k]nowing where one started allows one to understand where he or she is” (p. 4). Our place defines who we are. Place is embedded in both our conscious and unconscious. Place shapes our behavior. Place dictates why we are attracted to particular subjects. Place helps to explain the biases that are embedded within. Therefore, I cannot properly analyze my pathography unless I examine the birth-place of my story.

I have lived in Savannah, Georgia my entire life. My birthplace is characterized by hospitality, Spanish moss and Southern cooking (the latter made famous by our own Paula Deen). As an elementary student studying Savannah history, I interpreted that General Sherman spared Savannah from destruction on his March to the Sea because of her beauty, gifting the city to President Lincoln as an early Christmas present. In recent years, I have learned that this story, which has been handed down for generations, may be at least partially fiction. Southerners are known for the telling and retelling of stories. Stories are repeated countless times to the same audience so that one day, when the storyteller is no longer among her/his listeners, another storyteller will take her/his place and relay the story to future audiences. The art of storytelling is a part of my Southern heritage. Perhaps this is the reason I am drawn to autobiographical inquiry and moreover why I am compelled to share my pathography with others.

Although Savannah has a population of over 130,000, it has the feel of a small town. Everyone knows everybody in Savannah, including their relatives, where they went to school, who they married, and any other personal story that has been transmitted along the grapevine. Stories follow a person in this town. Reputation is everything. Some native Savannahian

women may feel required to maintain an immaculate household in which to display their Southern hospitality. My Grandmother's house was always immaculate when I visited as a child. Her motto was "Everything has a place and everything in its place." She once told me she kept her house this way because she never knew who might drop by and she did not want to be embarrassed for having a messy house. Even her closets were perfectly organized. I was always baffled by how she managed to keep such an impeccable house.

Because of my Grandmother's influence, I have tried to keep "everything in its place." But her motto pertains more to the living arrangements of my psyche than those of my household. I try to keep everything in its place, as I suppose others do. But sometimes items fall from the shelves or are strewn around the living room of my mind. When I hear someone knocking, I quickly rush around picking up, straightening up, throwing everything I can into the nearest closet. The closet is bulging. I have to press my back against it for fear of it bursting open. But at least my room looks good for my company. Maybe if I distract my guests by offering a glass of sweet tea they will overlook the chaos that lurks from under the sofa. After all, my living room must be presentable or the grapevine will be alive with stories about me.

Historic Savannah is organized in a grid-like pattern containing common areas, or "squares," which are bordered by some of the oldest and most grandiose places of dwelling and worship in the South. These squares beckon visitors to marvel at their beauty as they relax in the shade offered by the expansive live oak trees romantically draped in Spanish moss. Perhaps the careful organization of my birthplace influences a life of organization and control in hopes of supporting grandiose structures along its borders. Savannah is my home. I really cannot imagine myself living anywhere else. If I were ever forced to move from here I suspect that I would have great difficulty adjusting to a foreign place. Savannah is my comfort zone. I tend to

become too attached to areas of comfort; when chaos threatens to pull me from my area of comfort I do not fare well. But Doll (2000) speaks of “the necessity of being in foreign places” (p. viii). New experiences can be encountered in foreign places. But, the thought of being forced into a literal foreign place makes me shudder! I do not want to be in a foreign place, unless it is by choice. I would love to visit Europe or Hawaii, both foreign places to me. Even still, before I visited I would have planned out everything I wanted to see or do while I was there. I assume this excessive planning removes the “foreign” aspect from my visit.

Mark Taylor (2009) chronicles his journey with cancer in his memoir *Fieldnotes from Elsewhere*. Similar to Doll’s (2000) “foreign places,” Taylor (2009) suggests that “elsewhere” is “not so much a place as a condition that renders whatever had seemed familiar utterly strange” (p. 13). My previous medical training made the policies and procedures of the medical facility very familiar. Having taught high school anatomy for several years, I was familiar with the heart’s anatomy and physiology. Furthermore, having spent some time in the cardiology field, I was familiar with the diagnostic tests and surgical procedures required to examine and repair cardiac problems. “In the blink of an eye, everything changed. It was as if I had been transported elsewhere and now looked back to discover that all that had been familiar had become strange” (Taylor, 2009, p. 16). The familiar became strange when I was no longer the one in scrubs, prepping my patient for the doctor’s examination. I am familiar with journeying alongside close family members while they are dwelling with illness. However, Bradley’s situation was strange because he was more than a *close family member*—Bradley was a part of my body. Bradley’s congenital heart defect diagnosis was simultaneously my diagnosis. His broken physical heart was a reflection of my broken emotional heart. Seeing him lying in his bassinet was unbearably painful. Oftentimes, I had to force myself to be near his violated body.

Despite the brokenness, our hearts were beating as one. Bradley was always with me, even if I was not beside him. Where else could I have gone?

Doll (2000) says that it is a “necessity” for me to be in a land of strangeness. Perhaps this strangeness is what allows me to learn more about my Self. When I am out of my comfort zone I am no longer on autopilot, passively meandering from place to place. Instead my eyes are wide open, unsure of what lies ahead of me. Bradley’s birth marked the arrival of my second child. I felt confident in knowing what my future held, having already experienced childbirth and three years of raising a son. Learning of his defect thrust me into a foreign land, causing my head to spin. Being able to speak the language of the land provided little comfort. Not even charting my specific course through this foreign land could have prepared me for the experiences that were to come. I was not the only one thrust into a foreign place. Bradley was forced from the temporary comforts of my womb, where he had been nourished by my place/nta, into a world of chaos. I have often wondered the thoughts rushing through a newborn baby’s mind as they are forced from their comfort zone of warmth and contentment into a cold world of blinding lights and blaring sounds. I remember trying to comfort Bradley as he lay in his bassinet entangled in a chaotic labyrinth of tubes and wires. For several days after his surgery I was not allowed to hold his violated body in my arms, close to my chest so that he could hear the beating of my heart, the rhythm of his comfort zone. I could only hold his hand, promising not to desert him as we journeyed together through this foreign land.

Place and time are intertwined. I remember both the place and the time I first learned of Bradley’s defect. According to the clock that I could see from my hospital bed, the time was 8:07 a.m. The time struck me as ironic because it was the reversal of Bradley’s birth weight—7 pounds, 8 ounces. I had just called my friend Lauren to announce Bradley’s arrival when the

pediatrician came into the room with a solemn look on his face. As I hung up the phone, I suspected that the doctor was about to share something with me that would forever change my life. This life-altering moment is time, date, and place stamped into my mind.

Time has influenced my writing and the manner in which I have recalled the ordeal's events. Distance has separated me from the specifics, making my memory fuzzy in some areas. Morris (2001) describes memory as being "dense and scaffolded, horizontally and vertically, over time and place. Some memory traces haunt while others vanish" (p. 90). Memory is not linear; as a product of *lebenswelt*, it goes this way and that way, crossing multiple times and places. Memories of Bradley's violated body lying helpless in the bassinet haunt. I wonder what memories have vanished. I am sure there are some that have, specifically ones that are too painful to remember. But have they really vanished? I think not. I am frightened that they have only been repressed in a dark corner of my mind, awaiting their moment in the spotlight. The return of repressed memories also haunts.

Physical affects can result from the haunting of repressed memories. Morris (2001) discusses the embodiment of memory as it relates to Holocaust survivors. She tells me that "[m]emories that get repressed manifest in displaced forms which get acted out in sites in the body" (2001, p. 95). I am not suggesting that the experiences of Bradley's or my own illness should be compared to the horror experienced by those during the Holocaust. However, I can identify with the toll these displaced forms can take on the body. There have been times throughout my illness dwelling that I have awoken in the middle of the night in a hysterical fit of tears. Other times, I have been violently sick to my stomach. I am constantly fatigued. I frequently experience horrible nightmares. Perhaps I could be diagnosed as being depressed, if I sought medical advice. The more I strive to repress the memories of the ordeal, the more I

experience the effect of “displaced forms” on my body. Morris (2001) proclaims that memories “have a life of their own, traveling across an unconscious trajectory that offers up strangeness” (p. 98). The ill effects experienced by my body are strange. But strangely, since embracing the time to write about my experience, I do not experience the horrible nightmares, the sickness, the depression as often. Thus, I will continue to welcome the time spent working through my memories made while journeying through a foreign land of illness.

I question how the lapse in time influences my memory, the authenticity of my story, and the notion of my Self. Rita Charon (2006) says, “Autobiography cannot be considered apart from fundamental beliefs about the self, which in turn are influenced by beliefs regarding the nature of language, thought, consciousness, time, memory, and relation” (p. 70). While at Egleston Hospital in Atlanta for twelve days, I had a significant lapse in time. I rose in the morning when sleep could contain me no longer and collapsed into a heap of emotional and physical disarray when the mind/body could no longer maintain its façade of control. There were no windows near Bradley’s bed, no way of maintaining the circadian rhythm. Morris (2008) states that “[w]ithout the rhythm of time, one experiences a psychic death... Somehow the psyche remains in a state of dissociation, floating above and outside of the body. Perhaps this dissociation works to defend psyche against the reality of the illness-at-hand” (p. 66). In order to cope with chaotic events, the psyche separates from the body. The elimination of time has allowed the psyche to cope. My journey would be vastly different if I could work from the end toward the beginning, having already gained understanding of the battles! By consciously deciding to ignore the daily time-stamp, events became blurry and somehow more manageable.

As I have written my pathography, I have noticed an obvious shift in the tone of my writing. Morris (2008) suggests that one can write with the “mindheart” (emphasizing the

intellect) or with the “heartmind” (emphasizing the emotions). The entries written in my online journal are apparently written with the “heartmind.” As time and distance have separated me from the main event, I now find that I write with the “mindheart.” The lines between what actually occurred and what happened only in my mind are blurred. It is possible that some may cast my narrative aside with scorn, accusing me of romanticizing my situation. However, Grumet (1987) encourages me not to get caught up in this tug-of-war of what is and is not authentic. The meaning of autobiography is not in the accuracy of the plot, timeline, or characters involved; however, to gain meaning she suggests that personal accounts must be considered reflexively. Morris (2008) employs this notion of reflexivity in her book, *Teaching Through the Ill Body*. She includes a “Post (script)” at the end of each chapter and reasons, “I offer these small snippets of memory...to situate myself within the larger theoretical narrative. I write now looking back and thinking about what happened and how I dealt with being struck down by a terrible illness” (p. 13). Morris’ Post (script)s urge me to value reflection as a part of deriving meaning from experience. I agree with Taylor (2009) who says that “Life is lived forward but understood backward” (p. 14). Like the “stories about nothing and everything” that I occasionally pulled out from under my bed, reflecting on my writings helps me to gain a more holistic view of “nothing.”

The Voice of Pathography

The medical chart is plagued with facts and figures, numbers and transcriptions, the topography of the ill body’s landscape. However, the most precisely constructed chart does not reveal the story that lies under the surface of the ill body. Hawkins (1999) highlights pathography as a way to “[restore] the person ignored or canceled out in the medical

enterprise...[placing] that person at the very center...[giving] that ill person a voice” (p. 12).

When one becomes ill, the body is often administered medication or treatment to combat the illness. But illness does not only wreak havoc on the body; illness creates wounds in the psyche as well. Frank (1995) reminds me that ill persons are wounded both in body and in voice. He encourages ill persons “to become storytellers in order to recover the voices that illness and its treatment often take away” (p. xii). The voice is the channel through which the ill body communicates her/his story. However, the story becomes little more than background noise if the audience is not on the same frequency as the ill person. Pathographies can help ill persons recover their lost voice so that they can help others, and themselves, understand illness.

But what if the ill person has lost her/his voice? One suffering from laryngitis is almost inaudible. S/he strains while talking to others, desperately trying to communicate. *Don't talk*, the listeners plead. *I cannot understand what you are saying*. The ill person is shut down, forbidden to express her/himself, permitted only to be on the receiving end of the conversation. However, conversation loses its richness when it is a one-way street. To complicate the conversation, dialogue must flow back and forth between participants. Sometimes it is difficult for me to hold a conversation with Bradley because of his speech delay. After surgery, he was on a ventilator to relieve some of the burden on his heart. For four days, he did not make a sound because the breathing tube blocked the vibrations of his vocal cords. When he cried, it was as if someone had hit the mute button on his remote control. The memory of his silent cry haunts.

I am convinced that Bradley's speech delay was caused by the ventilation tube. He does not have a problem with his receptive language; he fully understands what you are telling him. Bradley has a delay in his expressive language skills; he has difficulty articulating his words. He

knows what he wants to say, but his vocal cords will not allow him to form the words. Bradley's voice has been physically wounded, prohibiting him from expressing himself in a way that can be understood by others. But what if an ill person's voice is psychologically wounded, causing them to suffer from psychological laryngitis? The ill person cannot make sense of what s/he is experiencing. Words do not exist to describe the dwelling place of illness. Articulated words have no meaning. The ill person is in the abyss.

Morris (2008) asks, "Does illness make for rigidity? Does it make one psychologically brittle?" (p. 103). I believe it does for people who are in the abyss. What help is offered for those who have sunken into the abyss? One way ill persons can emerge from the darkness is through free-association, specifically in writing. Free-association does not make any sense, similar to being in the abyss, similar to my "stories about nothing and everything." I find it interesting that, at such a young age and before I even knew the meaning of the term, I recognized the value free-association has for expunging thoughts and feelings that are difficult to verbalize and even more difficult to textualize in an organized fashion. However, free-association, or "automatic writing" (Britzman, 2006, p. 37), can help the ill person find answers. Britzman (2006) compares this style of writing to a Ouija Board:

There is an infantile desire for discourse to be telepathic, to give us what we wish for, and to automate without having to associate. It lures us into the answer we already knew was waiting. So come. Place your hands on the magic pointer, move right into language, and let it speak. Let language be magical and mean without effort. (p. 37)

When the ill person has lost her/his voice, the language of free-association can speak for her/him. This automatic writing can reveal a mixed bag of emotions. Automatic writing is the most raw

form of writing; it does not succumb to censorship. The ill person is completely vulnerable as s/he exposes the soul's nakedness.

Like water flowing from the source of a stream, thoughts flow continuously from the ill person's wound, turning this way and that as they swallow up rocks that try to hinder their journey toward the mouth of the river. Doll (2000) describes stream of consciousness as "[going] with the flow of impressions trying to reach back to where memory began, not forward to where intellect strains" (p. 162). Oftentimes I am too rigid in my writing, concerned with the perfection of the text's appearance. However, when I allow thoughts to freely flow I find that what appears to be a chaotic mess reveals what is most important. As I read between the lines, these chaotic thoughts often illuminate other information from my unconscious that I had not previously considered.

Taylor (2009) understands the power of the unconscious: "What is left unsaid...is as important as what is said, and the invisible is often as significant as the visible" (p. 13). Through my exploration in the area of psychoanalysis, I have come to appreciate the value of what is not shared or conveyed in the conversation. In a former paper, I wrote, "Learning of Bradley's defect made the first incision into my soul, an incision so deep I was cautious of bonding with him after surgery for fear that I may lose him again." The subject of the paper was on chaos, and specifically how I do not fare well when chaotic events disrupt my life. I have long attributed my illness to the fact that I am a "pre-crastinator"—one who plans out every minute detail and is unable to cope when life's events do not evolve as scripted. When I reflected on my writing at a much later time, this sentence which I had first glossed over became the focal point on the page. I feel that part of my illness stems from my fear of losing Bradley. Such a simple statement, one most definitely written by my unconscious, illuminated the possible etiology of my illness. Doll

(1982) says, “Like a thief at the gates, the unconscious slips through the cracks of conscious control” (p. 198). The lingering memories of dwelling with illness plague the un/conscious. Memories cannot be erased from the mind with the click of the delete key the way that I can erase cluttered thoughts from my computer screen. The effects of dwelling with illness remain.

Memory becomes problematic when trying to recall specifics about time and place. The authenticity of a personal account’s content is sometimes questioned because the depth of fictitious embellishment is unknown. For this reason, some listeners may disregard personal accounts as being invalid. Although Grumet (1987) places emphasis on the account’s meaning rather than the factual information, I feel that it is necessary to strive for accuracy throughout my pathography. Journaling during an illness can be one way to be more accurate in recording factual information. But more importantly, journaling during illness can help the ill person organize her/his thoughts. Reiniger (1989) states, “[J]ournal-writing becomes a method of personal discovery and of an intellectual challenge while it is also the analysis of our past and the synthesis of our future” (p. 26). Journal writing can help promote Pinar’s (1975) “Method of Currere” by encouraging the ill person to examine illness regressively, progressively, analytically, and synthetically. In retrospect, I am thankful that I maintained a written account of the ordeal because it has served to fill in the gaps created by time. For me, journaling helped to pass the time. Hovering over my child’s bed, listening to the vast array of beeping medical equipment, constantly reminded me that my child was ill. Countless times throughout my pregnancy I uttered the phrase, *I’m praying for a healthy baby*; staring at Bradley lying amidst a spider web of chaos confirmed that my prayers had not been answered. I felt isolated from my friends and family, my husband, my baby, and God. My writings provided companionship.

It is no doubt that journaling can provide insight into one's private world. However, when does the life story cross the line from being revered to being idolized? I am reminded of Farrah Fawcett and her battle with cancer. She chose to film a documentary, a sort of day in the life of a cancer patient. While I do not believe her intent was to romanticize cancer, the incessant media coverage of her illness was overwhelming. The media has a knack for making the unpopular popular. Other celebrities come to mind, (Michael J. Fox, Mohammad Ali, Patrick Swayze), as examples of those who have also gone public with their private illnesses. But at what point is the private too private to be shared? Are there not some things that should remain hidden from view? But then, if I choose not to share my most private feelings, am being honest with my audience by only revealing the part of my Self that I allow to be vulnerable? I feel that I am constantly battling for censorship in my writing. I struggle with these questions regarding vulnerability. Morris (2008) offers an explanation which helps to answer my questions:

A pedagogy of suffering might allow for exploration of physical as well as psychological woundedness. That woundedness is the site of vulnerability. The ill body teaches through this wounded vulnerability. (p. 2)

Illness creates both physical and psychological woundedness. A physical wound is a site of vulnerability, an opening that permits bacteria to enter the body and destroy healthy tissue. Likewise, the psychological wound opens the heart, making it vulnerable to anger and hatred that is often associated with illness. However, the voice of the ill person can emerge from the wounded heart as it strives to give meaning through this site of vulnerability.

Nettles (2001) says, "Invulnerability is the delusion of the arrogantly strong..." (p. 42). The variety of my life experiences pales in comparison to Nettles'. However, I believe I too was once arrogant and fell victim to this delusion of invulnerability. Illness can expose the delusion,

reminding the ill body of its careful teeter-tottering on the edge of im/mortality. Many of my high school students can relate to this delusion as well. I am not convinced that the traditional educational arena promotes situations that allow the students to feel vulnerable and express their inner feelings. It seems to me that the constant focus on standards has stripped the personal enjoyment and application from learning. Britzman (2006) states, “[T]he very structure of education invokes dependency, compliance, and apathy, and renders association so one sided and unfree” (p. 28). Traditional education does not promote free-association, which exposes vulnerability. As a high school teacher and a student of curriculum studies, I am charged with complicating the conversation with my students while maintaining a standards-based classroom. Deborah Britzman (1992) uses autobiographical inquiry in the classroom as a way of cultivating a sense of vulnerability in her students. She emphasizes the need for encouraging students to write their biographies as a means of better understanding themselves “as a construction and eventually, as a socially empowering occasion” (p. 43). Although biographies are different in nature from the dialogue journals that Meath-Lang (1990) emphasizes, both can serve as a means of giving voice to marginalized groups.

In her article “Why doesn’t this feel empowering?” Elizabeth Ellsworth (1989) states, “[T]he desire by the mostly white, middle-class men who write the literature on critical pedagogy to elicit ‘full expression’ of student voices...becomes voyeuristic when the voice of the pedagogue himself goes unexamined” (p. 312). Although Ellsworth is referring to oppression in the educational arena, I believe that her message can also be applied to the medical realm. The masculinity of the medical field demands answers to problems, a one-sided view of how illness should be treated. But there is much more to explore than this one-sided prescription

for healing. The personal side of the patient must be considered in the diagnosis and treatment of the illness.

Community and Pathography

Dwelling with illness can be frightening. When Bradley is frightened he runs to me, his source of comfort, for reassurance. Likewise, ill persons seek a source of comfort when they are frightened, unsure of what the future holds. Writing pathographies can help the ill person work through the uncertainty that accompanies illness. Textualizing experiences can help one make meaning from chaos. However, pathographies are not only beneficial for the writer. Sharing personal accounts can provide a sense of comfort for those who are dwelling with illness. Frank (1995) states:

As wounded, people may be cared for, but as storytellers, they care for others. The ill, and all those who suffer, can also be healers. Their injuries become the source of their potency of their stories. Through their stories, the ill create empathetic bonds between themselves and their listeners. These bonds expand as the stories are retold. Those who listened then tell others, and the circle of shared experience widens. Because stories can heal, the wounded healer and wounded storyteller are not separate, but are different aspects of the same figure. (p. xii)

I have learned much from reading the personal narratives of others. Although each narrative is unique, all share commonalties. Forming networks with others who are ill can encourage the healing process. I have a few close friends in my circle who I feel comfortable sharing some of my joys and fears. These friends afford me the time to vent my frustrations and occasionally offer suggestions on how I can continue to persevere. There is one such friend I call upon

regularly: www.amazon.com. This friend remembers our previous conversations and offers suggestions for books that I may find benefit in reading. It is through this friend that I happened upon Ruhlman's (2003) *Walk on Water*, a detailed look at the lives of pediatric cardiothoracic surgeons. Ruhlman's words took me inside of the operating room where I saw the surgical team standing over my child, working feverishly to perform the arterial switch procedure so that Bradley may have a chance at life. The scene was comforting/haunting to watch. Experiences with illness can be messy in this way. I often feel validated that my fears and emotions are similar to others who have experienced illness. However, these textualized accounts can be haunting as they conjure up images that have been long forgotten (or only repressed?).

Many written accounts of illness have greatly impacted me I have stumbled across by chance. I once read an article about Randy Pausch's (2008) *The Last Lecture* which enticed me to order a copy. Diagnosed with cancer and given only a short time to live, Pausch was determined to find a way for his three children to remember him after his death. "I was trying to put myself in a bottle that would one day wash up on the beach for my children" (Pausch, 2008, p. x). Accomplished professors are noted for giving a "last lecture." So, this presentation-turned-book became Pausch's legacy. He encourages me to find a way to leave my mark so that others can remember me when I am gone. Although I do not profess to be a *writer*, I see significance in the written word; my pathography will endure long after I have passed.

I might never have known about *Nick's New Heart* (May, 2008) had it not been for Lauren. Having been a friend for several years, Lauren was an active part of my life during the ordeal. A strong religious woman, she had asked some of her extended family to keep Bradley in their prayers. Through this network I learned that one of her family members' friends had given birth to a son with the same heart defect some twenty years prior and had written an

account of what she endured. As I read May's (2008) account, I developed an eerie sensation that someone had videotaped and later transcribed my entire life during the ordeal. At times, her words were validating; I have a multitude of exclamation points beside phrases that I swore I had uttered as well. At other times, her words were comforting; I truly felt as if there was another that could possibly share in the understanding of what I endured (am enduring). Although I easily finished the book in its entirety in an afternoon, the hours spent while reading were tremendously difficult. Memories of things forgotten, purposely repressed because of the damage it does to the psyche if remembered, came flooding back like a tidal wave pounding the shore of my soul. At times, I did not know if I could continue reading; the re-remembering had become too painful. However, I knew that sometimes the healing process can be painful, so I trudged on throughout the journey.

Studying others' personal accounts of illness has helped me to understand my own struggles, as Morris (2008) suggested they would. I must return the favor and chronicle my experience with illness dwelling in hopes that it will aid another on her/his journey toward restoration. Frank (1991) states, "To seize the opportunity offered by illness, we must live actively; we must think a lot, talk a lot, and some, like me, must write a lot" (p. 3). I have frequently been accused of talking a lot, especially about Bradley's illness. I'm not sure if I was specifically looking for healing or pity by sharing my personal account with others. It is possible that I was seeking both. Since the ordeal, I have discovered a passion for reading, specifically in the genre of literature depicting the personal side of illness. Reading has made me think, made me dig deep into my soul to examine parts that I had previously kept hidden from view. Internalizing the words I read has prompted me to write. I have always believed writing to be therapeutic. Sacks (1985) states, "We have, each of us, a life-story, an inner narrative—whose

continuity, whose sense is our lives. It might be said that each of us constructs and lives a ‘narrative,’ and that this narrative is us, our identities” (p. 110). Pathographies, or illness “narratives” as Sacks refers to them, can provide a channel for recovery. It is interesting to see persons from different cultures unified by the common thread of illness. Like lepers, they become the outcasts and find solace in one another. Healing and restoration can begin to occur within the community of the ill.

CHAPTER 3

ORDER IN DISORDER: FINDING MEANING IN A SYSTEM

OF INCREASING ENTROPY

Chaos was the law of nature; Order was the dream of man. (Adams, 1918/2008, p. 377)

As a child, one of my favorite pieces of playground equipment was the seesaw. When the teacher dismissed my class to recess, the notion of carefree magnificence of soaring through the air beckoned me to sprint toward the far end of the playground so that I could be the first to climb aboard the seesaw. Our seesaw was such an uncomplicated piece of equipment: a simple wooden board attached to a fixed brace about which the board can pivot. I explain to students in my science class that a seesaw could be classified as a first class lever: effort and resistance arms at opposing ends, separated by a fulcrum. As a force is applied to one end of the lever, the lever pivots along the fulcrum, moving the load in the opposite direction of the applied force. As the force is removed, the system returns back to its original state, with the load overpowering the effort.

Compared to my classmates, I was a rather small child and did not provide much of an effort force as my friends and I rode up and down on the seesaw. Ideally, partners on a seesaw are of similar weight distribution, allowing a harmonious balance between effort and load. Complete balance would not be much fun on the seesaw; neither partner would go up or down. Instead, both would remain in a horizontal position. Yet, similar weight distributions allow for little extra effort to be expended by the person at the bottom of the seesaw as s/he pushes up off from the ground, allowing for the effort and resistance arms to change positions. My small size required my seesaw partner to expend a great deal of energy to attempt to switch positions. I often found myself at the top, observing my friends as they played on the playground. However,

I was frightened being so high in the air with only a board separating my fragile body from the hard ground. This position forced me to be at the mercy of whoever was on the other side of the seesaw. I was not in control of my fate. As soon as I began to deal with my fears of being high in the air, the other person could choose to push off from the ground without warning, instantly changing my vantage point.

Dwelling with illness can be compared to riding a seesaw. Like two forces teetering up and down, illness oscillates within the body and the soul. The overwhelming load of the ill body pushes the soul high into the air and out of control. Occasionally, the ill body will let up and allow the effort of the soul to come back down to touch the ground where a sense of control can be gained, if only momentarily, before pushing the soul back into the air again. From this vantage point, the soul can see others who have both feet on the ground, seemingly moving throughout life with little adversity. Their lives appear to be controlled and stable.

Humans are nurtured to be controlling beasts. Extrinsic influences encourage one to be in control of her/his destiny, in control of her/his happiness, in control of the television. The house must be orderly; the bills must be paid on schedule. Everything is systematic and controlled. There seems to be a constant power struggle for control among some groups of humans. The one in control holds the power. Interestingly, this notion of order and control was not nature's intent. Humans were designed to be chaotic creatures, an apparent random series of events in which control was not something to be gained but embedded in the architectural design. As a white, middle-class woman, I am constantly vying for control in my life. My multiple roles as wife, mother, sister, daughter, teacher, student, church member, friend are demanding and make me dizzy. I long for a life of control and routine simplicity; yet, I suppose that this dream is a mere unattainable fantasy. I am in a constant tug-of-war pulled in multiple directions. I am

riding up and down, up and down on a seesaw, yet I always seem to be the one at the top. It seems that someone, or something, else is always pushing me back up as soon as I start to feel my feet touch the stable ground again.

I have oftentimes heard others dwelling with illness refer to their lives as a “roller coaster of events.” Most traditional roller coasters I have encountered move fluidly throughout the duration of the ride. Once the ride begins, the car will continue until it comes to its final resting place. There may be sharp turns, steep drops, or upside loops and corkscrews throughout the ride’s journey; however, many traditional roller coasters allow the riders to see the upcoming track, allowing for anticipation of what is to come. The roller coaster analogy does not describe my experience with illness. My journey has not been fluid, nor have I been able to anticipate what is looming ahead. My journey with illness has been up and down. Sometimes my feet are firmly planted on the ground and I feel that I am reasonably dwelling with the effects of illness. However, my comfort is short-lived as I am blindsided and thrust high into the air which bruises my soul, just as the seesaw bruised my rear end when I was forced into the air by my playmate.

The analogy of the seesaw is representative of my life since the birth of my son, Bradley. Life’s events frequently appear two-dimensional in this up and down pattern and seem to make little sense in my society that strives to have a concrete meaning or explanation behind every occurrence. My time spent riding up and down has allowed me to consider how seemingly insignificant events have a distinct order when looking at them from afar. We are only given a snapshot of our life at a time so that we may handle the task at hand without becoming overwhelmed. These tasks may appear chaotic and blurry, but in hindsight, the culminating picture of life’s events can provide meaning. I still question why Bradley was born with a congenital heart defect. I struggle to find the words to describe the hell that I endured (am

enduring) throughout his (my) illness. I have great difficulty in embracing the notion that I have not, am not, and will never be in complete control of this illness. Thus, I must search for the order in disorder in hopes of finding meaning in a system of increasing entropy.

Broken Pieces

In the first few pages of *Finding Beauty in a Broken World*, Terry Tempest Williams (2008) describes how the events surrounding September 11, 2001 stifled her ability to textualize her ideas. She struggled to find even one word that would spark her flow of creativity. Standing on the borderline between where land meets sea, Williams pondered how she would pick up the broken pieces of her life. From somewhere beneath the waves of the ocean, the word “mosaic” announces itself to her as a solution to repair her fragmented life. Williams travels to Italy to study the art of mosaic with her teacher, Luciana, who guides her more in the art of recognizing beauty in the life’s broken pieces than in constructing a tangible art piece.

The first few pages of Williams’ (2008) *Finding Beauty in a Broken World* spoke to me on an intimate level and are as equally influential as Frank’s (1991) *At the Will of the Body* and Morris’ (2008) *Teaching through the Ill Body* have been on shaping my understanding of illness. Like Williams’ difficulty textualizing her thoughts after September 11, I found great difficulty in using words to describe the shattered pieces of my life after learning of my son Bradley’s congenital heart defect. For the longest time, the fragments lay scattered on the ground, susceptible to more damage as passersby unknowingly crushed them with their hurried gait. I was in a state of despair and exasperation. How would I ever reconstruct the shattered pieces to resemble the life I lived before Bradley’s (my) illness? Illness completely distorts life’s picture, changing everything once believed as concrete. I tried to use adhesive to repair the broken

pieces of my world. But these bandages only provided temporary repression from the complex emotions that stemmed from dealing with illness. I was apprehensive of exposing the turmoil that was churning within my soul, determined not to appear vulnerable or to distort the image of togetherness I had worked so hard to portray to others.

I grew weary while trying to maintain my balance as I teetered on the edge between reality and fiction. Despite my efforts, the weight of illness' burdens proved to be too much to bear. One additional adversity disrupted my balance and removed the bandages, exposing the ugliness that I strived to conceal. In turn, this fateful tumble shattered most of what was once recognizable in my life. Relationships with those who are closest to me have suffered. My faith in God has wavered. I struggle with my concept of self worth. Ultimately, I have come to terms with the notion that my life will never resemble the portrait of apparent togetherness prior to illness. I no longer strive to reassemble life's shattered pieces in such a way that will bear a resemblance to the original canvas. Instead, a mosaic is being created from the chaotic shattered pieces of my lived experience with illness. Once the final mosaic tile has been put in its proper place, I may be surprised to find that the new art piece will be more meaningful than the original canvas.

Like an artist creating an original piece of artwork, I want to work from within while creating my masterpiece. No doubt, it will take considerable time to create this mosaic of illness. Masterpieces are not created in haste. Careful consideration must be given to how each shattered piece would be best represented in the final mosaic. Luciana's rules for creating a mosaic (Williams, 2008, pp. 7-8) will be at the forefront of my mind as I assemble the shattered pieces of my life. When the mosaic is complete, it will be a conversation: between what is broken; that takes place on surfaces; with light, with color, with form; with time (Williams, 2008, pp. 8-9).

A mosaic is an art piece of meaning and understanding. A mosaic invites conversation. In order to create a mosaic, material must be broken. The material used in mosaics is not flexible; it will snap if the proper amount of pressure is applied to it. However, mosaic tiles are not fragile either. They are made from layers upon layers of sturdy material that have been subjected to extreme heat, causing the layers to harden. The skilled artist knows exactly how much, and in the exact place, pressure should be applied to achieve the desired appearance. Similarly, the factions of life will break under pressure. As the initial shock of learning of Bradley's defect waned, the mounting pressure created a brokenness that was beyond repair. Like the mosaic tiles, the fragments of my life are hard and multi-layered after being exposed to years of extreme heat. Although my life is in pieces, the fragments are sturdy from prior conditioning. This is not the first time I have been faced with adversity. Then again, I am not sure if anyone is ever fully prepared to deal with the effects of illness. Illness sweeps the body up like a tornado and spins it around and around until it is disoriented.

Drawing meaning from a mosaic can be similar to drawing meaning from Frank's (1995) chaos narratives (as described in the previous chapter). A mosaic is best appreciated if viewed from a distance. If the interpreter were to stand juxtaposed to the art piece, s/he would likely question its meaning. A sense of constant interruption between tiles may be misinterpreted as carelessness in assembly instead of an opportunity for conversation to take place within each pause. The color palette would be distorted as differing hues of red tiles side by side distracted the observer from the ebb and flow of the differing shades of color that can only be observed if studying from afar. The individuality and uniqueness of each tile, each experience, would be overshadowed by the non-continuity of each tile's surface to the next, possibly suggesting that an unsteady hand had crafted the mosaic. When viewing a mosaic at a close proximity, light is

unable to dance among the tiles as it bends, angles, and reflects from one tile to the next, illuminating the crevices that were once hidden from view. Finally, when one views a mosaic up close, s/he does not appreciate the time required to assemble broken shards of tile into something coherent, beautiful, and meaningful.

An ill person living in a state of chaos has no sense of order. To try to draw meaning from day by day experiences is futile. Relaying a chaos narrative to an observer creates additional confusion. It is only when observed from a distance do chaotic events seem to take shape. Constant interruptions between chaotic events that seem to lack any sense of order confuse the ill person. Life experience is non-linear; it is filled with pauses. But these gaps cause the ill body to slow down, providing areas where conversations can occur. Life experiences, even chaotic ones, overlap; they flow from one event to the next while weaving a meandering path through the ill body. The ill person's experiences are individualized, similar to the mosaic tiles. Each experience is forged by extreme pressure and with intense precision. While two tiles may be similar, each has unique characteristics and should be regarded as individuals. The mosaic must be illuminated so that one can appreciate the beauty that can be found in the assembly of broken shards. Like the mosaic, the chaos narrative is not constructed over a short amount of time. As events unfold and new experiences are added, tiles must be shifted to develop a coherent piece. The chaos narrative is a work in progress as the ill person eternally dwells with illness. I must take a big step backwards in order to appreciate the unfinished mosaic that chaos has constructed in my life.

Chaos, Complexity, and Curriculum Studies

Chaos and Complexity Theories situate nicely within the field of Curriculum Studies because all three focus on interconnectedness and strive to uncover meaning that can be derived from these relationships. All three focus primarily on open systems (which exchange both matter and energy with the surrounding environment) as opposed to closed systems (which only undergo energy exchange) or worse, isolated systems (which are completely cut off from the environment). Traditional education can be viewed as a closed system, a monotonous repetition of a never-ending cycle that lacks creativity. Curriculum Studies strives to end this monotony by breaking the cycle of repetition and introducing new ways of considering curriculum. By introducing chaos and complexity theories into the field, Trueit (in Doll, Fleener, Trueit, and St. Julien, 2008) hopes to encourage a conversation that is concerned with change, “not by rearranging what is present, but by looking for what was not there before, assuming the cosmos we live in, and its integral parts, to be creative” (p. 95). Chaos and Complexity theories align with Curriculum Studies by searching for and drawing meaning from the hidden curriculum.

The theories of chaos and complexity are a part of a larger movement in the scientific community sometimes referred to as “New Science,” a term borrowed from the title of Vico’s 1725 manuscript. Like Curriculum Studies, Vico’s *New Science* “reject[s] the study of nature, which emphasize[s] categorization, measurement, and prediction, and stresse[s] the study of culture and human societies” (Fleener in Doll, Fleener, Trueit, and St. Julian, 2008, p. 4). Prigogine and Stengers (1984) use Vico’s philosophical stance to support the notion that (wo)man is not isolated from the natural world; instead, there is a mutualistic relationship between the two entities as energy and matter are exchanged between an open system and the environment. Vico’s primary focus was on the notion of “poetic logic,” emphasizing the

meaning derived from humanistic, relational, and social interactions as opposed to quantitative analysis and measurement.

The New Science strives to uncover patterns, interconnectedness, and relationships to further reveal hidden meaning. Modernism attempts to normalize by assuming universal truth which is perpetuated through quantitative analysis. But mathematical calculations were created by man as a means of verification. How then can one suggest what is absolute if truth is quantified with a device which was created to verify something else? Additionally, modernism suggests that life is predictable, like a clock, subscribing to the notion of determinism. But by focusing attention on only quantifiable data, all other facets are ignored. Fleener (in Doll, et. al., 2008) explains that by embracing a modernistic mindset

we have emphasized the rational over the relational, the given over experience, and truth over interpretation and feeling. Because we feel we can know nature better than ourselves by virtue of objective measures and mathematical prediction, we have separated understanding of ourselves from scientific investigation or tried to reduce the humanities to quasi-scientific approaches where the influence of the observer is removed.

(p. 8)

Modernism seeks to normalize society by removing subjectivities and focusing solely on aspects that can be quantified. In contrast, postmodern thought denies universal authority and seeks to identify and embrace difference and subjectivity. Because individualism and meaning are of such great focus in New Science, it is often analyzed through a postmodernist lens: “New Science potentially reconnects us with our own natural, mythical, spiritual, and metaphorical ways of knowing by offering an approach to relationship, meaning, and systems that overcomes the limitations of modernist emphasis on quantification, measurement, and certainty” (Fleener in

Doll, et. al., 2008, p. 6). I appreciate the connectedness of chaos and complexity theories to postmodernism. However, I have chosen to analyze these areas of New Science through a psychoanalytic lens. Like the postmodernists, I am concerned with individualism and the search for deeper meaning. However, I am ultimately concerned with how the concepts of the New Science apply to my illness. Fleener (in Doll, et. al., 2008) mentions three areas of the New Science that have personal significance: chaos, complex adaptive systems (or complexity), and dissipative structures. Throughout this chapter I will investigate the interconnectedness of each of these in an attempt to derive meaning from my dwelling with illness.

A Complex and Chaotic World

What existed before the beginning of the universe? This question has been asked cross-culturally for centuries. The Creation Hymn of the Rigveda, written 1700 years B.C.E., suggests

There was neither non-existence nor existence then; there was neither the realm of space nor the sky which is beyond. (Anonymous and Doniger, 1981, p. 25, stanza 1)

The ancient Greeks questioned the existence of “nothing,” if such a thing is even possible, before the birth of the universe. Greek logician Thales posed the question, “Does thinking about nothing make it something?” (Close, 2009, p. 5), which he answered by reasoning that “nothing” becomes “something” when one contemplates its existence. In colloquial usage, nothingness can be described as chaos. Derived from Greek, chaos can mean “gaping void, nothingness” (Hamilton, 1942/1998). *Theogony* tells the story of how Chaos spontaneously arose out of nothingness and gave birth to the gods. It is from the womb of Chaos that everything else emerged. Genesis Chapter 1 describes the beginning of creation as “The Earth was without form and void...” (New International Version). According to Biblical account, the Earth (and

heavens) did not exist until God commanded it done. Countless other tales of creation exist, many sharing the commonality that Earth, and thus humankind, was created out of nothingness, out of chaos.

However, chaos can be defined as more than nothingness. When my students were asked to define “chaos,” they used the terms “randomness” and “disorder.” I suspect many would define the term as an absence of order. The notion of chaos is often regarded as something to be abolished. When I am overwhelmed, pulled in multiple directions by those demanding my attention, my life resembles a state of chaos and I make necessary adjustments to assemble a more orderly life. Chaos may also be viewed as a problem one must work through. I would applaud the person who could engineer a way to help me avoid the chaos created by the traffic jams on my commute to work each morning. Oftentimes, people shy away from intentionally subjecting themselves to chaotic situations. But life is full of chaotic happenings. To embrace life to its fullest means to accept chaos.

Contrary to the everyday meaning of the term, chaos can actually represent a system of order. Prigogine and Stengers’ (1984) *Order of Chaos* forever changed the view of science, specifically the second law of thermodynamics. No longer was a chaotic system assumed to exhibit never-ending entropy. Now, entropy revealed a hidden order. Prigogine’s work with dissipative systems helped lay the foundation for the new science of chaos theory. Chaos theory is similar to curriculum studies in that both are cross-disciplinary: persons from all interest areas unite to exchange ideas and attempt to uncover hidden meaning. Chaos theory was popularized with the aid of Edward Lorenz’s (1993) lecture entitled “Does the Flap of a Butterfly’s Wing in Brazil Set off a Tornado in Texas?” Simply defined, the butterfly effect suggests how the slightest change in variables, no matter how seemingly insignificant, disrupt the future

predictability of a system. This idea seems obvious: even the smallest of deviations could have long-term effects. Linear systems subscribe to the notion of determinism and are predictable, where the result of internal system changes is proportional to the magnitude of the variation. However, chaos systems are non-linear. Short-term predictability is possible; however, the smallest variations can create errors that grow at exponentially large rates, making long-range predictions hopeless.

Linear systems uphold the notion that the sum of the parts is equal to the whole. Linear systems can be broken down into pieces, analyzed separately, and then recombined to provide an identical answer as if the system had been analyzed in its entirety. However, non-linear chaotic systems do not follow this assumption. In my chemistry class, we discuss the difference in mass when one accounts for the total mass of the atom's nucleus (containing protons and neutrons) versus the sum of the masses of protons and neutrons accounted for individually. To introduce this concept to my students, I ask them to visualize all of the members of the class getting on one large scale. If there are twenty students in the class, each weighing approximately 125 pounds, the total weight of the class would be about 2500 pounds. Next, if I take each student and weigh her/him separately and then add up the weights of all twenty students, the total weight should equal 2500 pounds. However, this is not the case when considering the mass of the atomic nucleus. The sum of the parts is greater than the sum of the whole. This inequality of mass is known as the "mass defect." The mass defect accounts for the binding energy needed to hold the nucleus intact.

The totality of the ill person can be compared to the nucleus of an atom. The ill person's body and soul are like the protons and neutrons held together by a binding energy. When considered separately versus collectively, there is a difference in meaning. However, contrary to

the nucleus of the atom, I feel that the collective meaning of the ill person is greater than the sum of its parts. The body and soul are mutualistic; that which affects one part also impacts the other. This analogy can also be applied to the treatment of illness. Treatments that may prove beneficial to one facet of illness in isolation may display very different results when used in combination with other treatments. For example, the drugs in a “drug cocktail” used to combat the ill-effects of AIDS are much more potent in combination than if taken in isolation. I remember the initial treatment for Bradley’s illness: as I listened to his doctors list the numerous things that were wrong with him, I followed their lead in focusing on one problem at a time before tackling the next issue on the hierarchy of concerns. I never considered the overlapping that the problems may have had, that one treatment may affect another facet, or may create an entirely new set of issues. I recall my time spent as a medical assistant in the cardiology office. My patients were frequently coming in to the office seeking advice from the doctor regarding how to best adjust their medications. It seems that one medicine would help in one area but create new problems in other areas. Treatment for illness should not be considered in isolation. The totality of the ill body must be considered when treating illness. It is possible that we choose to view things in isolation because it helps us focus our attention on one problem before going on to the next. But the effects of treatments can make for an unpredictable future.

Just as illness should be approached holistically, illness should also be treated individually. Western medicine encourages a type of checklist when seeking the diagnosis of and treatment for illness. If the patient presents with X, Y, and Z then s/he must have illness A, which responds to treatment B. This type of linear thinking is easily reproduced using computer models. And, oftentimes this type of checklist works...for the immediate future. But illness is not linear. Its chaotic nature means that predictability of the future is only for the short-term;

there is no guarantee what the future may hold. Furthermore, to accurately predict the future of illness from a set of normed references, variables that could affect the ill body must be identified prior to diagnosis. Only if the ill body is equipped with the same variables as the normed reference can the future be accurately predicted. Because each ill body is unique, there is no way to accurately identify every possible variable that would affect the outcome of treatment. Thus, treatment becomes a guess, at best. This “guesswork” can be unnerving. Because of the exponential growth of variances in a chaotic system, predicting distant futures is impossible. Another way of considering this notion of unpredictability is through the analogy of the Heisenberg uncertainty principle which states that in quantum mechanics, it is impossible to know two physical properties simultaneously. Applying this principle to illness, it is unachievable to know the location and growth rate of every possible pathogen in the body at the same time. If these important physical properties are merely estimated, the distant future affects of illness cannot be accurately predicted. The only affects that can be approximated are those in the near future. It is for this reason that one never truly separates from, or has control over, illness.

Life is non-linear; it does not follow a prescribed path, nor can one predict the future. Chaotic systems are essential components of our existence. Systems such as weather conditions, fluctuations in wildlife populations, geometric fractals, and disorders of the heart can appear random. However, once graphically represented with a computer model, these haphazard occurrences and chaotic happenings show a distinct order in their randomness. Congenital heart defects and other disorders of the heart are chaotic events, in every meaning of the term; yet, they can show distinct patterns. Gleick (2008) relates heart dysrhythmias, (such as atrial and ventricular fibrillations, and ectopic beats), to chaos theory. He discusses how these

dysfunctional rhythms, with no apparent pattern, show consistency when represented graphically. There is order in the chaotic beating of the heart. The entire developmental physiology of the heart is chaotic at its origin. The cells that comprise the cardiac muscle tissue are unique from any other cells in the body. Unlike skeletal or smooth muscle cells, the heart is not controlled by electrical impulses from the brain; rather, the heart has its own “brain” that regulates contractions, specifically pacemaker cells located in the sinoatrial node. The first primitive cells begin beating only days after fertilization. The brain has not even been thought of in the developmental process at this point; yet, the heart is already fast at work, demanding oxygen and other nutrients from the mother so that it can aid in the development of the remainder of the body. For centuries, doctors were performing operations on various parts of the body; however, the heart was taboo, not to be touched, *noli me tangere*. The heart’s vascular system does not make it a good candidate to be sliced open. In most open-heart procedures, blood flow to the heart must be stopped in order for the heart to be repaired. The patient’s blood must be rerouted from the heart and into a heart/lung bypass machine for oxygen exchange to occur. The patient becomes a cyborg, if only temporarily.

Unlike most heart dysrhythmias, congenital heart defects are present at birth. Chaotic events occur within the developmental process rather than in the physiological conditions of the heart itself. According to the American Heart Association, of the thousands of babies born each year in the United States with congenital heart defects, 10-11% are born with transposition of the arteries, the defect that Bradley had at birth. The medical community is unsure of how this defect occurs, or rather why what is supposed to happen does not.

Morris (2008) questions, “Does knowing the cause of a disease set you free? Free from what? Free to do what? Knowing the cause might depress even more. What if there is no

known cause? Does that make you free or not?" (p. 46) No one understands why Bradley's defect occurred. It is chaotic in the modern sense of the word. It is something that just "happens," or rather does not happen. This not knowing is binding. My controlling nature insists that there must be a cause for his defect and pinpointing one is a necessity. In some way, I feel like I could be mad at some "thing" if I knew what had caused Bradley's defect. Knowing the cause of Bradley's defect could possibly grant me some sort of power or control over it. If I were to determine that I was in no way responsible for Bradley's defect, then knowing the cause might also provide a sense of comfort. Nevertheless, if I could pinpoint the etiology of his defect, I could channel my anger toward the cause that made the def/fect. In a sense, knowing the cause could set me free from the constant searching for answers. But, I am left without answers to my questions. Then again, I am fearful that the only possible explanation is to place the blame on Bradley's sole/soul caregiver. If the Mother is to blame for Bradley's defect, then knowing the cause of his defect would not liberate; the cause would suffocate.

When I first learned of Bradley's heart defect, I could not have fathomed the butterfly effect it would have on what I hope will become my life's work. Initially, Bradley's heart condition was part of my private world and was out of place in my study as a doctoral student. Furthermore, his condition warranted no place in my professional life as an educator. This distancing of my personal from my professional life became nearly impossible as the Bradley ordeal began to manifest itself into something more than just a small defect. The flap of the butterfly's wings was creating a tornado in my life, throwing debris in every direction and destroying nearly everything that crossed its path. It soon became apparent that the personal and the professional lives could not be isolated from one another.

In the space between the personal and professional lives, the pause between the public and private arenas, lies a place for conversation. Like Williams (2008), I have stood on the edge between land and sea, waiting for the word(s) to be announced. As profoundly as “mosaic” proclaimed itself to Williams, “chaos” declared its relevance to my illness. Chaos and illness are similar to Williams’ notion of the mosaic. All are types of non-linear systems in their own respect. Strogatz (2003) insists that “[t]hey can’t be taken apart. The whole system has to be examined all at once, as a coherent entity” (p. 182). Bradley’s illness is no exception. The initial problem indicated that his pulmonary artery and aorta had been misplaced. The solution was to undergo open heart surgery to correct the misplaced vessels. However, he did not have a hole in his ventricular septum, an additional defect that usually accompanies the misplaced vessels. This defect allows for a mixing of oxygenated and deoxygenated blood which helps sustain closer to appropriate oxygen levels prior to surgery. To account for this non-defect, Bradley was given a medication to maintain the opening of the foramen ovale, the septal opening between the right and left atria that closes shortly after birth. But, the medication distorted some of Bradley’s fluid levels, thereby requiring careful monitoring during the critical days prior to surgery. Bradley’s illness did not allow for a scripted, linear approach to problem solving. Multiple variables had to be considered and a holistic approach had to be taken to ensure that Bradley’s physical needs were met.

Traditional mindset encourages us to compartmentalize our problems, isolate one from another so that we may focus energy on each problem individually. Toffler in Prigogine and Stengers (1984) suggests that “[o]ne of the most highly developed skills in contemporary Western civilization is dissection: the split-up of problems into their smallest possible components. We are good at it. So good, we often forget to put the pieces back together again”

(p. xi). I am guilty of perpetuating this mindset when I encourage my students to use the scientific method in their problem solving. “[T]he scientific method has become the paragon of truth, the ideal for reasoning, and the model of fairness and justice during the modern era” (Fleener in Doll, et. al., 2008, p. 7). A systematic, linear approach is used to find a solution to a specific problem. Additionally, variables are isolated so that only one factor is changed during the experimental process, sometimes referred to as “ceteris paribus---all other things being equal” (Prigogine and Stengers, 1984, p. xi). But all other factors are not “equal,” making a linear approach unacceptable in most real-world scenarios. Instances are rare that only one variable is present in a problem.

Complexity theory denies the reduction of complex systems to its constituent parts because this sort of reduction “fundamentally destroys complex relationships and emergent properties of dynamical systems” (Fleener in Doll, et. al., 2008). The goal of the New Sciences, like the field of Curriculum Studies, is not to simplify complex systems but to embrace the complicatedness. Dwelling with illness is complicated; it is a journey filled with twists and turns and surprises around every corner. But more than complicated, illness is complex. There are emergent dynamics in illness from which meaning may be derived that are waiting to be revealed. Emergence is the opposite of reduction, whereby a system’s properties are identified by understanding the interactions of the parts. Where reduction views a system as a breakdown of a whole, emergence strives to understand how a system’s parts relate to the whole. But emergent dynamics cannot be revealed if illness is reduced in complexity. To emphasize the importance of complexity, Davis (in Doll, Fleener, Trueit, and St. Julian, 2008) considers the notions of recursivity, scale independence, and self-similarity as they apply to understanding geometric fractals. Recursivity in fractals occurs when a rule is applied, netting a result and later

the rule is applied to the result to create another result, and so on. Scale independence refers to the notion that regardless of how a fractal is magnified or reduced in scale, the level of complexity does not change. Finally, self-similarity describes how one section of the fractal can resemble the larger fractal. All of these properties are considered when examining geometric fractals.

Just as many factors are considered when analyzing geometric fractals, so should illness be examined holistically while considering the affects of illness on body and psyche as well as the relationships between these two entities of the ill person. It may be difficult to think of illness holistically. Possibly, it is easier to compartmentalize different aspects of the illness experience than to try to deal with all variables at once. But there is a certain type of communication that flows between variables when considered as a whole instead of individual segments. Similar to the tiles in a mosaic, when these fragments are viewed holistically, a broader sense of understanding may be gained.

Chaos, illness, and the mosaic occupy a space between order and disorder. At first glance order seems to give way to erratic behavior. Events are non-repeating; they seem to disregard the concept of pattern. But hidden underneath the surface is a systematic meaning yearning to be uncovered. While chaos/illness/mosaics may appear disorderly and random, each is actually governed by a systematic set of laws. A series of unrelated events, such as experiences with illness or tiles in a mosaic, can appear chaotic when viewing them through a pinhole. However, when the vision field is widened it is apparent that there is order in chaos.

Alice in “Chaos”land

During our study of nuclear chemistry, my science students and I discuss the four primary forces guiding nature: strong force, weak force, electromagnetism, and gravity. The first three terms seem only vaguely familiar to my students. Yet, they can typically provide an accurate working definition for gravity, usually highlighting Isaac Newton’s law of universal gravitation. Gravity may be simply defined as the force of attraction between two objects where an object of greater mass exhibits a pull on an object of lesser mass. I demonstrate the effects of gravity to my students by suspending a pencil in the air and releasing it. We discuss how the lighter massed pencil is pulled toward the greater massed center of the Earth. This notion of objects falling to the ground is not a novel concept; we are introduced to the idea of gravity at an early age when, as an infant, we drop our bottle of milk. It could be difficult for us to imagine a situation on Earth that is not influenced by gravity. Without gravity, we could not breathe, our metabolism would not function properly, and life as we know it would not exist. Gravity is the force that gives mass weight. Gravity keeps humans grounded instead of floating off into outer space like an astronaut. However, if one has been accustomed to living in an environment with negligible gravity, the force of being thrust down to the ground without warning can be disturbing.

While on the seesaw, my greatest fear was falling from a high position. I feared that the other person would suddenly jump off the seesaw, causing me to come crashing down. Spectators would laugh at my uncontrollable flailing as gravity forced me to the ground. At least when I was on stable ground, I did not have to fear falling. However, gravity can make you fall below stable ground, deep into a hole to a place from which you cannot return. Although it was curiosity that initially coaxed Lewis Carroll’s (2000) Alice to follow the White Rabbit, it was the

force of gravity that pulled her down through the hole. “Down, down, down. Would the fall *never* come to an end?” (Carroll, 2000, p. 13) Alice’s rabbit hole can be compared to a black hole which exhibits tremendous gravitational force sucking objects deep down into an abyss. While falling, Alice’s frame of reference was distorted. The rabbit hole was lined with cupboards, bookshelves, and maps hung on pegs; yet, these artificial landmarks did not aid Alice in predicting what she would next encounter. Similarly, there are no landmarks to aid one in navigating the dark, cavernous, empty space of the black hole of illness.

Whereas Alice was enticed to follow the White Rabbit down the hole, the ill person does not choose to fall into the gulf of illness. Instead, s/he is engulfed by gravity which pulls her/him over the edge. This “edge” is scientifically referred to as the “event horizon”: after crossing this threshold, the body can no longer resist the hole’s immense gravitational pull. The gravity of illness may threaten to pull one down, down, down into the abyss. Calder (1979) warns that if I cross this event horizon “[my] body will never be recovered” (p. 40). But Morris (2008) encourages me “[t]o dive into the well. To sink into the abyss” (p. 52). Why would she encourage such a thing? It is frightening to think of purposely thrusting myself into the abyss. How will I get out? If I am fortunate enough for someone to throw me a rope, I am not sure that my own strength, or the strength of whoever is trying to save me, will be enough to overcome the overwhelming force of gravity. What will become of my self after gravity squeezes every encompassing particle to the most compact size?

No doubt, I was terrified of falling into the abyss created by illness. I was terrified of being alone. I was terrified of who I would become after the fall. I was terrified of what I might have to deal with in “Chaos”land, a world where nothing is as it seems. I was terrified of not being able to ever return to the riverbank where Alice and I could sit and listen to her sister read

stories aloud as we daydreamed of picking daisies and playing with Dinah the cat. I wanted to be normal, like those in my circle who were carefree from the effects of illness. I wanted illness, and its accompanying effects to just go away, disappear as suddenly as it had arrived. I did everything in my power to keep from falling into the abyss, teetering on the event horizon as long as I possibly could. But I grew very weary trying to maintain balance on the edge of the hole. When the slightest gust of wind came in my direction, I could no longer keep my balance. I found myself tumbling head over heels, plummeting into darkness.

I have sometimes heard others refer to depression as being “down in the dumps;” or, possibly one could equate depression as being in a sort of abyss or black hole. I have met Depression in my journey through “Chaos”land. I have also met Guilt and Anger and Denial and Hatred. But I have also met other characters such as Compassion and Empathy that, if I had not journeyed down into the abyss and entered “Chaos”land, I may never have met on such an intimate level. No doubt I have run across my fair share of Mad Hatters who speak complete nonsense and Cheshire Cats who cannot provide a simple yes or no answer before vanishing. I have taken elixirs that have made me feel either too tall or too short and in no way adept for sorting out the chaos I have encountered. But my greatest challenge has been from the Caterpillar:

“Who are *you*?” said the Caterpillar.

This was not an encouraging opening for a conversation. Alice replied, rather shyly, “I—I hardly know, Sir, I just at present—at least I know who I *was* when I got up this morning, but I think I must have been changed several times since then.”

“What do you mean by that?” said the Caterpillar, sternly. “Explain yourself!”

“I ca’n’t [sic] explain *myself*, I’m afraid, Sir,” said Alice, “because I’m not

myself, you see.”

“I don’t see,” said the Caterpillar.

“I’m afraid I ca’n’t [sic] put it more clearly,” Alice replied, very politely, “for I ca’n’t [sic] understand it myself, to begin with.....” (Carroll, 2000, pp. 47-8)

Like Alice, I know who I was before I fell down the hole, before the overwhelming effects of illness engulfed my self. But since arriving in “Chaos”land, I find great difficulty in describing myself. Surely, I am a different person now than I was before the onset of illness. Maybe this is why Morris (2008) encouraged me to “sink into the abyss” (p. 52). Is it possible that she knew that I would learn more about my self in the cavernous black hole, alone, with no lights or landmarks to guide me, than I would if I continued to pretend that illness was not affecting me? Maybe she too was frightened of going into the abyss. Maybe she wanted to ignore the reality of illness and its lasting effects in her life. Maybe, after she allowed herself to enter the abyss, she learned more about her self than if she had not ever been faced with illness. Maybe...I’m not sure. How she arrived at the conclusion of diving into the abyss is irrelevant. Her words have offered encouragement to me, somehow providing comfort in my assumption that she has journeyed through this land of chaos before me. I am sure that she is still meandering down a road in “Chaos”land because, as Calder (1979) warned, once one falls into the abyss of illness, the body never recovers. Likewise, my journey has not come to an end in “Chaos”land. I have yet to sip tea with the March Hare at his Tea Party or play croquet with the Red Queen, who will surely put me on trial for something that can only be explained as nonsense.

Once Upon A Time

During Alice's fall, she did not appear disturbed, as one might suspect while falling endlessly down a hole. Time appeared to be going very slowly as she fell: "Either the well was very deep, or she fell very slowly, for she had plenty of time as she went down to look about her, and to wonder what was going to happen next" (Carroll, 2000, p. 13). Alice's allusion of time supports scientific theory. Time travels more slowly as gravitational attraction increases, such as when one falls through a black hole. "Chaos"land is at the center of the black hole, the center of mass, and thus exhibits the most gravitational force. My time here has been drawn out; I feel as if I am moving at half speed. Tasks that would typically take very little time now take twice as long to accomplish. Those who are up there, on the ground, free from the gravitational effect of the black hole and "Chaos"land, seem to be moving at a much faster pace. Because time has slowed down considerably for me, the lasting effects of Bradley's illness are still a vivid part of my present. However, for others in my circle time passes more quickly and they have left the Bradley ordeal in their past. I seem to recall being like them, rushing from place to place, rarely stopping to ponder an idea for more than a few moments before rushing to the next task. Illness makes the body slow down. But illness also makes the soul slow down. Maybe time passes more slowly here so that I can attempt to draw meaning from the full effects of illness.

Gravity has a gradual effect on time, developing slowly as one approaches the center of mass. Calder (1979) refers to this gradual regression of time as "timeshells" (p. 42). Another way of visualizing timeshells is with the layers of an onion. The dense center of the onion can be equated to the dense mass at the center of the black hole, both representing the beginning of a person's life when time moves very slowly. I recall as a child anticipating an upcoming birthday as if the months, weeks, days would never arrive and when my day had passed, the eternity it

seemed before the arrival of my next birthday. Cisneros (1991) comments, “The way you grow old is kind of like an onion or like the rings inside a tree trunk or like my little wooden dolls that fit one inside the other, each year inside the next one” (p. 7). As you get further away from the center of mass, adding an additional onion layer with each passing year, time advances more rapidly. I no longer eagerly anticipate the arrival of my birthday. Instead, I have difficulty remembering how old I am because time passes so quickly. I have often pondered, *Where did the time go?* I believe that time passes quickly for a life without illness. But living with illness is like going back to the center of the onion. Time passes slowly. Never ending days seem to stretch on for an eternity.

I suppose there may come a time when the days pass quickly again. Maybe when I have journeyed further away from the center of “Chaos”land, I will look back and realize how much time I have actually spent dwelling with illness. In the meantime, I oftentimes feel as if my psyche is running off of an entirely different clock than those around me. Keeping accurate time during illness is difficult if not almost impossible. When one is moving between differing degrees of gravitational force, the timepiece must be frequently resynchronized to avoid error in timekeeping. Throughout Bradley’s hospitalization in Atlanta, I kept an online journal of events as they occurred. The computer date- and time-stamped each entry I recorded. However, the order of events, as I recorded them, suggest error. This point is evident when my husband and I recorded the same experience but ordered events differently. I did not synchronize my timepiece with a standard clock, which in this case would be Bradley’s medical records. For this reason, I have purposely omitted many of the time-related details about Bradley’s illness from my pathography. I grappled with this omission for quite some time, until I remembered Einstein’s identification that time is relative to the observer. The order of events does not really matter in

the broad picture. What is of importance is that the events occurred. Or, maybe they didn't and I am instead left to work through the effects created by a fictionalized event. Attempting to draw meaning from the chaos created by illness is both labor and time intensive!

Our first night at the hospital in Atlanta, Bradley's nurse took us to see another baby who was recovering from the arterial switch procedure that Bradley would undergo in subsequent days. The nurse took us through a step-by-step account of events that would occur before, during, and after Bradley's operation. This event would occur, then this event, and so on. This sort of reliability, or determinism, allows doctors and medical professionals to predict the future based on previous events. For Bradley, his fluid levels were not appropriate after surgery. He was administered a diuretic to help him release some of the excess fluid, which would in turn diminish the stress on his heart. But the addition of the diuretic created a new set of problems that had to be addressed. I felt as if we were in a never-ending cycle of monitoring and adjusting of medications.

Western medicine leads patients to believe that illness is predictable. If a patient suffers from ailment X, take medicine A and illness will subside. But illness is not deterministic in this way. Laplanche said that we could predict future events based on previous events if we knew the complete state of the system at a given time (see Calder, 1979). He believed these laws could also be applied to human behavior. Laplanche's mindset would be accurate, if predicting the complete state of a system was achievable. However, this notion of determinism was refuted with the development of quantum mechanics, the basis for much of modern day science and technology that no longer predicts a single definite result of an observation but provides a set of several possible outcomes and the likelihood of each occurrence. "Quantum mechanics introduces an unavoidable element of unpredictability and randomness into science" (Hawking,

1996, p. 73). Heisenberg's uncertainty principle, claiming the impossibility of knowing the complete state of a system at a specific time, further contradicted Laplace's claim. The more precisely one physical property is known, the less precisely the other properties are determined. It is not possible to predict future events if the present state cannot be accurately measured.

In lay-terms, "time" means a definite thing, something that is measurable, agreed upon by everyone. Every event could have a specific timestamp placed on it. The concept of time is often taken for granted. But the theory of relativity changed the way one thinks about time. Time is relative to the observer, measured internally by a specific observer and possibly in distinct contrast to other observers. Time is not definite. Time is not linear. The areas of quantum mechanics and gravity were united by introducing the concept of "imaginary time." You could float between time periods. Psychically, I work from "imaginary time" when I examine my past, seek to understand my present, and ponder the future as I search for meaning while dwelling with illness. But in the physical realm of "real time," time travel is not possible. One cannot travel between time periods, between the future, present, and past. To demonstrate this concept of irreversibility, Hawking (1996) uses the illustration of a cup falling off of a table and shattering into a million pieces. The intact cup on the table is a system of high order but a broken cup on the floor is in a state of disorder. The second law of thermodynamics states that in any closed system, entropy increases with time. It would not be possible for the cup jump off the floor and reassemble its shattered pieces onto the table. We can visualize the cup falling from the table and shattering into a million pieces, but not the other way around.

Time can slow down but it cannot reverse. This concept gives time an "arrow" or direction, distinguishing past from present. The past denotes a system of high organization whereas the future suggests a system of increasing disorder. The example of the broken cup

demonstrates what Hawking (1996) refers to as the “thermodynamic arrow” of time. There are three laws of thermodynamics; however, chaos theory is most concerned with the second law of thermodynamics: any system will eventually dissipate into an increasing system of entropy (disorder). This notion works well for isolated systems which do not exchange matter or energy with the surroundings. Because of this lack of interaction with the environment, isolated systems are predictable; variables can be controlled and futures can be predicted. However, most real systems, such as human interactions, are not isolated. They are constantly exchanging energy and/or matter with the environment. In turn, this exchange of energy (matter) can partially reverse entropy, and thus reverse the arrow of time. Prigogine and Stengers (1984) would describe these non-isolated systems found in nature as “self-organizing” structures. Waldrop (1992) provides specific examples:

A laser is a self-organizing system in which particles of light, photons, can spontaneously group themselves into a single powerful beam that has every photon moving in lockstep. A hurricane is a self-organizing system powered by the steady stream of energy coming in from the sun, which drives the winds and draws rainwater from the oceans. A living cell...is a self-organizing system that survives by taking in energy in the form of food and excreting energy in the form of heat and waste. (pp. 33-34)

At first, it appears that illness subjects the ill body to a system of increasing entropy. The random, chaotic events that accompany illness seem to support the arrow of time’s direction. Illness will perpetuate the system in this manner if the ill body does not exchange energy with the environment. I imagine this state as one of deep, irreversible depression, a state which sends the ill body over the edge to a point of no return. I wonder if experiencing this intense level of depression could be equated to drowning or suffocating from the weight of burdens. Is this the

point that Virginia Woolf reached and why she chose to commit suicide by drowning in the river near her home? However, in most cases, illness promotes an exchange of energy between the ill body and the environment. The exchange of energy allows for the ill body to become a self-organizing structure, attempting to make sense of the chaos that accompanies illness. Writing and reading pathographies can promote energy exchange between the ill body and the environment, reversing entropy and the arrow of time. The ill body can become adaptive to the affects of illness.

In Synch

As I excitedly anticipated Bradley's arrival into the world, I became anxious of the possibility that he would be born on Friday, April thirteenth. I have never considered myself to be a superstitious person; however, I was relieved when my doctor suggested that I meet her at the hospital on the evening of Thursday, April twelfth, narrowly escaping the impending doom that would surely accompany Bradley had he been born the next day. With several minutes to spare, Bradley was born just before midnight, escaping any "bad luck" that would have accompanied his arrival had he been born only minutes later. We were in the clear...at least for the time being.

As with many artifacts of folklore, the exact etiology of the Friday the 13th superstition is unknown. Friday has been considered an unlucky day for some cultures, marking the day of Jesus' crucifixion and the day of the stock market crash of 1869. In numerology, the number twelve suggests completeness. There were twelve tribes of Israel, twelve apostles of Jesus, and twelve gods of Olympus. There are twelve months in a year, twelve signs of the zodiac, and twelve hours on a clock. Thus, the number thirteen could be thought of as irregular or going past the level of completeness. Bradley was born on the twelfth of the month, but his heart was shy

of complete. However, he was born at 23:53 p.m., which numerically adds up to 13. Maybe his heart was numerically destined to be irregular. Or, maybe it is sheer coincidence.

Being born on or around the number 13 did not cause Bradley's heart defect. Illness just happens. Or, in Bradley's case, what was supposed to happen just didn't happen. Doctors have advised me that there is no known cause as to why his defect occurred. But I do know that his illness was not part of some divine plan, or "in the numbers," so to speak. It was just coincidence. But there were many other coincidences surrounding Bradley's illness. For example, what are the chances that my son would be born with the same heart defect as my childhood friend's son who was born six months prior? And ironically, my friend's mother worked with my mother at the time of Bradley's illness. How ironic it was to find a ladybug in my Caesar salad after reading a card from the restaurant's wait staff (who had learned of Bradley's impending surgery the next day) that said "Good luck." A few days following Bradley's surgery, the hospital clergy delivered a gift bag containing a Beanie Baby™ stuffed animal that had Bradley's birth date printed on the tag. Several months after Bradley's surgery, I learned of my friend Lauren's family friend's son, Nick, who was born with the same defect twenty years prior. Ironically, both Nick and Bradley shared the same pediatric cardiothoracic surgeon and both surgeries were performed at Children's Healthcare at Egleston in Atlanta. How ironic that my husband, squeamish of all things pertaining to medicine, introduced me to a made for HBO movie, *Something the Lord Made* (Krainin, Drake, and Sargent, 2004), which details the pioneering medical advancements in the field of heart surgery, specifically surgery to correct congenital heart defects in infants. Coincidentally, prior to my maternity leave, I had shown this movie to my anatomy students during our study of the cardiovascular system, serving

as a connection between the textual and the personal experience. These coincidences are uncanny.

Carl Jung (1969) might explain these coincidences as “synchronicity.” He uses this term to mean “the simultaneous occurrence of a certain psychic state with one or more external events which appear as meaningful parallels to the momentary subjective state” (p. 25). Jung spends considerable time exploring areas of the psyche, such as extra-sensory perception (ESP), that cannot be attributed to probability. Jung contends that synchronicity is dependent upon two factors. First, “an unconscious image comes into consciousness either directly (i.e., literally) or indirectly (symbolized or suggested) in the form of a dream, idea, or premonition.” Second, “an objective situation coincides with this content” (p. 31). Western mindset thrives on the causality principle, emphasizing cause and effect relationships. An objective stance is taken when seeking to understand causality. On the other hand, the synchronicity principle opposes this idea, insisting that there are occurrences that cannot be explained through causality. Instead, these events should be considered through simultaneity and meaning. The issue lies in the fact that meaning is subjective; there is a small probability that two persons would draw the same meaning from simultaneous events. For this reason, the notion of synchronicity is often scorned for its inconclusiveness and invalidity. Meaning is not measurable through empirical data. The results (interpretations) of meaningful events cannot be absolutely reproduced among individuals. Jung’s notion of synchronicity could be viewed as a soft science. However, cohesiveness in meaning is not essential. The underlying purpose of synchronicity is to gain individual meaning, not to arrive at some agreed upon conclusion.

The coincidences occurring around Bradley’s illness did not happen at precisely the exact time, or “simultaneously” as Jung describes; thus, employing Jung’s notion of synchronicity to

these experiences can only be done loosely. However, I am most interested in Jung's idea of the meaning that can be derived from unlikely coincidences. I am sure that statisticians could predict the probability that I would have a sixth degree of separation from someone whose heart surgery was performed by Bradley's surgeon at Egleston. Mathematical calculations could determine the chance that the Beanie Baby™ would have Bradley's birth date printed on the tag or that my students would understand the physiology of Bradley's heart defect having seen *Something the Lord Made* (Krainin, Drake, and Sargent, 2004), a movie that I may never have known about had it not been for my husband. However, I suspect that the infinitesimal likelihood of such coincidences occurring could qualify these incidences as having a type of synchronicity.

Drawing meaning from chaotic events is necessary for the ill person to gain a sense of stability. However, this is a work in progress. Nearly four years after the initiation of illness, I am still struggling to find meaning from the chaos that has been my persistent companion throughout this journey in the land of the ill. Considering the synchronous events that have taken place in my life during this time of illness, I am perplexed as to what meaning is waiting to be uncovered. It is possible that my husband and I watched *Something the Lord Made* (Krainin, Drake, and Sargent, 2004) in order to prepare us for the foreign territory that we would take up residence while Bradley was undergoing surgery. When one suffers from illness, s/he sometimes draws near to others who have experienced similar circumstances. This was the case when I learned of the story of Susan May's (2008) son, Nick. As I read the strikingly similar account of her experience in *Nick's New Heart*, I felt a deep, meaningful connection to a woman whom I have only known in a textual sense. Parts of me long to know May on a personal level, share intimate thoughts and feelings with her, and yearn for encouragement from one who has blazed

the trail before me. Interestingly, I have chosen to keep the childhood friend whose son suffered from the same defect at arm's length. She offered to share details of her son's surgery and recovery so that I would have a sense of what to expect. I declined her offer. I am not sure why. It is possible that her experience made what I was encountering too real. Then again, I have been known to deny help from those who are closest to me, instead seeking outside sources for guidance. In truth, I am not really sure what meaning these coincidences hold for me to discover. If nothing else, they have served as a place for pause, a marked event during a time of chaos, helping to divert my attention from the urgency of illness. Furthermore, making connections between these coincidences provides a source of comfort in believing that there is order in chaos.

Jung's (1969) thoughts on synchronicity relate to chaos theory in the notion that neither idea subscribes to a predictable cause/effect relationship. But synchronization has not always been an integral part of chaos theory. The notion of synchronization, or "sync," is often associated with rhythmic, repeating cycles. The informal usage of the term "chaos" suggests disorder, denouncing the possibility of synchronization. Traditional viewpoints drawing from Lorenz's (1993) description of the "butterfly effect" denied the possibility of two known chaotic events synchronizing with each other even if they started simultaneously. Minute variations in each system's initial states would create disorder within the system and deny the possibility of synchronicity. However, research in recent years shows that chaotic systems can synchronize. For example, Cuomo and Oppenheim were the first to demonstrate how synchronized chaotic circuits could aid in communication encryption (see Strogatz, 2003). Their experiment employs the concept of masking: background noise is added to the intended message at a loud intensity in order to "mask" the message. The receiver, guided by a hybrid signal comprising of both the

message and mask, is able to subtract the mask from the combined signal, revealing the intended message.

While the particulars of Cuomo and Oppenheim's experiment can be mind-boggling, their findings hold significance for interpreting illness' encrypted message. The signals emitted from the ill body are multi-layered. It can be difficult to decipher which signals carry a message and which ones should be regarded as noise. Suppose that a patient presents to a physician with a host of ailments. The doctor listens to each complaint and makes appropriate suggestions for each one. These complaints, affects of illness, are chaotic. Yet, they synchronize in a type of noise that can distract from the hidden message. Excessive time and energy is spent on isolating each individual complaint and finding proper treatment. In turn, the noise keeps the hidden message undetected. It is only when a skilled receiver subtracts the noise that the hidden message is revealed.

As I think about the doctor-patient relationship, I recall my time spent as a medical assistant before entering into the field of education. Many times my patients would list a host of concerns and ailments that they felt compelled to share with me. I dutifully jotted notes in the chart, recording as much of the information as possible so that the doctor could adequately assess the patient's medical status. However, there were times that I felt sure my patient was offering a host of extraneous information that, while important, was not the primary concern that needed attention. I remember several times when a patient would present in the office with heart palpitations, shortness of breath, chest pain, and elevated blood pressure. Outward signs and symptoms synchronize and suggest that the patient could be having heart attack. Yet, after spending some time in conversation with the patient, I would often discover that the patient was

anxious about a certain situation. Anxiety and heart attacks can have similar signs and symptoms. After the noise was subtracted, the hidden message was revealed.

I must consider my own illness when contemplating what hidden message is waiting to be revealed. I remember my doctor and others in my circle asking how I was holding up during the initial onset of the Bradley ordeal. Time and time again I maintained the same “I’m fine” response. But I was far from “fine.” I hoped that my quick response would thwart others from prying further into my private world. I remained silent about my anxieties brought on by illness. This silent noise served as a mask, hiding the message that was of great significance. I became skilled at diverting others’ attention from the plaguing affects of illness. But privately, I hoped that someone would be able to decipher my encrypted message and insist on walking beside me through this difficult time. Dwelling with illness, I have become more sensitive to what is not said, instead of focusing attention on what is verbalized. Oftentimes, the hidden message remains in silence. It is only after the extraneous noise is subtracted that the hidden message can be revealed. Meaningful conversation occurs in the gaps, in the silence.

Stability in Chaos

It is difficult for me to try to gain a sense of understanding from the chaotic events that accompany illness. I feel as if I am constantly sinking down, down into the abyss. Sometimes I call for help, but I am not sure if anyone hears me. I am in a system of increasing entropy. If I could only shift the system so that I could reach equilibrium, homeostasis would be achieved, and maybe I could get some rest. But Taylor (2009) cautions me of seeking a state of equilibrium: “Equilibrium must be indefinitely deferred for life to continue. In the incalculable calculus of pleasure, things are always out of balance, slightly off key, and life is richest far from

equilibrium” (Taylor, 2009, p. 111). Put it this way, maybe I am not seeking a place of equilibrium. In this state, life would show no creativity. It would be mundane, monotonous. Chaos makes the future unpredictable. I used to view unpredictability as a negative trait. By nature, I am a controlling person and do not like surprises. But is life really worth living if I know precisely what the future holds? Throughout my study in the field of curriculum studies, I have come to appreciate the significance of the journey, focusing less on the destination. I used to consider illness as an obstacle that I must overcome. But, I would overcome illness to get to...what? What was up ahead, beckoning for me to hurry? Illness is not a force to be reckoned with or a stumbling block in the road. Illness is a companion, albeit an unwelcomed one primarily, that travels alongside on the journey. The future, especially of illness, is uncertain. Thus, chaos, and illness, create the cobblestones that pave the meandering paths of life.

In another light, a life of equilibrium might even mean that I am not moving at all; equilibrium might mean death. If there is no movement, no life, what is there to consider? It may be more appropriate that to say I am living in a “field of competing energies” (Morris, 2008, p. 108). I am almost like a child at Christmas who wants to know what is in that big box with the pretty bow on top that has been sitting under the tree with my name on it. I want to peek inside to get a glimpse of what is in store for me. However, I do not want to open the box and ruin the surprise for later, or worse, be disappointed at what my future holds. Priogine and Stengers (1984) use an example of a chemical clock reaction to illustrate the notion of competing energies:

Such a degree of order stemming from the activity of billions of molecules seems incredible, and indeed, if chemical clocks had not been observed, no one would believe

such a process to be possible. To change color all at once, molecules must have a way to communicate. The system has to act as a whole. (pp. 147-148)

In the chemical clock reaction, competing molecules are vying for dominance. I have often performed this demonstration in my chemistry classroom. Students are amazed that the color changes instantaneously, not gradually, from blue to yellow, and then back again. This oscillation will continue for several minutes, back and forth, back and forth, until finally one of the molecules wins out and its color remains. Illness also creates a type of oscillation reaction, one that shifts between states of health. This back and forth oscillation adds an element of surprise to life. The continual flux in the system is unnerving. At many times, I just want the oscillation to cease, come to a conclusion as to which side will be the dominant force. But this is not the entire truth. I do not want just any side to be dominant; I want the side in which I am in control to dominate. However, this ideal is not possible because in the end, chaos wins out. And no one is in control of chaos.

To the observer, it may look as if the chemicals in a clock reaction have been haphazardly chosen and thrown together in a system. Initial observations suggest that neither molecule can decide which will dominate the reaction. But upon closer examination of the reaction's chemistry, one recognizes that the oscillations have a deeper significant meaning. The reactants, or participants, within the reaction are exchanging information back and forth within the system. The color change is actually an indication that information has been received by the other participant. The instantaneous oscillating color change looks chaotic; in actuality, this system requires a high level of ordered communication through a complex language system only understood by those who are involved. This type of oscillating reaction can be compared to dwelling with illness. To an observer, it may appear as if the ill person's life is chaotic, unable to

determine which competing energy is the dominant force. But the apparent chaos may be an indication that there is a deeper level of communication occurring within the system. Fleener (in Doll, et. al., 2008) states, “Language itself becomes an interaction among rather than a transmission of meaning” (p. 4). I want my pathography to interact with the reader in the same manner as the chemicals in the clock reaction so that meaning is not merely transmitted, but exchanged.

My life has always been chaotic, although at varying degrees of chaos. When I learned of Bradley’s defect, the chaos in my life was taken to an entirely different level. As I have searched for a deeper meaning throughout my journey with illness, my life has also been chaotic. Yet, this new chaos is intriguing. Instead of being best described as randomness, (which is the conventional meaning of the term “chaos”), this new chaos seems to have meaning, driven by a purpose. There is an apparent order to the craziness in my life, possibly a communication between energies that in some way is comforting, making me ponder how my experiences with illness are coming together to form a holistic meaning.

Living with chaos can be unnerving. I do not like to appear being out of control; yet, I fear that living with illness portrays my image in this manner. One way that I have found to cope with my fear of chaos is to reflect on times when my life did not appear so chaotic, when there was stability in my life. Or, at least I remember these times as being stable. Every summer, I spend at least one week in Walt Disney World. Before walking under the train station in the Magic Kingdom, I pause to read the sign that Walt has left for me: *Here you leave today and enter the world of yesterday, tomorrow, and fantasy.* Stepping onto Main Street and staring at Cinderella Castle looming before me, I am instantly taken back to the vacations I had there with my family when I was three, and seven, and twelve, when all was right in my World. When I

reflect on my trips to the World, I am reminded of the happy times I spent there with my family. I can see the four of us in our yellow Mickey Mouse ponchos as my sister and I splashed in the puddles at the base of Cinderella Castle, paying little attention to the summer shower's drenching rain. Knowing my mother, I am sure that she complained that we were getting our shoes wet and were going to catch a cold; however, my memory does not recall these specifics. I only know that we enjoyed quacking like a family of ducks as we marched around in our yellow ponchos.

I am my present as well as everything that has happened in my past. However, sometimes the way one remembers the past is in distinct contrast to what actually occurred. One may long for what once was, the days of yesteryear, simpler times when life was not so complex. Boym (2001) refers to this longing as "reflective nostalgia." I often long for the time in my life before I knew of Bradley's illness, before chaos disrupted my perfectly planned out life. Among my circle of friends, preparing for the arrival of a baby requires serious consideration. As soon as one can even possibly obtain positive results on a pregnancy test, news of the upcoming arrival is announced. And thus begins the next nine months of preparation. Registering for all of the trendiest yet safest baby gear, reading the latest research on developmentally appropriate toys, mulling over acceptable baby names, and designing the most sophisticated nursery are activities that fill the time until the new bundle of joy is delivered into the world. This pomp and circumstance is quite unnecessary; yet, I suspect that the "baby industry" revels in the frivolity of mothers-to-be. In previous generations, women would hide their pregnancies until late in the term due to the high risk of miscarriage and infant mortality. I assume that the declining rates of miscarriage and infant mortality over recent years have given rise to the supposed need for additional preparation for a newborn. Although I think this over-planning is superfluous, I am a hypocrite; I eagerly engage in such planning when I presume that I am with child. In retrospect,

this planning period allowed me to create an unrealistic world in which Bradley and I would never be allowed to reside. The night before Bradley was born I imagined what it would be like to have another child in my house within a few short days. I remember sitting in the rocking chair in his nursery, eager to rock my baby to sleep. I felt the softness of his baby blankets that were carefully folded at the end of his crib, wondering which blanket would become his favorite. I was denied admittance into my pre-planned, imaginary world when I learned that Bradley would spend his first twelve nights lying in a plastic bassinet in a sterile hospital rather than amongst the Mickey Mouse décor in his newly painted nursery.

I long not only for the time that I had before I knew of Bradley's illness, but also for those first few months I missed bonding with him when he was outwardly ill. I was content with Bradley's medical condition as long as it did not affect his outward appearance. However, when Bradley was discharged from the hospital with a feeding tube and an oxygen tank, I was not accepting of his new appendages. I became burdened by his medical condition, both physically and emotionally, and was fearful of bonding with him. I suppose my fear stemmed from the fact that I might lose him again, possibly forever. If I never allowed myself the opportunity to bond with him, I would not have to recover from losing him. It has taken me considerable time to allow myself to connect with Bradley. I am saddened to know how much precious time has been lost with him. I would do anything to turn back the clock, to have those first precious weeks with my child, instead of letting that time slip through my fingers. But like Hawking's (1996) broken cup, I cannot go back to a time before the chaos occurred. My only choice is to move forward in the positive direction of the time arrow. I cannot change the past; I can only prepare for the future.

Reminiscing about the “good ol’ times,” before chaos set in, helps me cope with the affects of illness. It is oftentimes easier to live in the past than it is in the present. Boym (2001) states that nostalgic thinking may be a type of defense mechanism, especially in “time[s] of accelerated rhythms of life” (p. xiv). I find myself longing to go back to a place where I believed that I was in control, particularly in times when chaos creeps into my life. Nostalgia was once believed to be a curable disease of which many were afflicted. Boym (2001) specifically highlights how immigrants coped with the affects of nostalgia. The cure was for one to return to the homeland. Eventually, it was recognized that one did not always long for a return to the homeland, but instead a return to an ideal or a place in time that never was. In these cases, there was no cure for nostalgia. This is true for my affliction of illness. I long for a place that never existed, an ideal that never came to pass. I cannot return to the homeland for there is no homeland to return to. I cannot go back to a time before Bradley. Separating me from Bradley will not diminish the pain acquired by the time I lost with him at the beginning of his life in this world. I must find a way to deal with this longing, with the illness of nostalgia.

I often wonder if my visits to “The Most Magical Place on Earth” are aiding me in my avoidance of dealing with reality. The Magic Kingdom has become my refuge, my escape from the present. Being in The World takes the pain away. For those few days, I am able to leave reality, leave a world that I have little control over, and embrace the nostalgia. The Magic Kingdom is timeless. Of course new attractions are added and minor adjustments are made here and there, but overall the atmosphere of the park remains unchanged. I know that if I do not return to the World for twenty years, I will still see Cinderella Castle at the end of Main Street, U.S.A. on my next return to the park. I believe it is this notion of continuity that draws me in and makes me homesick, specifically in times of intense chaos. I recognize that some, such as

Henry Giroux (2001), would scoff at my obsession with Disney while citing the numerous ways in which the company is in distinct contrast to the ideals of curriculum theory. Even still, when I return to my Home, I am taken back to a simpler time, when life was less complex. I have visited Disney World countless times, both before and after Bradley's birth. I find myself fantasizing (phantasizing?) about my next visit Home so that I may have a "new beginning" (Balint, 1968). *Nostos* means "return home" in Greek, which could help support the pinnacle homecoming in the hero myth. However, Nagy (1990) uses *The Odyssey* to support that the term refers to a return to life and light. Put another way, he suggests that *nostos* could refer to a return from unconsciousness to consciousness. I find his take on the word to be interesting because throughout this examination of my Self, I am striving to move from the unconscious to the conscious. I am trying to uncover what lies within my Self so that I may gain a more holistic view of who I am.

To be human is to be chaotic. If we are no longer chaotic, we are only cyborgs made from the same cookie-cutter mold. One must strive to be consistently chaotic so that s/he will not self-destruct. The thought of purposely inviting chaos into my life strikes me as odd; however, I am guilty of doing this very thing on a regular basis. I am often asked why I subject myself to such a chaotic schedule. I agree that I am stretched thin. I often have one too many balls that I am juggling in the air at any given moment. I am able to control the chaos, as long as something chaotic does not occur. I often hear those in my circle comment that I am "doing too much," that I need to "slow down a little." I am stunned by their comments. Do they not recognize that the timepiece of mortality is ticking and each passing second is one fewer that I have to do something with my life? Just as the Holy Spirit will only knock at man's door limited times before his heart turns to stone, so will Chaos only invite itself into life's arena on select

occasions before giving in to the monotony established by man's rituals. The opportunity has passed for growth and change. Chaos has succumbed to complete Nothingness.

As Adams (1918/2008) states, order is only a dream; chaos is the competing energy in control. However, there is order in the chaos found in a complex system. The point is to find a balance between chaos and order. Taylor (2009) discusses his personal experience with chaos:

I have long insisted in my teaching and writing that life is always lived on the edge, along the elusive border between order and chaos. What we call normality is a narrow bandwidth—a fraction of a degree more or less, and everything spins out of control. Along this margin reason and madness are simultaneously joined and separated by a membrane so thin and porous that one inevitably bleeds into the other. (p. 5)

There must be constant oscillations in order to sustain life. But a life filled with complete chaos is no way to live either. There must be some sort of harmony between chaos and stability. This balance point, or “membrane” that Taylor (2009) speaks of between chaos and stability in complex systems is often referred to as the “edge of chaos.” Waldrop (1992) describes the edge of chaos as a place where

the components of a system never quite lock into place, and yet never quite dissolve into turbulence, either...where life has enough stability to sustain itself and enough creativity to deserve the name of life...where new ideas and innovative genotypes are forever nibbling away at the edges of the status quo...the one place where a complex system can be spontaneous, adaptive, and alive. (p. 12)

The edge of chaos is a place between “spreading out, piling up” (Davis in Doll, et. al., 2008, p. 129). I am reminded of the sand castles that I used to build as a child while visiting my grandparents at their beachfront condominium. In preparation of building my masterpiece, I

would mix the sand with the ocean water in a bucket. Then, I would grab a handful of the mixture and allow the wet sand to trickle through my fingers. The sand would pile up and spread out as I carefully built my castle. The sand drippings were not controlled; they lacked any pattern. However, they were not exactly random either. The sand drippings were teetering on the edge of chaos. Davis (in Doll, et. al., 2008) suggests that “[w]hat you end up with can’t be predicted or controlled—but that doesn’t mean it defies comprehension. It just means that the structure emerges or the path that unfolds has to be lived through for its endpoint to be realized” (p. 129). Davis is suggesting why it is difficult to interpret Frank’s (1995) chaos narratives: it is only when chaotic experience is considered reflexively does meaning become apparent.

Chaos pushes one to the edge, to the limit, to the breaking point. Oftentimes, the weight of chaos can cause one’s life to shatter into pieces. Illness can bring on an overwhelming load of chaos that can crush the physical and psychic life out of the ill person. But chaos can also promote creativity because one is pushed beyond the normal limits, out of the comfort zone. Dwelling with illness is chaotic. Chaos can create brokenness. But life’s broken tiles can be reassembled into a mosaic that represents the experience with illness. However, unlike the tiles chosen by the artist to create a beautiful mosaic, the tiles used in a living mosaic are chosen for the ill person. To create a mosaic, one must be creative. One must understand patterns and relationships between objects that may not be typically juxtaposed. But it is in this type of chaotic order that meaning is derived.

For me, experiencing the chaotic affects of illness has fostered a type of creativity, specifically in my writing, that had previously remained hidden. I question how my dissertation topic, what I hope to be my life’s work, would be different if I had not experienced illness. It is probable that I would have chosen a suitable topic that would have allowed me to fulfill the final

requirements of the doctoral program. But I may have been passive about this type of work, only doing the minimum requirements necessary to “get finished.” Throughout my study, I have learned that one is never “finished” with illness; one consistently dwells with the affects of illness. Writing about my experience has pushed me to examine my self and question what I once believed as Truth. Writing about illness is meaningful and necessary for me to find order in chaos.

CHAPTER 4

PRIVATE MATTERS IN A PUBLIC ARENA:

A SELF-EXAMINATION

The South is a place where people maintain a closeness to the land and a feel for the rhythms of nature. (Kincheloe in Kincheloe and Pinar, 1991, p. 145)

The curriculum is not comprised of subjects, but of Subjects, of subjectivity. The running of the course is the building of the self, the lived experience of subjectivity.

Autobiography is an architecture of self, a self we create and embody as we read, write, speak and listen. (Pinar, 1985, p. 220)

I have lived my entire life dwelling among the marsh grass of Coastal Georgia.

According to the Georgia Department of Natural Resources, the marshlands of Coastal Georgia are some of the most extensive and productive ecosystems in the United States. The marsh serves to protect from offshore storms, dissipating the energy from the crashing waves before they are able to reach the mainland. When the marsh grass dies, bacteria decompose the material, transforming the plant into vital nourishment for the developing organisms that find safe haven among the grass. The beneficial nourishment provided by the decaying plant material is also the culprit of the distinct odor one smells when near a marsh at low tide. Many people would argue that the putrid smell of the marsh makes them wrinkle their noses in disgust. But for me, it is precisely this smell of decaying matter that is completely satisfying because it suggests renewal. Although the smell can be overwhelming at times, the gases given off indicate that a regeneration of life is taking place deep below the surface.

The livelihood of the marsh ecosystem is directly related to the ebb and flow of the tides. The incoming tide nourishes and feeds the grasses which serve as food and shelter for developing organisms. The higher the water level of the incoming tide, the more nutrients deposited into the rich mud-like environment. As the tide goes out, the waters transport food and nutrients produced by the marsh out to sea. The smell of the marsh is strongest at exceptionally low tides when all of the marshland has been drained of its water. While I have been dwelling with illness, my life has been giving off a sort of putrid marshy-smell causing many people to wrinkle their noses in disgust. The more that I vocalize my frustrations and drain my emotions, the stronger the stench becomes. Some have slipped away, unable to bear the disgusting odor. But a few have stepped closer to serve as encouragement, recognizing the smell as an indicator of the work that is taking place deep within my Self. The marshlands of my Self draw nourishment from those who encourage me, both in a physical and textual sense, and foster the regenerating facets of my Self.

The tidal waters in Coastal Georgia are in distinct contrast to waters found off the coast of Florida. Tourists tend to flock to the clear, pristine waters of Florida rather than step foot into the murky waters of my region that some would classify as down-right ugly. What many do not realize is that the murkiness of Coastal Georgia's waters is a characteristic of what is referred to as the "Georgia Bight"—a unique geographical feature that continuously re-circulates the water deep into the marshlands as it transports nutrients throughout the ecosystem. As the water comes back on itself, it fosters a renewal of life. The Self can be similarly murky and unwelcoming, making it difficult to navigate through the constantly moving emotional currents. However, allowing the waters of my Self to re-circulate has nourished my soul as I have come back to my Self time and time again through this journey of Self exploration.

Before embarking on this journey of Self exploration, I frequently found myself seeking guidance through outside sources: friends, relatives, teachers, God. Although these sources provided a wealth of sound advice, I still found myself wavering, unsure of what path I should choose. If I chose the path to the right, would this group approve of my choice? Or, I could choose the path to the left, knowing that this is the path most frequented by travelers, despite my uneasiness of traveling this road. As the song “Closer to Fine” by the Indigo Girls (Saliers, 1989) reminds me, there are many answers to the questions that I have, all which are telling me to go this way and that way. I began to see things differently when I stopped looking toward external means of guidance and began working from within. The less I rely on some definitive answer from outside sources, *the closer I am to fine* (Saliers, 1989). Psychoanalysis provides opportunities for one to search the Self for guidance, peering in through the windows of the conscious and the unconscious. The conscious is frequently attended to; this part of our Self often communicates with others and seeks guidance from outside sources. However, Powell and Barber (2006) state that “any action that brings genuine improvement will require working through unconscious material” (p. 50). Although not always an easy task, one way I have found to work through unconscious material is through writing which “enable[s] us to make sense of ourselves, so that our lives become meaningful” (Pinar in Pitt, 2003, p. vii). Words have a way of reaching to the depths of the Self, touching an area of the unconscious that is not always given the chance to come into the light. Atwell-Vasey (1998) says, “We fill our bodies with [words] to comfort ourselves; we send them into the air to join us to other people. Words stand for us on the page—they push themselves on the page, indenting, imprinting, impressing the sheet and impressing others” (p. 1). It is my desire that the words that I imprint on the page will in turn impress meaning upon others.

Archeology of the Self

Typically when a baby is born, her/his vital signs are assessed and then the neonate is wrapped snugly in a blanket and placed in her/his mother's arms. When I first held Bradley, tightly swaddled in his blue blanket, I too was swaddled in a security blanket of peace. Although this was the birth of my second child, this feeling of peace was not something I had previously experienced. When my oldest son, Tyler, was born, he was in distress and was immediately taken from me to be treated by the neonatal team. Fifteen long hours passed before I was able to hold Tyler for the first time. But Bradley's birth was different; his arrival into the world was peaceful, textbook, just as I had planned. As Bradley lay sleeping serenely in my arms, I closed my eyes and drifted off to sleep, awed by the miracle of life.

Upon awakening the next morning, my first thought was of my precious newborn. How perfect he seemed! I was eager to begin calling family and friends to announce my perfect baby's arrival into the world. But as I was soon to learn, outward appearances can be misleading. Bradley's external perfection only served to mask the internal complications that remained undetected. An echocardiogram exposed the congenital heart defect that had remained hidden from view. Having no indication of his illness prior to birth, the diagnosis of his heart defect created an eruption of chaos in my otherwise linear, rigid life of predictability. I found it hard to comprehend that my child, who on the outside looked perfect, was struggling to survive because of the misplaced arteries in his heart. I questioned why I could not see outward signs indicating that something internal was threatening Bradley's life. With heart defects such as Bradley's, the body has a short-term coping mechanism to manage the life-threatening condition. However, the increasing needs of the developing body eventually prove to be too demanding for

the malformed heart. In the end, the only chance for survival is to undergo heart surgery to correct the misplaced arteries.

Throughout Bradley's hospitalization, I kept an online journal for friends and family to stay informed of his prognosis. Countless people, some whom I have never met, wrote to say how they could hear the optimism in my writing. They seemed impressed with my strength throughout the Bradley ordeal. I quickly became accustomed to donning this façade of peaceful buoyancy. Yet, in reality, I wanted to drown in a turbulent sea of emotion. When my family first arrived at the hospital, an awkward silence fell over the room. I intervened by commenting, "And to think, I did not want him to be born on Friday the thirteenth for fear that something bad might happen!" (Bradley was born just before midnight on Thursday, April 12). When my comment eased the tension, I quickly realized the role I was to play throughout the ordeal: the strong, optimistic, cheerful actress. I clothed myself in the façade and prepared to make my debut on the stage of illness.

The term "façade" is derived from the French language meaning "front" or "face." Hollywood often employs the use of façades to create an illusion that a particular structure is something that it is not. In architecture, the façade sets the design element for the structure. If one passes a building adorned with a steeple and a cross, it is possible to assume that the building is used as a place of worship. One can draw assumptions as to the building's interior space and purpose based on what is viewed from the outside. But not all places of worship are adorned with a cross and a steeple. A building with no such adornment can equally serve as a place of worship. Considering how the outside appearance suggests inner activities, similar assumptions can be made about individuals who are ill. Sometimes, it is obvious that a person is ill because the ill person has a certain "look." But the ill body does not always show outward signs of

distress. At birth, Bradley appeared normal. There were no immediate indications to suggest a heart defect. But inside, buried deep below the surface, a minute malformation was threatening Bradley's chance for survival. If the defect had remained undetected, he would have died. The assumptions made from external observations were misleading and inaccurate. And, had it not been for the skilled medical team who detected the slightest discrepancy in his vital signs, these preliminary assumptions could have cost Bradley his life.

Similar to the inaccurate primary assumptions made regarding Bradley's physical health, assumptions have been made regarding my own emotional health based on what is portrayed on the outside. I find it easier to portray myself as the strong, optimistic, emotionally stable mother than to allow myself to deal with the overwhelming uncertainty that encapsulates the Bradley ordeal. Subconsciously, I feel the need to be the heroine, the role-model that others can look up to. I want onlookers to admire my strength. My façade becomes my coping mechanism, allowing me to deal with my emotional illness, similar to the internal coping mechanism that Bradley's heart assumed to help him sustain life. Only now am I beginning to put my coping mechanism to rest, to strip off the façade to allow others an opportunity to glimpse into my private world. Yet, exposing these grotesque parts of my Self, such as my emotional illness, threatens to push others away. Because of its putrid stench, for quite some time I tried to keep my emotional illness hidden from myself. I brushed my emotions under the rug, assuming that if I ignored my pain it would disintegrate. I question how long I would have ignored my illness if my mentor Marla Morris had not introduced me to the genre of pathography. Reading the pathographies of others served as the echocardiogram for my emotional heart, detecting the malformations that remained hidden from view yet demanded attention. I am frightened to think of the emotional death I would have encountered if my illness had not been revealed. Embracing

the opportunity to explore myself psychoanalytically through autobiographical writing has been the surgical procedure needed to make sense of my illness. Having surgery oftentimes requires the opening of the body. The physical scars on Bradley's chest from his heart surgery serve as constant outward reminders of the internalized chaos that remained concealed for so long.

Additionally, his scars remind me of the psychological scars that are on my own heart. A scar indicates that two pieces of tissue have been fused back together after being separated. Bradley's scars indicate where his thoracic cavity was separated in order to gain access to and correct his misplaced arteries. Likewise, my psychological scars indicate where my emotional heart has been examined and healing is beginning to take place.

Throughout the Bradley ordeal I have been concerned with how others view me. Many people I know would agree that this notion is silly and possibly a little immature; why should I care what others think of me? But, I do care. And, I suspect that I am not alone. Pennington (2000) posits that the reason for seeking others' approval stems from the need for security. He illustrates his point by considering the developmental process of the individual. In the womb, the fetus' needs are met without any action by the fetus. After birth, the newborn quickly realizes that s/he must verbally communicate her/his needs. As the child matures, Pennington (2000) suggests that s/he begins to subscribe to the idea that "Mommy will not love me if..." Put another way, the child believes that "they are lovable only because of what they do. They have value, they have worth, they are lovable because they perform in an acceptable way" (Pennington, 2000, p. 30). Pennington (2000) believes that this notion follows us into adulthood and contributes to the formation of the "false self, made up of what I have, what I do, what people think of me" (p. 32). I feel as if trying to maintain this false self, this façade, only places additional burdens on my already weary self. But, I think that society also places an added

burden on the ill person to appear strong. I am reminded of a story of my friend's father who was dying of cancer. During his final days, he commented that visitors encouraged him to stay strong, to fight his illness. As my friend stood by her father's bedside, holding his hand, he admitted that he no longer wanted to be strong. He wanted to give up. But his fear was that he would disappoint his loved ones by surrendering to illness. I do not doubt the power of encouraging words spoken to uplift those who are ill. But for me, I needed to know that it was okay to fall apart, to break down, to appear weak. I needed to believe that I did not have to shoulder the burden in isolation.

Although I strive to construct my façade so that it appears resilient and impeccable, my interior is in disarray. While striving to maintain a strong outer appearance, I am silently calling out for help. I want someone to notice the subtle signs of weariness. Yet, if someone detects my weakness, I fear that they will judge me as a counterfeit. What inhibits me from feeling at ease sharing my true self to others, assuming that I even know who my true self is? I have very few individuals whom I feel comfortable even allowing a glimpse into my private world. Thus, I feel alone despite being constantly surrounded by a seemingly close circle of friends. Nearly four years after the ordeal's onset, I am still tangled in a web of emotions. When I mention something about the Bradley ordeal to anyone, I tend to get the "What's the big deal? His heart is fixed" look. I want to scream, "No, damn it! He is not 'fixed!' Now my child has developmental delays! Don't you see? The effects of illness linger!" My reality is not recognized by those who are around me. I long to disclose my intimate feelings and the inner reality of my world in order to gain connection with others; but, the fear of rejection fosters my continued isolation.

I feel caught in a paradox of my true and false Self. I am not the person that I portray to others. Who am I then? In a way, am I living a double life? Pinar (1985) addresses the notion of what is true and false as it applies to the Self. Drawing from Foucault's (1970) concept of the "archeology" of the Self, Pinar questions "Is there an authentic self?" (1985, p. 201). My Self is heavily clad with extraneous clothing beyond recognition. I believe others view me as fun-loving and upbeat, and possibly a little overdramatic. Pinar (1985) describes these qualities as a part of my personality, what is portrayed to others, but I question how authentically this persona represents my Self.

In my science classroom, my students are taught the principles underlying the law of conservation of energy: energy is neither created nor destroyed. Pinar (1985) uses this scientific definition as a way to describe Freud's (1917) notion that everything that once was with us remains with us forever: "that all that happens to us as infants and children remains, almost always hidden from view, but present nonetheless" (Pinar, 1985, p. 202). Pinar (1985) equates the different aspects of the Self to sedimentation—layers upon layers of experiences—similar to the sedimentation of rock layers. And, similar to geologic rock layers, parts of the experience are similar to fossils, remains that have been hidden from view for quite some time but are unearthed and brought out into the light to be reexamined. The process of fossilization is intriguing. When something dies, its remains can become trapped under layers of debris. Over time, considerable amounts of heat and pressure fossilize the remains, turning them into a stone-like substance. Many fossils remain buried deep within the layers of the Earth. However, some are unearthed by skilled archeologists who know in just the right places to excavate. Many times when fossils are discovered they look just as they did when they were first buried, and can be compared to living creatures of today. Although, sometimes the fossils bear little resemblance

modern variety, suggesting a sort of foreign ancestral species. Fossils can be compared to hidden emotions, waiting to be unearthed. Emotions are buried, deep within the earth of the Self. Extensive amounts of time, enormous amounts of heat and pressure harden the emotions as they are further covered up by the earth. These emotions are hidden from view and seemingly forgotten about. However, when the Earth is disturbed in just the right manner, the emotional relics can reveal themselves. Sometimes they are in the form of recognizable objects; sometimes they are foreign and rear their ugly heads. In any case, they demand attention and must be dealt with and handled with extreme caution or fear that they might crumble.

The Self's "Other" Language

Recently, I experienced "Dialogue in the Dark," an interactive encounter in which I was immersed in a world of darkness to simulate how the blind must adapt to a sighted world. As I traveled through the various rooms designed to be replicas of what one who is blind might encounter on a regular basis, my sense of sight was of no value; my eyes could no longer bridge the gap between the known and the unknown. I had to rely on my other senses to help interpret my environment. Running my hand along what my tactile senses told me was a countertop, I felt a small, round item. It had a paper-like covering that crackled when I moved it around in my hands. Unable to rely on my sense of sight to confirm its identity, I held the foreign object close to my nose and inhaled---Oh, yes, an onion! Such a familiar object had become unfamiliar in the dark. This new dialogue I was exchanging with my environment was both confining and liberating. Initially, I stayed close to the wall of the room, fearful of losing my footing, fearful of unseen obstacles, fearful of the unknown. But as I became more comfortable with drawing information from my other senses, I began to explore my familiar yet unfamiliar world.

The Other is similarly familiar yet unfamiliar to the Self. I am interested in the dialogue exchanged between one's Self and Other, as well as the dialogue exchanged between two individuals and their multiple components. Buber (2002) describes three types of dialogue:

There is genuine dialogue...where each of the participants really has in mind the other or others in their present and particular being and turns to them with the intention of establishing a living mutual relation between himself and them. There is technical dialogue, which is prompted solely by the need of objective understanding. And there is monologue disguised as dialogue, in which two or more men, meeting in space, speak each with himself in strangely tortuous and circuitous ways.... (p. 22)

Here, Buber challenges the very meaning of the term "dialogue." What is commonly thought to be an exchange of communication between two persons is now seen in a different light. Who are we really talking to when we talk to someone? Are we speaking to the individual, or her/his Other? Who is doing the talking--my Self, or my Other? And, for that matter, how do we begin to decipher what is being said? Pinar (1985) suggests a systematic method of psychoanalysis as a means "for uncovering that which one does not say, does not know, who one was once but is not (exclusively or consciously) now" (p. 205). The field of psychology is concerned about the conscious mind. However, Freud, the father of psychoanalysis, "thought that consciousness was only a thin slice of the total mind, that like an iceberg, the larger part of it existed below the surface of awareness" (Hall, 1954/1999, p. 54). Freud believed that there was also an unconscious part of the mind that shaped personality of which we were not aware. Although, knowing about the actions of the unconscious does not provide awareness. Awareness implies consciousness and one is not conscious of the unconscious.

Freud identifies two qualities of the unconscious, the preconscious and the unconscious proper. The unconscious is what is being suppressed by the opposing force of the conscious. Memories are often suppressed deep within the Self because they are too painful to remember. Hall (1954/1999) states:

In order for ideas or memories to become conscious, it is necessary for them to be associated with language. One cannot think or remember unless what he is thinking or remembering has been linked with words that he has seen or heard. (p. 56-57)

What if one cannot put experience into words? I am reminded of my Grandpa who was a prisoner of war in World War II. He could not put into words what he saw, felt, lived while he was imprisoned for eighteen months. I can only guess that there are no words to describe the horror that he lived. His conscious had gone beyond temporarily repressing the memories of these horrific events; in some way, his conscious had built a brick wall to seal off this part of his life. Yet, as much as Grandpa wanted to forget the horror, the affects of his experience were reflected in his temperament. I assume that his verbal outrages were reflective of the verbal abuse he endured as a prisoner. Similarly, his hoarding tendencies and bizarre eating habits most likely stemmed from his lack of material possessions and nourishment while he was at the mercy of the enemy's hands. Only on rare instances would one catch a small glimpse of what was behind the wall. Grandpa would go into a trance-like state, almost as if he were narrating a movie. And then suddenly, SNAP! He was back in the living room, sitting in his red recliner. I can only assume that this breakthrough of the unconscious was tempered by conscious control.

In reference to my experience with my Grandpa, it is also possible that his preconscious allowed him reprieve from his vivid memories. In relation, the preconscious allows one to repress memories in order to give pause, allow the psyche to stabilize. The preconscious is what

is on the tip of the tongue. It is only slightly held back and needs only a little coaxing to come into the conscious. Freudian slips could be an example here. Suppressing memories serves as a defense mechanism, a way of dealing with the traumatic at a later time. Freud called this “*nachtraglichkeit*” meaning deferred action, a process by which events are suppressed and even disguised as something else in order for one to deal with the trauma. Psychoanalysis acknowledges that it takes time to work through emotions, distinguishing the field from other disciplines that force a conclusion to an issue. Eigen (2005) comments that “much of our social and political and personal time is organized around speed and a show of strength and action” (p. 43); this ideal is in distinct contrast to what psychoanalysis teaches--slow down, allow for vulnerability. Eigen (2005) refers to the process of working through emotions as “digestion.” Instead of attempting to digest an entire emotional meal, Eigen suggests “partial digestion” which allows the body time to break down the complexities of the situation and absorb the nutrients (if any) that are present.

Four days after surgery, Bradley’s ventilator was removed and he was finally able to take formula from a bottle. His stomach was unaccustomed to digesting food and struggled with the process. Often, he expelled any formula that was given to him. He was then given a partially digested formula, one that his body was able to absorb without additional stress. Over a period of several months, he began to digest larger quantities of the regular formula. Similarly, emotions and traumatic events must be partially digested so that the body does not expel what it takes in. Digesting emotions can be stressful and cause one to choose starvation over tasting the bitter rations. However, Eigen (2005) cautions that one cannot leave emotions undigested because “[u]ndigested experience leads to emotional indigestion, which hurts” (p. 43). I was anxious over losing my child so I repressed emotions which turned in to control. There came a

time when my emotions could no longer be controlled; repression had failed. For quite some time, I subscribed to the notion that my primary issue was that of control, or fear of chaos. As I tried to flesh out this obsession with control, I became bewildered when the more I sought answers to the burning problems that lay within, the more “emotional indigestion” I experienced. I was shocked/relieved/exposed when I awakened to learn that this fear of the chaotic was not the primary focus of my illness. This epiphany came when re-reading a sentence from a paper I had written for a previous class: *Learning of Bradley’s defect made the first incision into my soul, an incision so deep I was cautious of bonding with him after surgery for fear that I may lose him again.* For some time, I had misdiagnosed my illness and had been attempting to treat it with medication that did not agree with my system. Through my writing, my unconscious revealed the true source of my fear: losing my child. This is what Bollas (1987) refers to as the *unthought known*: “reliving through language that which is known but not yet thought” (p. 4). Although the unconscious appears to be secondary to the conscious, it will find a way to bring the private into the public’s view. Writing can be therapeutic, helping to identify what is known but not thought. For me, I consider how writing about my experience has helped to understand, (and sometimes possibly confuse), my Self. My computer is non-threatening, allowing me to express my true feelings. It is only when I allow others to view what I have written in my private world that I feel vulnerable.

The beginning of one’s recognition as both a private and public Self is rooted in Lacan’s (Roseboro, 2008) “mirror stage.” Here, the “mirror is both a literal and figurative concept...[representing] both the physical mirror and the environment as mirror” (Roseboro, 2008, p. 16). When a child sees her/himself in the mirror, s/he can recognize that the reflection is her/himself but is outside of her/himself. The reflection in the mirror is both familiar and

strange, or Other, and allows the child to develop a self-concept about how others view her/him. The mirror also allows the child to recognize the body as a unified whole, a sum of all parts. No longer will the child think “This is my hand” or “This is my foot” without recognizing that each are a part of a larger system. During Bradley’s hospitalization in Atlanta I recall not having looked in the mirror for days to visibly observe how my emotions were affecting my appearance. It was on Bradley’s one week birthday that I first saw myself in the mirror. I did not recognize myself. I remember this strange feeling that overcame me, a feeling that can only be described as “otherness.” Experience told me that the reflection was mine, although I did not recognize the image staring back at me. Maybe it was the emotion of the day as I recalled what had occurred one week prior or maybe it was seeing the reflection of what I had become for the first time that caused me to break down. I was not the same person I had been seven days prior. I was not sure of my Self. Lacan speaks of how seeing an image in the mirror helps one recognize the order of all body parts. On the contrary, seeing myself, my Other, in the mirror caused me to fall apart.

The Other can be strange, alien, eccentric, unconscious. How can my unconscious, which is within me, be so foreign? If I continue to engage with my Other through psychoanalytic inquiry, will it become more recognizable, just as a stranger may become more familiar over time? Morris (2008) states, “The point for autobiography—or in this case pathography—is to point to our eccentricities and the ways in which illness makes us strange and strangers to ourselves” (p. 3). This “pointing out” or making public my strangeness makes me vulnerable. I feel I am constantly in a tug-of-war, confronting the “duel”ism of the Self and the Other. Each competes for representation in the public sector. Yet, this relentless competition is tiring and creates chaos in my private world. “Only when the individual knows the other in all his otherness as himself, as man, and from there breaks through to the other, has he broken

through his solitude in a strict and transforming meeting” (Buber, 2002, p. 239). Recognizing the presence and influence of the Other makes me aware of the dialogue that I exchange with others and their Others. Atwell-Vasey (1998) cites Kristeva who says “language is a joint, not a gap—it is both what you mean and what others mean, and it is both not what you mean and not what others mean” (Atwell-Vasey, 1998, p. 50). The term “joint” reminds me of a joint on the body, such as the elbow or the knee. Each of these joints connects a set of bones so that a task can be accomplished. How difficult it would be to scratch my nose if it were not for my elbow joint! If language is a type of “joint,” then it serves to accomplish the task of making meaning out of experience. However, if there is no Truth in language (only smaller truths), then how does one know what the other means? Are we then dis”jointed” with one another and with our Other? It is possible for psychoanalytic theory to help make meaning of this communication dilemma that desires to exchange dialogue in the dark.

Publically Exposing Private Matters

Writing about illness has allowed me to delve deeper into myself to discover parts that have been hidden from plain view. Writing has become my source of creative expression. I enjoy writing. When I am not writing, I think about what I could be writing about. Words play with each other in my mind until they have formed into thoughts, sentences, paragraphs, and pages of text. Oftentimes, the ideas assemble and then rearrange themselves into something new before my fingers can record their patterns. Writing is a creative mode for examining my Self. Winnicott (1971/2005) writes, “[I]t is only in being creative that the individual discovers the self” (p. 73). Here, Winnicott is specifically stressing creativity through the use of play. I recall the Child Life Specialist at Egleston who spent time with my oldest son Tyler who was a little

more than three years old at the time of Bradley's birth. She used a form of play therapy to help Tyler understand what was wrong with his little brother's heart. Free-association through play in a non-threatening environment afforded Tyler an avenue to express his private concerns in a public arena. However, the private does not always reach the public's view in such a nonchalant manner.

The process of transference is one way that private material actively engages in the public realm. Bollas (1987) cites psychoanalyst Paula Heiman who asks, "Who is speaking?" when decoding the hidden messages transferred between analyst and analysand. Heiman concluded that the analysand could utilize the analyst as an object of transference, projecting specific emotion toward the analyst who has now become mother, father, husband, wife.... Recognizing transference can occur within the realm of therapy, I can only assume a similar phenomenon takes place within the classroom. Cohler and Galatzer-Levy (2006) describe how erotic desires may be transferred within the teacher-student relationship. They draw from Freud when describing erotic transference as "the analysand's conscious desire directed at the analyst...[which] can result in enactments that threaten to take the place of understanding and working-through" (p. 249). Here, Cohler and Galatzer-Levy are specifically referring to the sexual relationship (or desire for) within the teacher-student context. However, the teacher can play many roles in the relationship, such as mentor, Mother, or analyst, all which are vulnerable to the affects of transference.

I am reminded of a particular situation, in retrospect somewhat embarrassing, when my emotions decided they had waited behind the curtain long enough and it was their time to take the stage. From seemingly out of nowhere, I erupted during a class meeting conducted by my mentor, Marla Morris. Like the analyst, Dr. Morris was someone that I felt comfortable allowing

glimpse into my private world; yet, something that was said, although I do not remember the specifics of the conversation, caused me to strike out at her. I had repressed my emotions as long as I could until they would no longer stay contained. But I question, was Dr. Morris the source of my anger, or had she momentarily become the doctors, Bradley, God, everyone that I wanted to yell and scream at and tell them how I felt about the whole ordeal? Britzman (2006) writes, “The teacher’s psychological world...is woefully ignored, until...’it’ seems to erupt out of nowhere, a destruction made to break relations with others” (p. 123). I wish to substitute my own name for “teacher.” My emotions demanded the attention they had not been afforded. The time had come to digest my experience despite the bitter taste. Because of this experience I am always cautious of how I handle students who strike out during class. My colleagues have criticized me for not writing them up because I should demand respect and not tolerate such behavior in my classroom. They suggest I am showing a lack of classroom management. Maybe I am too much of a push-over; maybe I need to rule with a firmer hand. However, I tend to believe that my students’ uncharacteristic actions are intended for another. Their private life has been uncontrollably transferred into the public domain.

As a teacher, I find it hard to direct the traffic of my merging private and public lives. I have often been cautioned for being too “open” with my students, allowing them to peer in through the window to my private life a little too long. I understand my boundaries with my students; however, I am possibly more candid about certain things than maybe I should be. Britzman (2006) states, “Teachers, we often feel, must be adept at brushing off their private world like so much accrued lint...Crises belong to others” (p. 131). I often feel that I must leave my personal life in the parking lot before I enter my school building. However, we are all on a journey, maybe not side by side but together somehow, and it is in this communion that we draw

our strength and encouragement. My students need to know that I have fears, concerns, feelings, stressful situations similar to their own. I am not exempt from these things that they confront on a daily basis. “The teaching body, which gets up to speak and convince, or leans over to write, presents itself to its public in its naked naivete...” (Serres, 1997, p. 3). As a teacher, I am vulnerable; I have lost my safe place. That which was private threatens to become public, in plain view for all to see and judge.

I struggle with knowing how much of my private life to share with the public world. The private/public paradox of life is troublesome. I have already claimed to instill a sense of openness in my classroom with my students. But where do I draw the line? How much is too much to share? This question is also my struggle within the confines of the doctor/patient relationship. When my obstetrician called me after I came home from Bradley’s hospitalization to ask how I was doing, I told her that I was “fine.” Why did I say that? Why did I remain silent about my emotional state? I was far from “fine!” At the time, it was easier for me to lie than it was to admit to her (and myself) that I was falling apart. I was devastated that my baby would not eat from a bottle, that I was getting little sleep, that feedings lasted over an hour and then started again within two hours, that I remained trapped in my house because of all of the medical equipment, and that I felt like I was neglecting my other child and husband while caring for Bradley. I could tell that she knew that I was lying but she just said “okay” and did not pry. I doubt I would have divulged my hidden emotions had she have tried to get me to open up. Meath-Lang (1990) comments, “Lonely, grieving, and marginalized persons are accustomed to silence” (p. 12). In the days immediately following Bradley’s birth, I spent most of my energy suppressing my feelings of overwhelming fear and grief. Had I become accustomed to living in silence, a life behind a façade? I suspect I felt at the time, as I do now, that most people who ask

how I am doing do not truly want me to divulge the inner workings of my Self. It is customary to express care and concern for those who are ill; but what does it mean, to “care?” Nel Noddings (2003) addresses the notion of caring. She discusses the conventional applications of the term and differentiates between how the text defines “care” versus how it is defined from a humanistic approach. She uses the example of caring for an elderly relative and contends, “I cannot claim to care for my relative if my caretaking is perfunctory or grudging” (Noddings, 2003, p. 9). Her comment troubles me because it identifies an issue that I thought was hidden from view. When Bradley was ill, I was his primary caregiver. And while I love my child, I am not sure that I cared for him, in the humanistic sense, if I dreaded everything that pertained to his medical condition and maintenance. It is difficult for me, the Mother, to think I might not be a “good-enough Mother” (Winnicott, 1971/2005) or that others may view me as something other than “good-enough.”

It is possible that I feel alone and choose not to disclose the hidden parts of my Self, except possibly in my writing, because there is not a great deal in the literature about the emotions associated with being a caregiver. There has been much written in the area of self-help books or on how to care for elderly parents. There has also been some works that explain the intricacies of caring for and coping with the loss of a child with a life-threatening illness. But in my research, I have not been encouraged by the literature available on the care for a child with a chronic condition. It is true that support groups exist for caregivers of children with specific medical conditions, but Bradley’s condition is not severe enough to be classified with this cluster. My dilemma is that what I am enduring cannot be attributed to a diagnosed medical condition. Thus, the loneliness returns.

I feel guilty when I compare Bradley's illness to those of a more serious nature. A good friend of mine gave birth a few months before Bradley was born. Late in the pregnancy, the baby was diagnosed with a fatal genetic condition. The baby only lived for a short time. I still have Bradley in my arms; he has been "fixed." (I use the term loosely because I do not feel that one is ever truly "fixed" after enduring illness.) My friend's child could not be "fixed," and I feel guilty comparing my situation to hers. However, I must be cautious in comparing narratives, a sort of "my illness is worse than your illness" competition. I think this unspoken "competition" has fostered my silence. The thought that Bradley's situation could have been much worse makes me question the validity of my feelings of fear and uncertainty. On the other hand, enduring an illness does not make one noble. Anne Fadiman (1997) tells the story of Lia Lee, a Hmong child who suffered from epilepsy. Despite the doctors' persistent convincing that their daughter's illness could be cured, the Lee's refused medical care for their sick child because their culture identified her seizures as a sign of nobility. Although the Lee's hailed from an entirely different culture than my own, I have learned from their story that I must not romanticize illness. Freire (1970/2007) cautions about romanticizing suffering, "as if God were the creator of this 'organized disorder'" (p. 62). I am not a better person because I have suffered. But I am different—and it is my desire to share my experience with those who will listen.

Competing Voices

How does one begin to bridge the gap between the public and private spheres when dealing with illness? Within the medical community, HIPPA laws are enforced to protect the patient's privacy so that the patient can remain, in a way, anonymous. This anonymity can result in the patients being viewed by the medical staff as nameless, faceless cases instead of

individuals. The patient's identity may be reduced to a case number or a particular illness. But, the patient is comprised of much more than what is recorded in the medical chart. How, then, does one voice the personal side of the patient? Britzman explains:

Voice is meaning that resides in the individual and enables that individual to participate in community....The struggle for voice begins when a person attempts to communicate meaning to someone else. Finding the words, speaking for oneself, and feeling heard by others are all a part of this process.... (as cited in Pinar, et. al., 2004, p. 524)

Voice is a necessary precursor for community. Without voice, both individual and collective, community cannot be formed and change cannot occur. Conveying the intended meaning of words may be difficult, but this complication should not deter one from exercising her/his voice. What happens when one does not have a voice, either psychologically, physically, or politically? Oftentimes, a patient is given a sedative to keep her/him comfortable during a procedure or to ease the pain of an illness. Although this medication can perhaps help one endure thresholds that could not be reached otherwise, this denying of feeling robs the body of expression. When a patient is sedated, or even in a relaxed state of bliss, they are unable to communicate with those who are treating her/him. Does this apply to the classroom as well? Are we over-medicating our students, with both prescription drugs and our fast-paced culture, under the pretense that it is to make them more focused, when in actuality we prohibit them from engaging in authentic dialogue?

When those in my circle ask what I am spending so much time writing about, I reply that I am writing a pathography, a life story about illness. Many do not seem impressed with my work, silently asking, "How hard can it be to write a story about yourself?" But the longer I dwell with illness, and specifically the more that I write about this dwelling, the more circuitous

my story becomes. Life is not linear, a time-line of specific events and characters that can be summed up in a few short pages, written from a singular viewpoint. Raggatt in McAdams, Josselson, and Lieblich (2006) states that “the life story is really more like a *conversation of narrators*, or perhaps a *war of historians* in your head” (p. 16). There are parts of my Self that choose to step into the light at distinct times. It is difficult to know which part of my Self is actually responsible for what is written on the page. Connelly and Clandinin (1991) suggest the dilemma of addressing the “multiple ‘I’s” (p. 139) when writing a narrative. Here, they are referring to the numerous individuals (researcher, storyteller, and those who have influenced these two) who strive for representation in the final manuscript. This dilemma will be ever-present in my own research, as the “multiple ‘I’s” of mother, wife, sister, daughter, teacher, church member, friend jockey for position within my story. Although much of my work is written from the first-person viewpoint, which of these aforementioned are “first?”

I have struggled with the notion of ensuring that my writing is authentic. By “authentic,” I mean that I want my writings, especially of the specific events of the Bradley ordeal, to be represented as they have actually occurred. Additionally, “authentic” writing means that I am writing out my emotions that I have kept hidden from the public’s view. It is my desire for my writings to be completely transparent to my reader, to be uncensored. But even as I have written the past few lines, I have found myself typing and deleting, typing and dele..... I have not allowed every thought or idea that has entered my mind to be imprinted on the page. To be completely uncensored in my writing, I would have to write in the style of Virginia Woolf (1992) in *To the Lighthouse*. Her work is exemplary of the type of stream of consciousness necessary to have uncensored writing. However, writing in this manner can cause great

confusion for the reader. Thoughts and ideas are not linear, troubling the reader to find some sort of cohesiveness in a jumbled plot that traverses time and place.

Although I still deliberate the notion of authenticity in my writing, many of my concerns have been relieved by studying Paul Ricoeur's (1992) narrative identity theory. Ajit Maan (1999) summarizes part of Ricoeur's theory:

[T]he narration of life stories is guided by the principles of classical aesthetics. This means several things. It means that the meaning assigned to present experience, narrations of past experience, and future action, will conform to certain principles of emplotment. And...it means that personal identity will be developed in accordance with those same aesthetic principles. (p. 1)

There are two "pasts" to consider when recalling events: the past that actually occurred and the past that is remembered. How specifics are remembered is dependent upon the environment in which the experiences are relived. Furthermore, my identity will morph according to these "principles of classical aesthetics." But instead of this shifting identity being troublesome, I am beginning to regard the diversity as a part of my uniqueness. In his book *Oneself as Another*, Ricoeur (1992) discusses identity in respect to sameness and selfhood. He describes sameness as oneness, similarity, lacking diversity. On the contrary, Ricoeur (1992) describes selfhood as the identity that belongs to an individual. This identity differs from the identity of another individual. But one's selfhood can also differ between one's Self and her/his Other. According to Ricoeur (1992), the Self and the Other cannot be separated. Therefore, the selfhood is the totality of the multiple facets of the individual. Using Ricoeur's (1992) work as support, I am beginning to make sense of my narrative identity. Instead of being tangled in the notion of authenticity, I recognize the dialectic nature of sameness and selfhood and their importance in

my pathography. As Pinar (1985) reminds me, the Self is not a stagnant entity; it is a work in progress, created as “we read, write, speak and listen” (p. 220).

Memories on a Mystic Writing Pad

The lyrics of the song “Memory” (Nunn, 1981) from the Broadway musical *Cats* have been imprinted in my memory for as long as I can remember. My mother first introduced me to the song, specifically Barry Manilow’s rendition, while riding in the car. I loved the tone of her voice as she sang and especially the way her voice would crescendo and decrescendo to emphasize the meaning of the words. When I began playing the piano, one of the first pieces of sheet music I purchased was “Memory.” I recall as I played the piece, although not very well, feeling a unification of my emotions. As I closed my eyes, I let the music flow through me as I spoke through the piano’s sound. I was careful to emphasize the dynamics of the piece in the same way my mother had when she sang the words. Even though my 10-year old mind did not fully comprehend the meaning of the song’s lyrics, I understood that music could be powerful in expressing emotions that otherwise may have remained repressed.

Music has always played an integral part of my life. I am by no means a musician; I tinkered with the piano when I was younger and enjoy singing in my church choir, but this is where the extent of my musical ability ends. However, I do find it interesting that when I am going through a crisis in my life, I am often guided by music. I find therapeutic connections between songs and current life events, even if the song as intended has little correlation to what I am experiencing psychically. “Iris” by the Goo Goo Dolls (Rzeznik, 1998) is one of many such songs. As I sat beside my son’s bassinet in the hospital, the chorus frequently flooded my mind: *I don’t want the world to see me, ‘cause I don’t think that they’d understand.* When we finally

came home from the hospital I had many people who wanted to come by to see us, so I had a big “welcome home” party for everyone to stop by and say hello. While many people thought I was doing too much by inviting everyone over, I had ulterior motives: I wanted to get it all over with at one time. I could entertain everyone, answer any questions, let them make those “Oh you poor dear” sympathy looks, and then send them away so that I could be left in peace. Although I invited over 200 people to stop by the house that day, my visitors were not met at the door by my authentic Self but rather some façade that was hoping to appear intact. I didn’t want the world to see the authentic me because I wasn’t sure that they would understand.

Other songs remember the events of the Bradley ordeal, even when I have forgotten the details. I am an avid watcher of the show, *American Idol* (Lythgoe, 2008). The song “Home” written by Chris Daughtry, a former *Idol* contestant, was played each week of the show’s sixth season as a contestant was voted off the show. When Bradley was finally discharged from the hospital, I wrote in my online journal the closing lines to the chorus, “*But these places and these faces are getting old/I’m going home*” (Daughtry, 2007). Still to this day, when I hear “Home” playing on the radio, I have difficulty fighting back the tears. I often feel silly admitting to myself, and especially to others, that a song can stir up so much emotion.

Music must possess some type of healing power because there is an entire branch of therapy that employs its use with patients. In *Musicophilia*, Sacks (2008) chronicles stories of patients who have suffered from numerous neurological ailments yet have shown remarkable improvement through the aid of music. Patients who appear emotionless are suddenly transformed when they hear music. But when the music ceases, they are transformed back to their pre-emotion state, as if nothing transpired. The healing power of music is intriguing to me. I often find that when listening to music in solitude, emotions that I have repressed find their way

to the surface and beg to be dealt with on a more intimate level. It almost seems that I am able to communicate my feelings more accurately through listening to music than by talking with others about my dilemmas. Is it possible that listening to or playing music could serve as a substitute for personal relationships? Storr (1992) does not agree completely, but entertains the idea. He says that music can provide a source of comfort for people who do not desire to be alone. He describes the difference between solitude (wanting to be by yourself) and loneliness (not wanting to be alone, desiring relationships). He uses the example of one turning on the radio while at home or in the car so not to feel alone. I am so accustomed to hearing my children's voices in the backseat while I am driving that when they are not in the car with me, there is a silent eeriness that almost beckons me to turn on the radio. With my hectic schedule, times of solitude are rare occurrences that I should embrace when afforded the opportunity. But when I turn on the radio, I may be missing out on the benefits of doing "soul work" (Morris, 2008) that oftentimes accompanies solitude. On the other hand, music could possibly tap into parts of my soul that remain concealed, activating a sort of work to begin that may have otherwise been stagnant.

Music has a way of uniting people, physically and spiritually. This is why music is often used during specific events in life: graduations, weddings, funerals. In times of joy and sadness, music is played and people bond emotionally. In reference to people attending a funeral, Storr (1992) comments that "[t]hey will certainly be sharing some aspects of the same physical experience at the same moment, as well as sharing the emotions aroused by the funeral itself" (p. 24). At my grandmother's funeral, I sang "Amazing Grace," one of her favorite songs, at my mother's request. Recently, we sang this song in church and I watched as tears streamed down my mother's face. Music has a way of remembering, recreating moments. I recall a song by

Trisha Yearwood, “The Song Remembers When”: *For even if the whole world has forgotten/the song remembers when* (Prestwood, 1993). Memories that have been temporarily forgotten can be revived through music. Is it possible for music to restore some sort of balance in the psyche? This could be the answer Storr (1992) was looking for when he questioned why music fills his mind when it is “unsummoned and perhaps unwanted” (p. 125). He notices that while performing routine tasks that require little concentration, he finds himself humming a tune or singing a song. He also considers times when a song randomly pops into his head for no apparent reason, later to recognize that there is a connection between the song and a current life event. Does music help to keep the rhythm of the psyche, helping to put order in chaos?

Music has a way of photographing a particular moment, allowing me to recall the memories at a later time. For me, music has become a sort of “Mystic Writing Pad” that Freud (1925) speaks about. Memories, and their accompanying emotions, can be problematic. What is remembered is not always what actually occurred. Likewise, what occurred may not be remembered at all. Freud suggests writing out important events, especially focusing on the emotional aspects, so the memories can be later examined in their unaltered states. He suggests two places to write out emotions: with pen and paper or with chalk and slate. Both methods of writing have positive and negative facets. As the pen imprints the textualized emotions onto the paper, a “permanent memory-trace” (Freud, 1925, p. 207) is created which is preserved for an infinite length of time. However, the paper loses its value if the memory is no longer of interest or if it no longer needs to be retained. Thus, the paper must be thrown away. I think about all of time, the countless hours, I spent writing in the online journal during Bradley’s hospitalization. I vowed to print off the pages and have them bound in a book, a memory book of sorts to help us reflect on the Bradley ordeal. Four years later, the pages of my online journal remain in

cyberspace, unbound and almost forgotten. It is not that the memories are no longer of interest; they most definitely could serve as reference as I write this pathography. I believe I have not bound the journal because part of me no longer wants to retain the memories of the Bradley ordeal. It is possible that my unconscious does not want me to have a hard copy of the ordeal's details, forcing the memories to remain in cyberspace with the journal's pages.

To record temporary memory traces, Freud (1925) suggests using chalk and a slate. The writer retains the memory as long as deemed valuable and then the slate can be wiped clean. Unlike the paper that must be thrown away after it is used, the slate retains its receptive characteristic and can be reused numerous times to record memories even though the original memory is gone. However, in order to put fresh memories on the slate, the old memories must be discarded. A slate does not provide any means of storing permanent memories. Freud's descriptions of the paper and slate as means of recording memories makes me question how I have chosen to record my memories. There are some memories that I have written on the paper, such as the joy I felt when I first held Bradley in my arms. These memories I want to relive time and time again. These are the memories that ground me emotionally and pull me through the difficult times. Although, there are other memories that I have tried to wipe from the slate, such as the feeling I got when the pediatrician broke the news to me that something was seriously wrong with Bradley's heart. These memories haunt and traumatize, sending me into a dark retreat.

Employing Freud's two suggestions of memory recording, I am left with two choices: either record memories on surfaces that are renewable or on surfaces that must be destroyed after being deemed invaluable. But Freud posits that neither means accurately portrays how memories are actually recorded. He suggests that memories are recorded on a type of "Mystic Writing

Pad” (Freud, 1925). I had forgotten about these simple three layer pads of cellophane and wax that I scribbled on in the backseat of my parent’s car. I would draw a picture or write a few words, and then separate the cellophane/wax paper from the wax backing to magically erase my work. The cellophane sheet is what is actually being written on, pressed upon by the stylus. Although no marks are being made on the cellophane, it serves as a transparent medium of transference. The translucent wax paper actually receives the stylus’ imprint. Whatever is written is recorded on the wax paper. Lifting the papers off of the wax backing erases the imprints on the wax paper, making the paper clean as if it were never altered. The surface is now cleared, ready to receive the next set of imprints from additional stimuli. However, close examination of the wax backing will show that the original impressions are still predominately legible. While they may no longer appear on the surface of the writing pad, the impression’s remnants linger. Similarly, memories can be superficially erased, but their effects, having been permanently imprinted on the mind, linger. Memories of painful events may be forgotten, but they have not disappeared permanently.

To attempt to recreate experiences from memory can be messy, similar to how it is difficult to accurately reproduce the original imprint on the writing pad with the exact pressure and stroke of the stylus. Once the imprints have been erased they cannot be reproduced to resemble the original imprint. While the wax backing remembers the original imprint just as the unconscious remembers the details of the original experience, it is difficult to reproduce the image on the surface. This notion of irreproducibility is problematic when trying to write in an autobiographical style. However, it is possible that the unconscious does not allow the images to be reproduced in original format in hopes of protecting the conscious from re-experiencing traumatic events.

Toni Morrison's (1987) *Beloved* is an important literary piece revealing how traumatic events are never completely forgotten and, more importantly, how they can resurface from deep within the unconscious. *Beloved*, similar to illness, is not linear. It shifts from plot to plot, past to present, and everywhere in between. The story is loosely based on the personal account of Margaret Garner, a former slave. Yet, Morrison's vivid descriptions of the slave life are far from fictionalized. *Beloved* has been met with such high regard because, as Susan Bowers illuminates, "most original authors of slave narratives did not reveal the true horror of slavery for fear of offending the white abolitionists, or because they themselves did not want to dwell on the painful memories" (in Bloom, 2004, p. 16). Dwelling on this thought for a moment, I pause to reflect on how I have recorded the memories of my experience with illness. I do not mean to suggest that my dwelling with illness is near at the same level of trauma as those who dwelled in slavery. However, I wonder what experiences I have omitted for fear of offending someone. Or, what experiences have I omitted because they are too painful to remember? And, how do both of these omissions affect the authenticity of my pathography? Bowers believes that Morrison's rendition of the slave narrative "is one way of giving African Americans back their voices" (in Bloom, 2004, p. 16). Similarly, pathography is one way of giving the ill person back her/his voice. I do not intend for my pathography to be simply a story of illness. It does not chronicle day by day events of what happened here and there. Instead, my intent is that it captures my complex dwellings with psychological pain which can be viewed reflexively to help me understand my illness.

Traditional slave narratives tell the physical journey of escaping slavery, "the individual's life in slavery, escape, and journey to freedom" (Bloom, 2004, p. 104). Likewise, stories of illness often depict the ill person's battle with illness, course of treatment, and restoration to

health. Both slave narratives and stories of illness of this magnitude are plentiful. However, Morrison's (1987) account reveals that the process of escaping slavery (or illness) "must be repeated twice: first to leave physical enslavement by whites and second time to escape the psychological trauma created by their brutality" (Bloom, 2004, p. 104). *Beloved* begins with the characters being numb to their experiences, incapable of feeling or working through the complex emotions created by traumatic events. It is unsettling to think that in order for healing to begin one must relive the painful events. This is in distinct contrast to how I initially dealt with the trauma of the Bradley ordeal. I tried to push the pain away, somehow convincing myself that if the pain did not exist then it would disappear. Working through the pain, meeting it head-on as I have relived the traumatic events, has caused me to fall apart. Ironically, I feel more complete in my brokenness.

Beloved's main character, Sethe, a runaway slave, copes with the trauma of slavery by trying to remember as little about her past as possible. Blocking out her past becomes her defense mechanism, as I am sure it is for many people who have experienced significant levels of trauma, like my Grandpa who was a P.O.W. in World War II. However painful, memories stored in the unconscious will find a way to resurface, oftentimes without warning. I was once told that time is a healer of pain. In other words, as time separated me from the events of the Bradley ordeal, the pain I experienced during this time would subside. But, no matter how much time has passed, Sethe cannot separate herself from the trauma she experienced as a slave, illustrated by the paradox of marveling at nature's beauty while remembering the horror of the slave boys hanging from the trees. Similarly, as I view pictures of my friend's new baby in the hospital bassinet, I cannot help but visualize Bradley laying in his bassinet covered in a tangled

web of tubes and wires. Time might help to separate one from trauma, but it does not help to erase the memory. Sethe comments:

It's so hard for me to believe in it. Some things go. Pass on. Some things just stay. I used to think it was my rememory. You know. Some things you forget. Other things you never do. But it's not. Places, places are still there. If a house burns down, it's gone, but the place—the picture of it—stays, and not just in my rememory, but out there, in the world. What I remember is a picture floating around out there outside my head. I mean, even if I don't think it, even if I die, the picture of what I did, or knew, or saw is still out there. Right in the place where it happened. (Morrison, 1987, p. 35-36)

It is unclear who, or what, “Beloved” is. She could be a real person, because Sethe and others interact with her. Or, she could be a ghost, as textual references are made describing her mysterious appearance. Still, she could be a collection of memories, or a part of Sethe, possibly Sethe's Other? Whoever, or whatever, Beloved is, it is apparent that after she arrives “Sethe's repression of countless painful memories begin to lift. Beloved generates a metamorphosis in Sethe that allows her to speak what she had thought to be the unspeakable” (Horvitz in Soloman, 1998, p. 95). Heinze (in Soloman, 1998, p. 205) further elaborates that “Like a childhood trauma, Beloved comes back in snatches until finally her history is retold, a discovery process shared by Morrison, her characters, and the readers as the primary step to collective spiritual recovery.” Beloved sucks the life out of Sethe, nearly destroying her as she demands the retelling of stories time and time again so that Sethe has to remember the painful events. As much as I would like to forget many of the painful memories of the Bradley ordeal, they are forever imprinted on the wax backing of my mind's Mystic Writing Pad. Many of them lay just under the surface and only require a little coaxing to resurface, which they do “whether we want it to or

not” (Morrison, 1987, p. 14). Others I have forgotten, but not entirely; these memories are imprinted in my unconscious and shape my personality, whether or not I am conscious of their affects.

Memories serve as a snapshot of time, a mental photograph of lived experience. However, the developed photograph is sometimes a censored translation of the actual representation. Serres (1997) states, “[a]s soon as we experience something as time, as soon as we become conscious of the dimension of time as such, the memory is already in play; in other words, the pure present knows no specific consciousness of time.” He recognizes the act of remembering as a three stage process. The first stage, Day, is when memories are made; activities take place, interactions occur, and dialogue is exchanged during this process. The storage of memories occurs during the Night. “The night remembers the day without containing it; this nothing remembers something; memory, which is musical, does not take up room. The voices enter in silence, and there they work, in the dark, in the light of intelligence” (Serres, 1997, p. 22). Morning arrives and memories are remembered. What has been concealed for an unspecified amount of time is now unearthed, reborn. The images of places, events, and interactions are brought up from the depths of the soul, “...resuscitated from the empty tomb” (Serres, 1997, p. 22). Once forgotten, these images now possess new meaning, have a different light shed upon them. They are recreations of actual events; they are not exact replicas, but are developed so that they give meaning to the individual.

Serres’ (1997) three stage process for remembering can be juxtaposed with the song “Memory” (Nunn, 1982) as sung by Grizabella in *Cats*, a has-been glamorous cat who is now only a fragment of her original self. *Cats* was the first Broadway musical I ever experienced. Although it has been over a decade since I first saw the performance, my mind remembers that

night as if it were only yesterday. Seeing Grizabella propped against a lamppost on the stage of the Fox Theater in Atlanta, I feel the tattered cat before me is a reflection of my Self. Like Grizabella, I am captivated by nostalgia, longing for a time that no longer exists when I too was at the peak of Daylight and everything was in my favor. Midnight arrives, not literally but figuratively; as I am entranced by Grizabella's song I do not recognize the foreshadowing of midnight in my own life. Over a decade later, the Bradley ordeal would begin at the hospital in Atlanta a little less than ten miles from where I was sitting at the Fox Theater. In my time of illness dwelling I have gone through mourning and have now arrived at Morning. By spending time writing about my illness dwellings I am beginning to make new meaning of my memories. I believe *a new day has begun* (Nunn, 1981).

Bridging the Gap between the Known and Unknown

As a child I had a particular fondness for horses and, for a brief time, took riding lessons from a family friend. I felt an overwhelming sense of power sitting atop my horse's arched back as I galloped around the field, the pounding of the hooves on the dirt keeping time with the pounding of my heart in my chest. Although my equestrian training was short-lived, I still find myself in awe of this marvelous creature. When I am stressed and need to collect my thoughts, I drive to the stables near my workplace and pull over to the side of the road. As the horses graze peacefully in the pasture, unaware of the automobiles speeding down the road only feet away, I feel a sense of serenity envelop me. I cannot pinpoint exactly what it is about horses that capture my attention. Maybe I can relate to the distinct contrast between their gentle and wild demeanors. I generally handle minor fluctuations with ease until something comes out of nowhere which startles and sets me off running. I am baffled at how a horse's slender legs are

able to withstand the overpowering weight of its body when I feel as if my own legs are crumbling from the weight of my burdens. Even more, I feel a deeper connection when I look into a horse's eyes as if I am looking into the eyes of a human-like creature who understands parts of my Self that even I do not understand.

For several years, I have had dreams about horses. I do not remember any details regarding the horse's color or other specifics such as what has occurred in my dream. My dreams make little sense to me. Freud (1952) recognizes that dreams are often filled with trivial things that appear to be of little interest of us when we are awake. However, he suggests that dreams function as the "guardians of sleep" (Freud, 1952, p. 65). The mind organizes external stimuli into dreams so that one may remain asleep. Doll (1995) further elaborates on the purpose of dreams, suggesting that they "can heal, prophesize, compensate, illuminate. Their power is immense...Dreams can re-mind us of what we need to put back into our minds" (p. 5). What are my dreams about horses trying to "re-mind" me? What am I trying to repress that finds its outlet in my dreams? I believe that horses, as well as other animals, can offer a source of healing that is sometimes disregarded. The healing power of horses is exhibited through equine-assisted therapy and its benefits for children with various medical conditions. Could the horses in my dreams provide some sort of healing power for me? Freud (1978) states that dreams are a form of "wish-fulfillment" (p. 33). He uses a personal example suggesting that when he eats salty food before retiring to bed, he dreams he is taking a long, cool drink. The dream awakens him and he has the desire to quench his thirst. However, Freud (1952) also stresses that dreams are the language of the unconscious. Horses are powerful, capable of pulling heavy loads long distances. Do I desire to be more like the horse, so that I am able to bear my load for the duration of the journey? Jung (1974) states that the horse archetype represents the "non-human

psyche, the subhuman, animal side, the unconscious” (p. 107). It is interesting to note that the archetype of the mother also represents the unconscious. Jung (1959) puts responsibility on the mother as the carrier of the archetype “because the child lives at first in complete participation with her, in a state of conscious identity” (p. 102). I am reminded of Lacan’s “mirror stage” (Roseboro, 2008) and the child’s realization that s/he is apart from yet still a part of the mother. My mother was the first to introduce me to horses. I loved to hear stories of how she used to ride her uncle’s horse at his farm. This admiration for horses unites mother and daughter. Are the connections among the horse and mother archetypes, my relationship with my mother, and my admiration for horses purely coincidental? Or is my “unconscious [slipping] through the cracks of conscious control?” (Doll, 1982, p. 198)

Jung (1959) believed that the unconscious was multi-layered, a collective unconscious of universally shared archetypes which were innate. Although archetypes are unconscious, they become conscious as they are individually perceived and expressed. “Archetypes are complexes of experience that come upon us like fate, and their effects are felt in our most personal life” (Jung 1959, p. 30). Jung (1959) identifies three primary archetypes: persona (personality), anima/us (the unconscious), and shadow (the repressed unconscious). These three are combined in what Jung refers to as the “self” which is the collective wholeness of the other three. In *Re-visioning Psychology*, James Hillman (1975) uses Jung’s archetypes to investigate the notion of the “soul.” He suggests that “we have all become de-souled” (Hillman, 1975, p. 3) by ignoring the importance of the personification of the unconscious. The “soul is always in the thick of things: in the repressed, in the shadow, in the messes of life, in illness, and in the pain and confusion of love” (Moore in Hillman and Moore, 1989, p. 113). I think of how the care of the soul is neglected, especially in times of illness. The physical body is usually the primary

focus. The mind is given medications to numb the pain that the body inflicts. Even the spirit is attended to by the church who regularly prays for those who are ill. Yet the needs of the soul, “the living thing in man...which lives of itself and causes life” (Jung, 1959, p. 26) are overlooked, repressed until another time. Marla Morris (2008) uses Jung’s archetypes as a way of working through illness in her book *Teaching through the Ill Body*. She discusses the personal meaning of the practice of bodyart, specifically her tattoos of tigers. She states, “I began getting Tattoos because I felt that I needed power to fight my illness. So I chose Tigers” (2008, p. 89). Morris suggests that she draws strength and healing through her tattoos. I was intrigued by the notion that something, such as tattoos, could have such a healing effect on the soul, which in turn helps to heal the physical body as well. For me, tattoos represent pain. I am terribly afraid of needles and I could not fathom intentionally subjecting my body to the pain that needles inflict. However, I question if this practice allows Morris to feel control over the pain her body is already experiencing. Morris (2008) mentions the “uncanny” (p. 90) fact that she was born under the sign of the Tiger. Curious, I researched and discovered that my birth date is five days shy from being born under the sign of the horse. Uncanny, indeed.

Jung (1959) states that archetypes are often expressed in myths or fairytales, both of which can provide an outlet for the unconscious to phantasize, to free-associate. Storytelling through myths is one way to navigate through the “middle passage” (Serres, 1997). Roseboro (2008) states:

Classical myths/narratives held deep possibility; they could serve as a translating medium, a way to bring the unexplainable into conscious explanation. And, they could bring the unconscious, the unexplainable into the realm of lived experience even though this lived experience might ‘live’ only in the text of a classical narrative. (p. 31)

In *The Hero with a Thousand Faces*, Joseph Campbell (1949/2008) uses the myth of the hero's journey to depict the individual's struggle for individuation. Although the term "hero" is of masculine connotation, it not the sex of the myth's lead player that concerns but rather the individuation process that occurs along the journey. The hero "signifies the potential anticipation of an individuation process which is approaching wholeness" (Jung 1959, p. 166). The individuation process requires the hero to work through the anima/us and shadow. Campbell (1949/2008) suggests that the hero quest is summarized in three stages: the departure, the initiation, and the return. To depart for the journey, the hero must receive a call. For an ill person, this is often a sign or symptom, recognized by either the individual or a physician. Initially, this call is often ignored; recognizing its existence requires the ill person to consider what lies ahead. However, a time comes when the call must be answered. In preparation, the hero seeks supernatural aid to equip for the journey. The initiation stage begins when the hero seeks to alleviate the body from the sign or symptom. The hero is traveling in a world that is unfamiliar. Experiences gathered along the way will shape the hero and affect his persona when returning to the previous world. Ironically, it is possible that the hero does not want to return to the previous world. Having first denied the call for departure, the hero has become accustomed to the new world and struggles with the idea of leaving. Over the course of the journey the hero is transformed, born again, afforded the opportunity of a "new beginning" (Balint, 1968). One way Balint (1968) defines "new beginning" is by describing it as a "regression for the sake of progression" (p. 132). The hero is able to return to the beginning, having redefined the Self, and begin anew. Marlan (2005) details what happens to the Self in this process:

In that [death-rebirth] process, ego identity dies or is symbolically killed along with one's former perspectives of oneself and of life...What Jung calls the Self is not destroyed.

What is killed or analyzed to death is the negative (destructive) ego or false (inauthentic) Self. The primary Self as an archetypal image of the Supreme Being remains connected to the secondary, reconstituted ego and the true (authentic) self, which can be renewed and live its personal myth with joy. (p. 73)

I must pause to emphasize my concern for individuation throughout the journey. It is not my intent to employ the hero quest as a means of romanticizing illness. During my travels I hope to obtain experience which will further unify my Self. It is also my desire to serve as encouragement to others who are ill. I am concerned for the individual's story, for I feel that this part of the illness experience is largely ignored. Frank (1995) would label this type of narrative as a "quest journey" because the ill person is able to voice her/his story; this is in opposition to restitution narratives (focus placed on the remedy) and chaos narratives (focus placed on suffering). Quest narratives consider marginalized ways of being ill. "As the ill person gradually realizes a sense of purpose, the idea that illness has been a journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking" (Frank, 1995, p. 117). For me, the journey is about perseverance, not conquering.

I was recently asked to reflect on my teaching style for a professional development class. I was having difficulty in writing anything of value, so I asked my students to describe my style. An overwhelming majority of my students commented on how I use stories to bridge the gap between the known and the unknown. I feel that this is an accurate description and possibly why I am drawn to Jungian psychology. Jung (1959) states:

Just as the archetypes occur on the ethnological level as myths, so also they are found in every individual, and their effect is always strongest, that is, they anthropomorphize

reality most, where consciousness is weakest and most restricted, and where fantasy can overrun the facts of the outer world. (p. 67)

Jung employs archetypes, scientific concepts (alchemy), and stories to unify the Self and ourselves. Doll (2000) suggests the use of fiction in understanding the educational experience contending that fiction is more than a literary writing style, but a way of insight into the psyche. “[R]eading literary fiction is not an ‘only’ experience. On the contrary, fiction—more than fact—teaches wisdoms about the human condition precisely because fiction connects readers with what courses within themselves” (Doll, 2000, p. xi). Writing from an autobiographical style, Doll encourages readers to examine metaphors and myths as a way to better understand the self. Curriculum theorists encourage the writing of stories with multi-layered elements in hopes of fostering “complicated conversation” (Pinar et. al., 2004, p. 848). Although I write from an autobiographical stance, it is possible that some of my writing may be considered fiction. Time is multi-faceted and memory is not representative of actual occurrences. Thus, what is written is only an interpretation of the writer’s experience. And even still, what is perceived by the reader may be interpreted in a way that is not in alignment with what was intended as written. While my work does not employ the literary elements in the same manner as Doll’s work, I do feel that I have a story tell that will hopefully cultivate “complicated conversation” and possibly give encouragement to those who are willing to listen.

A New Beginning

In retrospect, the most challenging part for me in coping during this time has not been the medical aspects of the Bradley ordeal. Instead, I have found difficulty in finding the time needed to deal with my own emotions surrounding the situation. Had I not been encouraged by those in

my academic circle to develop my dissertation topic around the Bradley ordeal, I am not sure if I would have ever allowed myself the time necessary to work through my emotions. I tend to portray myself as the upbeat character, a Pollyanna of sorts, striving to look at the bright side of life. I find that I am better accepted by those around me if I opt to fulfill this role. After all, who really wants to befriend Debbie Downer? Although, Eigen (1996) comments that “High-energy individuals can suffer massive depressions and depletion, while low-energy individuals persevere” (p. 10). It is possible that maintaining this consistently optimistic façade only encourages further repression of my emotions. This conscious repression will serve as a coping mechanism, but only for a matter of time. Repressed emotions demand their time in the spotlight as well and will find the most inopportune times to take center stage.

I once believed that I was an open and honest person around others. However, I now believe that these characteristics are only true if all is well in my life. I am comfortable allowing the public to glimpse into my private world when my life is surrounded by a white picket fence and beautiful flowers in the garden. Yet, when adversity strikes, I hastily lock the gate to keep others out and draw the curtains so that no one may peer in through the windows. I may throw a few flowers in the flower bed to camouflage the neglect of the exterior, but the flowers are of the artificial kind, like those that my neighbor has in her front yard which do not wither in the cold but fade over time, adding to the grotesqueness of her dilapidated home. If afforded adequate attention, my neighbor’s house could be transformed to reflect the beauty it once portrayed. Similarly, my Self can be transformed if I allow proper time to dwell with the complex emotions that have accompanied illness.

When one is overcoming acute illness, time is needed for rest and recuperation so that the body can be restored to a state of health. Although Bradley’s illness cannot necessarily be

classified as acute, his external appendages providing support for oxygen and nourishment were short-lived compared to others who are permanently attached to their appendages. It was almost six weeks before I felt that Bradley's exterior had been restored. For the first time since 6:30 a.m. on Friday, April 13, he was freed from feeding tubes and oxygen support. Finally, I was able to see my baby's face without medical tape covering his cheeks. Now, almost four years later, one would never know by looking at him that he had such a rough start in life. He has been restored, as much as possible, to his original health. But I question whether the same is true for me. Except for the stretch marks across the abdomen that will never be flat again, I have recovered physically from childbirth. However, I am not convinced that I have recovered emotionally from the Bradley ordeal. I feel the restoration of the emotional dimension is an enduring process from which my personal life may never be fully restored.

Unlike fairytales, there are no "happily ever-after"s in illness. Illness is not a part of "God's will" as I was encouraged to believe. Illness just happens. However, illness happens to many people on many different levels. Susan Sontag (1978/1989) reminds:

Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (p. 3)

The Bradley ordeal created chaos in my otherwise linear life. My life was not supposed to be like this. I had planned to go to the hospital on a Thursday evening to induce labor. My husband and I picked our oldest son up from school and headed to the mall for a few hours while I waited for the initial signs of labor to begin. Bradley was born just before midnight. Textbook, orderly, just as my "pre"-crastinating mind had planned. Then, as quickly as a horse grazing calmly in a

pasture is startled and bolts running, I was obliged to enter the “kingdom of the sick.” Eigen (2005) states:

Inside the heart there are different kinds of smiles. Simple, joyous heart smiles...[Blank smiles]...Anguish comes again, acute stabs, hearts shake in shock, stiffen, close. And after going through something, opening begins again. A growing faith rhythm. This is the core of our work, the very core. (p. 49)

My heart smiled when I first held Bradley in my arms. Then I learned of his heart defect. Blankness, numbness set in. I felt nothing and everything simultaneously. My heart began to close as they opened Bradley’s heart. Hard-hearted, arteriosclerosis of the emotional heart. I had lost my elasticity, impairing the ability of my emotions to flow. Slowly, I am finding myself back into rhythm, but this will continue to take time. I do experience those “simple, joyous heart smiles” on occasion. As I have been writing, Bradley has been next to me coloring on some of my notes and singing his version of the “ABCs.” These are the simple things that make life bearable and make me smile. However, even my dear friend Lauren, who has walked beside me throughout the entire ordeal, could not help but shed a tear when Bradley showed her his surgery “boo-boos” recently. The scars on his chest are constant reminders of the scars that are on my heart. I am not depressed really. I just feel alone. I am in what my students refer to as a *funk*.

When I look into the mirror, I often see someone other than myself, my Other. I feel like the infant in Lacan’s “mirror stage” (Roseboro, 2008) who does not recognize that the image is that of herself. This image staring back at me is a stranger. I am not the person I portray myself to be. Thus, the silencing of my complex emotions most likely stems from my feeling that I do not meld with a particular group. Freire (1970/2007) says that this type of omission is a form of oppression. I am marginalized, cast to the side, left to fend for myself. Eigen (2005) states:

We are creative beings capable of rediscovering, redefining, recreating ourselves and contributing to the lives of others. Some take this for granted. Some overuse, exploit and abuse it. Some do not rise to the struggle...What we produce reflects who we are, creates who we are in multifarious ways. (p. 40)

I am not the same person I was when I began my journey into the field of curriculum studies. I have embraced the opportunity to be transformed into something new. Woolf (1929/2007) suggests that we cannot begin to help others if we do not know our own soul. For this reason, illness narratives are of utmost importance. By exploring my narrative, I have begun to come to terms with my repressed emotions. They are woven together in the form of an ugly monster that resides in the depths of my soul. Although it has been painful to allow these emotions to emerge, it has been therapeutic. It is my desire that my pathography helps to give voice to those dwelling with illness so that they too may have a place in the canon.

CHAPTER 5

DEFINING “GOOD-ENOUGH”: THE MOMMY DILEMMA

You can't go home to the old things you grew up with: the house, the parents, the furniture. But you can come home again to your self because you never leave your self...Home is my self, not my house. (Doll, 1995, p. 165)

Mark Taylor (2009) states, “Life is a tale of leavings” (p. 66). Similarly, my pathography has been a tale of leavings. Just as Bradley was forced from the comforts of my womb and into the world, I was forced from the comforts of a life I had imagined into one of illness. Given no other choice, I left my baby in the care of strangers in hopes that he would be given the chance to live. I was forced to leave my home to go to an unknown city where my child would be nurtured in a manner that I could not provide. Upon leaving the hospital in Atlanta, I was saddled with the burden of caring for a child with special needs. I begged others to leave me alone so that I could sort out my emotions. But, in reality, I only wanted to conceal my anxiety of dwelling with illness. I left my emotions hidden under the rug, swept from the public’s eye so that I could appear intact. In doing so, I neglected my needs, and in many ways, Bradley’s needs. Leaving Bradley’s needs unattended makes me question my worth as a mother.

Dwelling with illness has forced me to leave the comforts of the known terrain and venture into the unknown, uncharted waters. But here, as an active resident in the “kingdom of the sick” (Sontag, 1978/1989, p. 3), the newfound knowledge I have gained about my self is immense yet, in comparison, is minimally revealed within the pages of this text. In the following passage, Taylor (2009) captures my conflicted emotions regarding the relations within my self and with others as I have dwelled with illness:

No matter how hard I think or how much I analyze, I can never know myself by myself but must always come to myself in and through an other. This other bears many names—it can be a parent, teacher, or pastor whose gaze we flee or guidance we seek. The other can also be the enemy we struggle to destroy, the beloved in whom we long to lose ourselves, or a child in whose eyes we see our own reflected. There are, however, different others that are within rather than without. They might be ghosts of the departed or demons that possess us. The deeper I probe, however, the more I suspect that beneath, beyond, or within these uncanny spirits, both holy and unholy, there is an other other I can never fathom, that some name the unconscious and others name God. I am no longer sure where I end and these others begin, and thus the story I thought was my own is also the story of many others. (p. 5)

My pathography is as much a reflection of my Self as it is a reflection of the influence others have had on my illness dwelling. Bradley is one “other” of significant consideration that has shaped my Self concept. Over the past four years of his short life he has brought out the best, and at times the worst, in my self. Through his illness, and subsequently my own illness, he has taught me what it means to live. Because of him, othered parts of my Self which were previously hidden have been exposed. At times revealing these parts of my Other have been traumatic, specifically when facets of my Self were exposed that suggested I may not be qualified as a “good enough” mother. Still, I recognize there are parts of my Self that are nameless and faceless and may never be illuminated, that are buried deep within that equally influence my pathography.

While grappling with the complexities of my illness dwellings I have struggled with the notion of how the others “without” have contributed to my concept of self image. I have felt

caught in a paradox of needing to be accepted by those in my circle and wanting to illuminate the uniqueness of my illness. Why is there an “overwhelming fear of the stranger that permeate(s) our culture?” (Silin 1995, p. 212). Laplanche (1999) believes that each of us has at least one “other.” Drawing from Freudian theory, he suggests that everyone has what is known to society to be the “person” as well as one or more “others.” It is difficult, if not impossible, for one to determine the dominant being: the “person” or the “other.” Oftentimes, the “other” is one with repressed feelings which may have come from lived experiences in previous years and will only emerge if provoked. In turn, the “other” may actually be the dominant being, whereas the “person” only emerges in the sanctuary of intimacy. In this same manner, I live a doubled life, maintaining the expectations of society while balancing the otherness within.

Attempting to balance the notion of societal acceptance and distinct individuality is a psychological mind-game. At times the conflicting energies can make me feel as if I am losing myself. Lather (2007) views “getting lost” as “not so much about losing oneself in knowledge as about knowledge that loses itself in the necessary blind spots of understanding” (p. vii). Throughout my dwellings with illness, I have stumbled upon those “blind spots” within my Self, facets that were always present but had not yet been illuminated. Once revealed, these previously hidden parts of my Self required attention, an understanding of their place within the total realm of my being. Similarly, this is how one should approach curriculum. It is not enough to know curriculum; one must also seek understanding. I am seeking a place of understanding within my writing. However, my understanding is two-fold. First, I seek to better understand my Self as I complete this written portion my pathography. I have come to learn that through writing I am able to tap into my unconscious as the words drive out repressed emotion that demands attention. Secondly, I desire for my readers to gain an understanding of the ill

experience and the difficulties of dealing with the societal pressures of being “normal.” As Doll (1995) reminds me, “[Y]ou can come home again to your self because you never leave your self...” (p. 165); thus, I will heed Doll’s suggestion and come back home, to my Self, to investigate my Self as a mother dwelling with illness.

Home, Sweet Home

“Home is where one starts from” (Eliot, 1943, In 190 pg 31). These words inspired the title of a collection of essays by psychoanalyst D. W. Winnicott (1986) and capture the essence of psychoanalysis and curriculum studies: working from within, from Home. Taylor (2009) suggests that “Home is less a place than a state of mind” (p. 38) and although things may be settled here, Home does not necessarily provide security. Similarly, my Home, my Self, is not always a place of security; I oftentimes feel anxious, especially when my Other visits and wants to chat awhile. But I am beginning to learn to cope with the visitations of this sometimes unwelcomed guest. She, my Other, seems to appear most often when the others have retired for the evening, specifically when I am afforded the time to reside alone with my writing. Although She reveals herself in singular fashion, She represents the totality of the Others who are constantly in my midst. As we chat over a cup of coffee we tend to disagree, particularly when She is identifying areas in my life that need to be addressed. However, this dialogue exchanged between my Self and my Other ultimately helps to foster unity between these two complex parts of my being.

Home is where the individual’s journey begins. Storr (1992) explains, “We all have to ‘leave home’ by severing some of the ties which bind us to it, so that we can make our own way in the world and achieve a new home of our own” (p. 82). It is necessary to sever “some of the

ties which bind” so that the individual may embark on her/his own journey. However, s/he may not always heed the initial call to the journey; s/he may need some coaxing to be weaned from the comforts of Home. The title for Grumet’s (1988) book *Bitter Milk* is derived from the concoction given to babies in Sri Lanka in order to be weaned from the breast. Before a young woman is to be married, she is again given the “bitter milk” as a reminder of being weaned from the breast, and possibly as reassurance that this is not the first time that she has been encouraged to leave the mother, the Home. Serres (1997) also encourages the child to depart from the mother in order to find her/his own way:

Departure requires a rending that rips a part of the body from the part that still adheres to the shore where it was born, to the neighborhood of its kinfolk, to the house and the village with its customary inhabitants, to the culture of its language and to the rigidity of habit. Whoever does not get moving learns nothing. (p. 7)

Serres’ words have held great significance for me as I have dwelled with illness. Remaining stagnant while dwelling in the confines of familiarity would be uncomplicated; however, nothing is learned if I never venture into the unknown. Dwelling is an active process in which one encounters flux; thus, one cannot be stagnant and completely embrace the act of living. Initially, I found great difficulty in beginning my writings about my illness dwelling. I wanted to ignore illness, pretend it did not exist, so that I could maintain the “rigidity of habit” that I had become accustomed to maintaining. But, my illness is encompassing; the call to embark on the journey of writing about my illness could no longer be ignored.

Several times throughout my pregnancy with Bradley I experienced pre-term contractions, calls for Bradley to be delivered into the world. However, Bradley was not ready to leave the confines of what he had known to be familiar, and ignored the calls. Finally, the call

could no longer be ignored as my body rejected his and thrust him into the “kingdom of the sick” (Sontag, 1978/1989, p. 3). In his departure Bradley was ripped from my womb and from the lifeline that my placental blood supply was providing him. While he was a part of me I was able to sustain his life. When he was ripped apart from me, I could no longer provide what he needed to continue to live. The detection of a fatal congenital heart defect required him to be ripped from my arms and placed in the care of strangers who could provide for him better than I could. Ripped, rip, R.I.P. Without my placenta, Bradley was dying; without Bradley, I was dying. Eigen (2005) states, “The radiance of new life makes one’s own heart new, makes one’s own heart shine with radiance” (p. 34). If the heart is not broken, this notion may be true. And it was true for me for a short period of time. My heart did “shine with radiance,” which was evident in my phone conversations with my friends as I announced Bradley’s arrival. But my heart was no longer radiant when I had to turn Bradley over to strangers who would now provide for his needs.

My heart was dark, hardened, and retreated while Bradley, who was once a part of me, was now apart from me. It was several days after surgery before I was able to hold my baby close to my chest, to again feel his heart’s rhythm in sync with mine. As we locked eyes for the first time in what seemed like eternity, I wondered what he saw staring back at him. Winnicott (1971/2005) suggests that “what the baby sees is himself or herself” (p. 151). The mother’s face is a mirror in which the infant sees her/his own reflection; the two appear to be one in the infant’s eyes. As the infant matures, s/he realizes that s/he is apart from the mother but somehow a part. S/He continues to come back to the mother, possibly to read her face to reconfirm her/his Home. Winnicott (1971/2005) suggests that “[i]f the mother’s face is unresponsive, then a mirror is a thing to be looked at but not to be looked into” (p. 152). Was my face unresponsive?

I am not sure what was reflected as I stared at this unfamiliar yet familiar part of myself. Is it possible that a deeper connection had been made, that the ragged, worn, violated body before me was a mere reflection of myself? Were Bradley and I, in fact, mirror-images of one another?

When connections are made between the child and the mother, the child is encouraged to keep coming back Home. I recognize that not everyone desires to “go home” in the literal sense. However, I do believe that most have a Home from which strength is drawn. Occasionally, it is necessary to slide into Home base in order to gain strength. Rounding third base, heading for Home, the ball is thrown to the plate, the catcher prepares for the tag, s/he’s.....SAFE! Home run! Or, run Home? One may also run Home to escape reality. The need to go Home could be conscious or unconscious. Segal (1991) speaks of Freud’s distinction between Fantasy (conscious) and Phantasy (unconscious). She comments, “One could say that generally for Freud phantasy is pretty close to day-dreaming. It is a wish-fulfilling idea which comes into play when external reality is frustrating” (p. 16). Phantasy is linked with defenses, or wish-fulfilling, to protect against harmful realities. Could phantasy then be an unconscious motivator for regression to return Home, back to child-like ways?

Regression allows the ego to go back to an earlier developmental stage so that it can thrust whatever adult-like situation that is troubling back into the unconscious because it cannot be dealt with in the present time or place. Balint (1968) encourages that most regression is benign because it creates a space in which issues can be addressed, but cautions that regression can become malignant if used frequently as a means of avoidance. According to Balint(1968), not all need regression, although many find it necessary to allow for adaptation to reality. As long as one goes back Home with the intention of progressing, then regression is healthy. Regression becomes problematic when one goes back and stays there.

Benign regression, as defined by Balint (1968), can be viewed as a type of nostalgia, a yearning for a return Home. The notion of nostalgia is evident in Heidegger's (1962) *Being and Time*. He argues that the world is comprised of false selves and false ideals which bring about anxiety. "Heidegger perpetually wants to go back, to return, to go home again, to some earlier, more primal, more immediate, less articulate, but definitely more authentic state or condition" (Megill, 1985, 119). Although Heidegger had a desire to return back to his literal home, his birthplace, I can identify with his desire to return Home, to a place of authenticity. I long to return Home to a time when I am ignorant of Bradley's illness. At moments when I feel anxiety squeezing the breath from my lungs, I allow myself to regress to the time of total euphoria when I first held Bradley in my arms. Regression can help me "get through" the tough situation that I am currently facing. Returning Home allows me to strip away the facades, come back to what I know is authentic. However, knowledge dispels ignorance and changes my perception of authenticity; once I learned of Bradley's illness, I could not change the notion that my imagined life of utopia was crumbling. Regression illuminates the sense of loss I feel for a time with my son that I cannot regain. When I return Home, I am not the same person I was when I left. I am equipped with the knowledge that out there, in the world, not all of what I encounter is false as Heidegger (1962) encourages me to believe. Illness is very real. Illness consumes my thoughts. Illness makes me not want to stay Home for very long because Home reminds me of a life that cannot exist. This concept of Home is not a place of comfort.

I am again reminded of Doll's (1995) notion that my Home is really my Self, not some literal place as Heidegger (1962) suggests. As I continue to dwell with illness, I gain new knowledge that changes my perception of authenticity. I continue to struggle with the notion of the authentic Self, to feel comfortable stripping away the façade so that my true Self may be

transparent. Although, I am learning that authenticity is subjective between the knower and the known. While I dwell with illness, the authenticity of my Self, and my Home, is constantly evolving.

Roles of the Mother

A sign by the front door of my home quotes Dorothy from *The Wizard of Oz*: “There’s no place like home.” I agree; there’s no place like my Self, the complexities of what is conscious and unconscious. For Dorothy, Home is a literal place. While in Oz, Dorothy yearns to be back on the farm in Kansas, back to the comforts of her familiar surroundings with Auntie Em. Dorothy’s longing for what she knows to be authentic is apparent as she frequently cries out for Auntie Em in times of distress. Often, maternal figures are viewed as the center of the home, as Auntie Em is for Dorothy. My South Georgia upbringing persuades me to believe that I am the center of my home, responsible for overseeing the entire physical, social, and spiritual well-being of my two sons. I feel as if I am looked down upon for teaching and working towards an advanced degree instead of focusing my entire attention on my children. However, I do not feel I am well suited to be a stay-at-home mom. Admittedly, I place great emphasis on my education and would be dissatisfied if I did not use my knowledge to its fullest capacity. Although the stress of being a working mother can be exhausting at times, the interactions I have with my students and colleagues are stimulating. For me, working outside of the home, specifically teaching science to high school students, is fulfilling and provides a sense of self-worth. I must pause here to acknowledge that stay-at-home mothers do indeed “work,” although their workload is often underappreciated. Each summer, when I am home with my two children, I am able to get a glimpse into the stay-at-home mother’s world. While I cherish the time to spend with my

children, I yearn for the upcoming school year and excitedly anticipate the new relationships that will be forged. However, as a means of clarification within this text, I will reserve the term “working mother” to mean the mother who has significant career responsibility outside of the home.

Many in my circle have chosen to quit their jobs in order to stay home with their children. I feel a sort of peer pressure from them, as if I am not a good mother because I have not opted for the same path. At the same time, I cannot help but question how my decisions will affect my children’s future. There are instances when I feel apprehensive in revealing my chosen path for motherhood. In some ways, I feel “othered,” as if I am in the wrong by choosing to balance a career and a family. However, I find my feelings of otherness unnecessary because my endeavor to be a working mother has become common in recent decades. It is possible that my feelings of otherness stem from the historical image of the “mother” in my mind. I have been encouraged to believe that the mother is the nurturing, compassionate, and submissive counterpart to her husband who, with gentle flare, commands the attention of those in her domestic realm. The mother’s charges follow her every move as chicks follow the hen. She is the religious stronghold of the family, instilling the need for salvation in each that listens to her readings from the Bible before bedtime. This picturesque description is what typically comes to my mind when I hear the word “mother.” In my circle, contradicting these standards is to be viewed as the “other” and therefore defies the norm.

Throughout my research I have learned that the aforementioned description is not an accurate portrayal of historical motherhood. In her book *The Myths of Motherhood*, Shari Thurer (1994) takes the reader on a comprehensive journey through the differing historical representations of motherhood from prehistory to the late twentieth century. It is true that the

mother held many of these romanticized qualities, but she was not always the submissive domesticator that my American history books would have me believe. At one time, men and women worked cooperatively to ensure domestic needs were met. Childrearing was a joint effort, not sole responsibility of the mother. The husband spent time cultivating the fields for harvest and raising livestock while the wife created meals to nourish the family. This cooperative time period is termed the “matriarchy.” Nevertheless, this period of familial cooperation saw its demise with the inception of private property and production. A new way of living allowed man to relinquish all domestic duties to his wife as he found his duties outside the home. This role-change made the wife financially dependent on her husband, thus trapping her in an isolated bubble from the “man’s world.”

Ballan (1978) states, “It was only after social production was transformed into private production that the nature of the family changed from a socially cooperative foundation as it existed under the matriarchy to the private property foundation of the patriarchy” (p. 8). The private property foundation has contributed to, although not solely responsible for, the oppression of women. In her essay *Women: The Evolving Educational Consciousness*, Miller (1980) recognizes the educational institution’s male tendencies of practice. Many of American ideals are derived from a predominantly male vantage point. The manner in which debates are conducted, the hierarchy of management, and the process of achieving tenure are only a few examples of how American society functions as a patriarch. In order for the working mother to survive in this sphere, she must conform to patriarchal ideals. However, she is still subject to be othered by males in her workplace. As Miller (1980) comments, “In truth, then, the woman is, as ever, one step behind her male counterpart” (p. 37). Likewise, the working mother may be

othered by non-working mothers because her attention is split between her duties inside and outside of the home. Thus, the working mother is caught in a paradox of otherness.

In response to Thurer's (1994) analysis of the evolving cultural implications of motherhood, I am prompted to examine how culture has shaped the ideal mother-image since the conclusion of her account. Since the 1990's, the cultural emphasis on organic and whole foods shuns mothers who must resort to microwavable or fast-food alternatives to feed their children. The overwhelming supply of educational toys and aids insists that if the mother does not begin teaching her baby to read by the time s/he is ten months old, s/he may be lagging educationally. These nutritional and educational "pushes" have become the norm; anything that deviates from this norm is othered. I have personally felt this need to push my children to be normal. Bradley's former speech therapist suggested that he was not "normal" because he did not play with the kitchen set or play with baby dolls like the other children at daycare. Instead, when given free play time he gravitated toward the cars and trucks. When I suggested that he mimicked his older brother's actions at the same age, she insisted that he was not displaying "imaginative collaborative play" that was exemplary of children Bradley's age. According to the therapist, my child was not "normal." Immediately, my mind was flooded with the multitude of possibilities as to how I contributed to Bradley's deficiency. What had I done wrong to cause him to be anything less than "normal?" Obviously, I was not the "perfect mother" I was trying to portray myself to be. Apparently, I had failed at both being the perfect mother and appearing as if I was one. However, I felt ashamed to admit this feeling of failure to anyone other than myself.

As a working mother, I sense societal pressures to conform to the norm or fear being othered. I often feel persuaded to live a doubled life, stripping away the teacher-clothes and

school bag as I don the perfect June Cleaver attire of spotless white apron atop the freshly pressed dress. My teaching responsibilities must be left in the school room. Upon arriving home, I am pressured to make baked goods for the latest community project while overseeing the care of two young children and preparing a home-cooked meal to have on the table by six o'clock. Attempting to maintain this doubled life is dizzying. However, I am encouraged to do so in order to be accepted by those in my competing worlds, possibly because I feel as though I am somehow less of a mother if I am not accepted.

Lather (2007) struggles with the notion of feminism as a doubled science. Drawing from Derrida's concept of "doubling," Lather (2007) approaches her work as "working within/against the dominant" (p. 14); she must situate herself within the dominant course of thought while simultaneously resisting its influence. The hegemony of cultural oppression is so subtle when one is immersed in its influence it can be difficult to recognize the extent of its power; however, when viewed from afar the power is obvious and to deny its effect is to be oblivious. I must be cautious when resisting the forces of oppression because I will be cast away as a "radical" and risk losing my message of valuing the ill individual. Audre Lorde (1984) suggests how individuality can be recognized in the context of community:

Advocating the mere tolerance of difference between women is the grossest reformism. It is a total denial of the creative function of difference in our lives. Difference must be not merely tolerated, but seen as a fund of necessary polarities between which our creativity can spark like a dialectic. Only then does the necessity for interdependency become unthreatening. Only within that interdependency of different strengths, acknowledged and equal, can the power to seek new ways of being in the world generate, as well as the courage and sustenance to act where there are no charters. (p. 111)

In her essay, Lorde (1984) emphasizes the necessity of women to begin to celebrate their differences rather than ignore them. Although, it is not enough just to recognize these differences. According to Lorde (1984), when one recognizes differences, the difference is either ignored, copied if viewed as dominant, or destroyed if viewed as submissive. Lorde's (1984) words can also serve to encourage the ill person. Instead, of normalizing characteristics among ill persons, their differences should be used as a starting point for dialogue and change to occur.

Equally frustrating is trying to maintain a balance between being a good mother and a successful educator. I feel that I am fighting a losing battle, that neither side approves of my decision to be a working mother. As an educator, I must decline invitations to chaperone school functions or attend after-school meetings if it conflicts with my childcare responsibilities. As a mother, I must deny my children of playtime while I finish writing my pathography or developing the week's lesson plans. I oftentimes conceal feelings of guilt that I am unable to fulfill the role of the perfect mother while my attention is split into two separate entities. The image of the perfect mother plagues my thoughts and makes me anxious about my mothering decisions. I suspect that I am not alone in my anxiety. In the introduction to *The Myths of Motherhood*, Shari Thurer (1994) states:

As a psychologist I cannot recall ever treating a mother who did not harbor shameful secrets about how her behavior or feelings damaged her children. Mothers do not take easy pride in their competence. Popular mother culture implies that our children are exquisitely delicate creatures, hugely vulnerable to our idiosyncrasies and deficits, who require relentless psychological attunement and approval. A sentimentalized image of the perfect mother casts a long, guilt-inducing shadow over real mothers' lives. Actual

days on Planet Earth include few if any perfect moments, perfect children, perfectly cared for. Watching a three-year-old dress in agonizing slow motion, or a ten-year-old gorge herself on junk food and then despair of her appearance and blame us, provokes powerful emotions in us that do not cohere with our notion of the maternal. We have become highly judgmental about the practice of mothering, and especially about ourselves as mothers. Parental performance anxiety reigns. (xi)

Reading her text, I feel a connection to Thurer (1994) as a working mother. She seems to acknowledge the guilt I carry for trying to balance both career and family. She recognizes the blame I have placed on myself for Bradley's illness. More importantly, she illuminates the oppressive oath of emotional silence that women take when they become mothers. Her desire to give voice back to the mother so that "her" story may be told is in alignment with my yearning to give voice back to the ill person, specifically mothers whose illness stems from her child's illness.

Thurer (1994) stresses, "Our contemporary myth heaps upon the mother so many duties and expectations that to take it seriously would be hazardous to her mental health" (p. xvi). The pressure I feel to uphold this myth, this façade, has been hazardous to my mental health. For some reason, I subscribed to the notion that harboring my emotions about my illness would facilitate the perfect mother image. For centuries, usually mothers in America have been the child/ren's primary caretaker. Mothers from the South are often portrayed as the picture perfect stay-at-home mother, attending to the child/ren's every need. Submissive to her husband, the Southern mother is active in all aspects of the community, especially church organizations, yet maintains an impeccable home environment. In more recent years, mothers, including those in the South, have begun to move into the paid labor force. However, finding work outside of the

home has not diminished the task load from within the home. Mothers are required to maintain a balance between these two realms and are sometimes even made to feel guilty if choosing to dabble in the workplace. Chodorow (1978) blames the early American capitalistic society for creating the ideal mother image. She states, “[w]omen of all classes are now expected to nurture and support husbands in addition to providing them with food and a clean house” (p. 5).

However, the familial support system that mothers once had for helping to uphold domestic responsibilities has been greatly diminished due to the increase in capitalistic industrialization.

The aforementioned has been my experience as a Southern mother. In many ways I feel that my work outside the home is validated, as long as it does not interfere with my responsibilities within the home. I feel that some may excuse my work because I am a teacher, often referred to as the “perfect mommy job” because of the mirroring of the work schedule to the child’s school day and because I can transfer my nurturing skills between my children and my students. However, the moment one of my children is sick I feel this daunting force begin to encompass me, suggesting that I am neglecting my children for the sake of my own ambition. Thurer (1994) suggests that “[f]or many women, perhaps most, motherhood versus personal ambition represents the heart of the feminine dilemma” (p. 287). This “feminine dilemma” is overwhelming and painful. Ironically, I feel that as a teacher I am a sort-of-mother to my students, my other children. How do I possibly balance the multiple duties of mothering both my two sons and my students when my role as mother is ever-changing? Furthermore, what qualities validate my efforts as a good mother?

Good Enough

Doll (1995) states that “[e]verything is the parents” (p. 162). I have internalized this to mean that everything is the “mother.” Individuals differ vastly from one another in their desires, physical characteristics, and emotional states. Despite these differences, Rich (1986) reminds us that there is one commonality among all individuals: each spent a considerable amount of time developing in the womb of the mother. “Most of us first know both love and disappointment, power and tenderness, in the person of a woman” (Rich, 1986, p. 11). The mother has been bestowed/burdened with a great privilege/charge. It is only within her womb that the miracle of life can occur. I feel an overwhelming sense of satisfaction knowing that I am irreplaceable in this task. Yet, I am reminded that the toxins that invade my body long before conception can significantly affect fetal development. Could my body have been exposed to a toxin that ultimately caused Bradley’s heart defect?

Throughout the gestational period, every emotion, every sickness, every action is felt by both mother and fetus. Although the umbilical cord is severed at birth, there continues to be a bond, whether strong or weak, between mother and child. The mother is accountable for the holistic wellbeing of her child which can cause some mothers to feel an overwhelming burden to be the perfect mother. So not to be charged with contributing to the delinquency of her child’s future, some mothers become overprotective of their children in hopes of ensuring a life free from trials and shortcomings which inadvertently restrains the child from embarking on a journey that can be both adventuresome and unnerving. It is unhealthy for the child to forever remain at Home because s/he will not gain independence and individuality from the mother. Here, the term Home does not refer to a literal dwelling, but instead a figurative place, a primary object that provides safety and security. This could be a geographic location or in the embrace of

a person, such as the mother. Home can be in a realm of the internal or external, or sometimes both. In a similar sense, Mother is not necessarily a literal female biological mother. Winnicott (1971/2005) emphasizes this point:

The good-enough 'mother' (not necessarily the infant's own mother) is one who makes active adaptation to the infant's needs, an active adaptation that gradually lessens, according to the infant's growing ability to account for failure of adaptation and to tolerate the results of frustration. (p. 13)

Oftentimes, one's own biological mother is a "good-enough" Mother, but this is not always the case. When the biological mother is not suitable, which could be for a multitude of reasons, one finds another Mother to fill this role. I am reminded of the Dr. Seuss book *Are you My Mother?* (Eastman, 1960) which tells the story of a baby bird, recently hatched from an egg, who goes on a search for his biological mother. There is a burning desire for the little bird to find his mother, any Mother, who will look after him. He encounters several possibilities to fulfill the role of Mother, but finds none to be suitable. He is overjoyed when his biological mother appears, feeling a sense of completion of his identity.

Although Winnicott (1971/2005) uses "Mother" in a figurative sense, I have taken his description of the "good-enough" mother literally. I am concerned with how I fare against his qualifications. I agree with Salvio (2006) that Winnicott puts great responsibility on the mother to be "good-enough." She argues that "the position of the good enough mother requires women to overwrite their own desires with those of their children, and to deny the rage, pain, fear, and ambivalence that is an inevitable part of mothering" (p. 67). Was Winnicott's intent to try to lessen the burden some have of trying to live up to the unrealistic ideals of being a perfect mother? Still, I find his qualifications for being a "good-enough" mother demanding. What if,

for some reason or another, I am not capable of being “good-enough” for my child? What if I cannot provide what my child needs? During the time of Bradley’s illness, he did not know that I was devoted to him because I could not provide for his basic needs. The excessive amounts of fluid retained by his body caused his eyes to become swollen shut; he could not see me even if I were standing beside his bassinet. But I did not want to be standing there next to him. The sight of seeing him hooked up to tubes and wires coming out of every area of his body was too painful to bear for long periods of time. Some one, some thing else had to take my place as Mother. Because of Bradley’s special circumstances, am I afforded some other set of rules to follow that would make me “good enough?” Those first few days of bonding between mother and child are irreplaceable, irreproducible. I feel like I missed my chance to bond with him on such an intimate level. Will I always feel this way? I love him dearly, but I still feel like something is missing. Will I ever feel like I was, or am, “good enough?”

Particularly during the first months of Bradley’s life, I do not feel that I was a “good enough” mother. I wanted to run away from him when the demands of his illness became too much for me to endure. I did not want to make accommodations for him because by doing so meant acknowledging his illness and that he was not “normal.” Additionally, I do not feel that my mental state allowed me to be a “good enough” mother. Yet, I felt an overwhelming need to adorn a façade, pretending that I had my chaotic life under control. Salvio (2006) states,

In the vent that she is incapable of providing the child with what she needs, the mother must learn to “act as if...” she is good enough, masquerading, if you will, so as to provide her child with what is necessary for her development. Thus we bump up against a paradox in the work of Winnicott. While on the one hand, a mother must be genuine, personal, confident, and spontaneous, on the other hand, if she is depressed, anxious, or

preoccupied, she must “act” in the presence of the child who is too anxious or fearful to bear the presence of the mother’s difficult subjectivities. (p. 73)

To dwell in this Winnicottian paradox is dizzying! It is only through my writing about illness that I have been willing to admit to myself, and to others, the hidden feelings of insecurity regarding my qualifications for motherhood. In the midst of trying to uphold the image of the “good enough” mother, I feel as if I have lost a part of my Self. Salvio (2006) briefly cites Michael Eigen’s (2004) notion of the “lost-I feeling” when she discusses Anne Sexton’s failure to be a “good enough” mother. For Sexton, her psychic state perpetuated a sense of failure as she struggled with her past actions as well as her future shortcomings. Some may suggest that Sexton had become evil, devil-like. Eigen (2004) speaks of a patient, Smith, who had similar evil tendencies. Smith’s insensitivity toward others morphed him into a monster, an image that sometimes appeared to Smith in the mirror. Smith lost sight of himself, the “lost-I feeling.” Freud would argue that Smith’s and Sexton’s urging forces (cathexis) overpowered his/her checking forces (anti-cathexis).

Contemplating the psychic states of Eigen’s (2004) patient and Anne Sexton, I can only assume that the pressure of being “good enough” caused each to snap, so to speak. How does one get to this mental state of pure evil, where cathexis overpowers anti-cathexis? Stories abound concerning mothers whose internal frustrations have manifested in evil manners. I am reminded of Susan Smith, the mother from South Carolina who, in the fall of 1995, drove her car into a lake, killing her two children as they slept in the backseat, strapped in their car seats. Several accounts have been written speculating Susan Smith’s mental state before and after the murder of her two children. Her outward appearance did not suggest that she was someone capable of such a wrongful act. She was well-liked by those around her, had a prestigious job in

her community, and was a loving mother to her two boys. But her outward appearance did not shed light on the lifetime of rejection that remained unrevealed. A letter from Tom Findlay, her boss's son with whom she was in a relationship, cited numerous instances in which Susan interpreted as not being "good enough" for him. Additionally, he remarked that he neither wanted children, nor wanted to raise her two children. In attempt to regain Findlay's attention, she destroyed the obstacles that were in her path.

The case of Susan Smith is one of extreme. While there have been other accounts of mothers who have taken their children's lives, a mother who physically kills her child is not the norm. Although, I wonder if mothers who suffer from severe post-partum depression are, in a way, emotionally killing their child? I have long upheld the notion that I did not (am not?) suffer from post-partum depression. I did not feel the urges of suicide that some mothers encounter. But, maybe depression is the term best suited for my mental state. In her book *Down came the Rain*, Brooke Shields (2005) describes her urges of suicide as well as the taboo that surrounds the mother in admitting she suffers from post-partum depression. The release of her book put a celebrity face with a common illness, much in the same way that Michael J. Fox's and Farrah Fawcett's personal accounts have done for Parkinson's disease and cancer. But the glaring difference between Fox's and Fawcett's diagnoses and Shields' is that their illnesses are an attack on the physical body, whereas Shields' is an illness of the mind. In response to Shields' diagnosis of post-partum depression and use of the anti-depressant drug Paxil®, Tom Cruise went so far as to state that "psychiatry is a pseudo science" and that "[t]here is no such thing as a chemical imbalance" (Bell, 2005). Why are mental illnesses treated as taboo and not held in the same light of severity as illness of the physical body?

I question how many mothers do not want to admit their sufferings of post-partum depression because this diagnosis could possibly taint their image of the “good enough” mother. Working mothers are often not afforded the time to work through depression. Working mothers are given time off from work to recover from the physical demands of childbirth and the emotional demands of nurturing a newborn. While the US Department of Labor’s Family Medical Leave Act allows up to twelve-weeks of unpaid leave time, taking more than six weeks time off from work is often frowned upon in many circles. The “six-weeks standard” may have come from the time at which the mother’s physician releases her from obstetric care because by this point, the uterus should have returned to its pre-pregnancy position. While six weeks may be ample time to physically recover from pregnancy and childbirth, this short time span is hardly adequate for a mother suffering from depression. At six weeks old, Bradley was having difficulty feeding and was taking weekly trips to numerous doctors. At six weeks post-partum I was in a state of despair because of Bradley’s physical demands. I had not even begun to sort through my complex emotions and was in no state of mind to be able to teach my students. Fortunately, Bradley’s timely birth was near the end of the school year, allowing me additional weeks to recover. If he had been born at a different time of year, I would have taken the allowed twelve weeks, which I am confident would have been met with a paradox of understanding of Bradley’s medical condition and concern for my students’ education. But what is to be said for mothers who have healthy babies and who personally have few physical complications from childbirth? Is six weeks recuperation enough time to mentally heal from the demands of a newborn baby? I believe that many mothers suffering from post-partum depression do not admit their illness or seek help because of the expectation of bouncing back to the workplace after

giving birth. Admitting the illness not only taints the image of the “good enough” mother, it also distorts the image of the “good enough” worker.

It is impossible to eternally uphold the “good enough” mother image. The infant gradually realizes that the mother will fail, will no longer be “good enough.” However, in the beginning, the mother must do everything to keep from failing because the infant is not ready to accept the mother’s inability to take care of everything. After all, while in the womb, the mother literally meets all of the infant’s needs; the infant does not even have to make a sound in order to be fed, rocked, comforted. The infant begins to associate the mother with one who cures, who takes the pain away, which can create a feeling of indebtedness to the mother. Turini in Mendell and Turrini (2003) states

Gratitude and the perceived debt to her seem likely to be connected to memories of the need for her curative abilities that provided relief from suffering. If infants suffer severe pain during this early period that the caretaker cannot ameliorate, the ego’s threshold for tolerance can be disorganized preventing any remembrance of the curing mother; this in turn prevents the child from connecting hope to any object. (p. 150)

I am concerned about Bradley’s attachment to me because I could not provide him with a cure or comfort, especially in the first weeks of his life. Winnicott (1971/2005) suggests that the infant will gradually learn that the mother will not respond immediately to satisfy her/his needs; however, he suggests that at the beginning, this time gap between call and response must be short. In Bradley’s case, it could not be short because I was unable to help him. He was in pain, crying out, calling out to me and I could not comfort him. Oh, the pain the mother feels when she wants to help her child and is unable to! After surgery, Bradley had a ventilation tube down his throat and could not let out a full cry, only moan and struggle. When the tube was gone, the

damage to his vocal cords caused him to cry silently. A silent cry. Painful. Similar to my silent cry that I experienced in loneliness that was heard only in solitude. Similarly painful, crying out for help but no one could hear me. I wanted to help him, but I could not. Bradley's heart was broken; my heart was breaking.

On the contrary, mothers who rush to their child's aid at the sound of the first whimper are equally failing their child. Mothers must walk a fine line between affording the child the opportunity to explore, to learn from her/his own experience, and making all of the decisions for the child. Wooten's (2006) music teacher, who was a sort of Mother to him, insists on the need for Wooten to learn from experience:

Truth? What is truth? And tell me, what importance does truth have anyway? Did you learn from the experience? Now, that is important. And by the way, if I always tell you the truth, you might start to believe me. (p. 8)

My role as a teacher is to act as Mother, offering support when necessary, but slowly making adaptations so that the student can learn to make her/his own decisions and carve out her/his own life path. It is hopeful that the Mother rears the child so that s/he will be able to mentor another in a similar fashion. While in the womb, the unborn child's needs are being met through the umbilical cord attached to the placenta, an organ that is specifically designed and developed in order to care for the fetus in utero. In the same way that the cord to the placenta is severed so that the infant can begin to sustain life by his own means, so must the cord be eventually severed from the Mother so that the child can embark on a journey toward independence.

Interestingly, the description of the perfect mother varies across culture, region, and time. Thurer (1994) points out that while a characteristic may be considered fundamental in one place, it may be considered superfluous in another. The trends of motherhood change with each

passing season. How, then, is it possible for me to become the perfect mother if the job description is ever-changing? Thurer (1994) states, “The current standards for good mothering are so formidable, self-denying, elusive, changeable, and contradictory that they are unattainable” (p. xvi). Often, I feel I am on the Mad Hatter’s Teacups in the Magic Kingdom of Disney World as I am spinning, dizzying, trying to uphold the facades of the perfect mother, wife, daughter, sister, teacher, student, church member, friend. Fincher (2007) refers to these many roles as corsets: binding, inflexible contraptions of oppression. She encourages me to cease cramming my foot into Cinderella’s glass slipper when it is not my size. Cinderella may be the image of perfection to some, but she is not reality. Instead, I need to put on my own shoes and loosen the corsets. I feel that it is only then that I will be “good enough.”

Psychoanalysis and Motherhood

When I became pregnant with Bradley I felt prepared for the adventures having another son would bring for our family. It had been almost four years since my first son Tyler’s birth. As I dug through the bottom of what would become Bradley’s closet I came across a copy of *Bringing up Boys* by James Dobson that a friend from church had given me at Tyler’s baby shower. I flipped through the pages which had been dog-eared as a reminder of specifics to incorporate in my parenting method. If only parenting were so simple, that I could follow the guidelines of some book which would classify me as a “good enough” parent! It seems that literature regarding relationships between mothers and their children is a bit lop-sided. Volumes are abundant on the deep, entangled relations existing between mother and daughter. However, I have not been encouraged by the amount of literature on the relationship between mothers and sons. I am specifically interested in my crushing sense of guilt which stems from not being able

to bond with Bradley, in what I believe to be a proper way, during those first few months of his life. Additionally, I sense an overwhelming anxiousness to be his healer, to “fix” Bradley so that he is normal, like the other boys his age. Throughout my investigation into this part of my self, as a mother, I have sought support through psychoanalysis. It is in this mindset that I tease out my relationship to my son Bradley in hopes of fleshing out my feelings of guilt and anxiety.

When I learned in the twentieth week of my first pregnancy that I was carrying a son, I was overcome with mixed emotions. I was oblivious to the massive collections of matchbox cars and excessive pieces of sports equipment that would soon begin to fill my house. Growing up with a younger sister, I was accustomed to playing with dolls and kitchen sets. When my sister and I would play “house,” I was always the mother to a blue-eyed Cabbage Patch® doll with blonde pig-tails. When I became pregnant, it seemed natural that I would give birth to a daughter. I knew that the differences between having a daughter versus a son were not a matter of hair bows and wrestling matches. In my mind, I would not have to try as hard to bond with my daughter because a mother-daughter bond occurs naturally, as it did between my mother and me. For me, having a son meant working at a relationship that I knew would eventually fade when he begins a life of his own. Although I was apprehensive about having a son, Adrienne Rich (1986) was ecstatic when she learned she was carrying a male child. She describes her feelings about giving birth to a son:

I wanted to give birth...to my unborn self...someone independent, actively willing, original—those possibilities I had felt in myself in flashes as a young student and writer, and from which, during pregnancy, I was to close myself off. If I wanted to give birth to myself as a male, it was because males seemed to inherit those qualities by right of

gender.....Giving birth to sons has been one means through which a woman could leave “her” mark on the world. (p. 193)

As Rich (1986) suggests, what Bradley (and Tyler) does in life becomes my legacy. This notion places a great burden on my shoulders to strive to be a “good enough” mother. Learning of Bradley’s diagnosis put a sense of fear in my mind that he may not *be something* in life. I feel entirely responsible for Bradley’s heart defect because it occurred while he was in my sole care. Thus, I have an overwhelming sense of urgency to guarantee my legacy through Bradley or fear tainting my status as a “good enough” mother.

As with Rich (1986), Wendy Atwell-Vasey (1998) is also concerned with maternal legacies. Drawing from Kristeva, Atwell-Vasey (1998) describes three “legacies”: the creation of the body-subject, the development of the intersubjectivity, and the provision of a potential space between mother and child (p. 56). While Atwell-Vasey uses these legacies as a means of reconceptualizing her pedagogy, her discourse can be applied to my Self as a mother. The first of these legacies, the body-subject, is rooted in what Kristeva refers to as the pre-oedipal period, when the baby stores rhythms and vibrations that are “partially regulated by itself and partially regulated by another” (Atwell-Vasey, 1998, p. 57). The mother becomes the safety net in the event that the infant’s intuition fails. What Atwell-Vasey is most concerned with here is the infant’s language development and its relation to the body. The mother is the infant’s primary teacher of language. But the infant not only hears and reiterates the mother’s words; the infant becomes the mother’s words. She uses the example that when the infant is making a “Mmm, mmm” sound, s/he is not only imitating the suckling of the breast, the infant becomes the breast. Language is embodied. Bradley suffers from a speech delay. He has difficulty articulating what he is thinking, feeling, needing. If language is not only a tool for conveying meaning but is also

a mode of identification, then I am concerned about the development of Bradley's self concept as it relates to his speech delay.

According to Atwell-Vasey (1998), the second maternal legacy is intersubjectivity, which involves "complex relations among people as they become subjects who know the world" (p. 58). I agree with her expression of the "difficulty of acknowledging how one can be both part of an other and not a part, or how one was once a part of something and is not longer" (p. 58). I have often expressed the complexities of giving birth to a child who was a part of my innermost being, who is now apart from me. Yet somehow, my child will always be a part of me. Acknowledging this paradox of being a/part of/from the mother is fundamental in the child's ego development. Kristeva (1986) stresses the importance of the "thetic break" (p. 98), where the child creates boundaries for his/her drives and makes new meanings of experiences. The thetic break not only identifies areas that the child wants to keep, but also illuminates areas that need to be discarded. It is here that the child is able to gain independence, to be apart from the mother while still being a part.

Finally, the child needs a potential space to explore and imagine. The third maternal legacy suggests the need for this space in order for the child to actualize her/his powers. Winnicott (1971/2005) would argue that a "good enough" mother allows for this potential space. He states:

From a state of being merged in with the mother the baby is at a stage of separating out the mother from the self, and the mother is lowering the degree of her adaptation to the baby's needs both because of her own recovery from a higher degree of identification with her baby and because of her perception of the baby's new need, the need for her to be a separate phenomenon. (p. 144-145)

This third maternal legacy makes me pause to examine how I have fostered the development of “potential space” for my own children. While I have been around many mothers who are overbearing, giving in to their child’s slightest whim, I would not necessarily classify myself in this cluster. My mothering style is quite the contrary, attempting to make my children as self-sufficient as possible. However, driving my children to be prematurely independent, thereby giving them too much “potential space,” could be as equally damaging as smothering my children while suppressing self-sufficiency. It is difficult to recognize the exact amount of space to provide, and when to allow for expansion of the space.

Providing “potential space” in order to foster independence is a necessary responsibility for me as a mother and as a teacher. Like my biological children, my students, my *other* children, need “potential space” in which to imagine, create, and think independently. Knowing exactly how much support to provide my students without deterring their development of self-sufficiency can be troublesome. I want to offer guidance so that my students can build self-esteem, yet remove the braces at just the right moment so that they can soar in their newfound confidence. Recognizing this balance of support is a characteristic of a “good enough” teacher. However, there is at least one glaring difference between my students and my own children. As students leave the proverbial nest of the classroom, new students will arrive in search of guidance. My job as teacher continues in much the same capacity. Yet, when my children leave the comforts of home, there are none to take their place. Thus, my role as mother ceases.

The woman goes through a figurative transformation of birth, life, and death as a mother. It is partially through the mother’s death that the child gains independence. In her essay “Motherhood Today,” Kristeva (2005) further elaborates on the importance of the mother’s symbolic death as a means of fostering independence and exploration:

[T]he mother allows her child to represent not the mother...but the mother's absence: if and only if she leaves the child free to appropriate maternal thought by recreating it in his own way of thinking-representing. The "good enough mother" would be she who knows how to leave to make room for pleasure, for the child, for thought. To leave room, in other words to disappear. Thus a kind of symbolic matricide operates through the child's acquisition of language and thought which diminishes his need to take pleasure from his mother's body; he comes to find pleasure in thinking, first with his mother, as far as the intermittent nature of maternal thought permits, then alone, in her stead. This happens provided the mother knows how to turn her message into a witticism rather than a way of wielding influence.

Becoming a mother has been the most profound, life-altering experience of my life. The first moment that I held each of my children in my arms I knew that I would die for them. For Kristeva (2005), being a "good enough" mother means that in a way, the mother does indeed die, as if she encounters a sort of symbolic matricide. As a mother, I am entrusted with nourishing an alien that inhabits my womb that, when emerges, is apart from me yet still somehow a part of me. Throughout my self-study, I have had difficulty textualizing the complexities of motherhood in a term which captures the essence of my experience as a mother. Motherhood is more than a set of complex emotions driven by biological tendencies. Motherhood cannot be reduced to an instinct that is inherent to women. If this were true, how does one explain the notion that some women do not desire to have children? I am drawn to Kristeva's (2005) discussion of maternal passion as a way for me to textualize my feelings about motherhood. Kristeva (2005) contends that while motherhood stirs up emotion, it is better attributed to a deep passion:

Motherhood is a passion in the sense that the emotions (of attachment and aggression toward the fetus, baby and child) turn into love (idealization, planning for the child's future, dedication) with its *hate* correlative more or less reduced. The mother is at the crossroads of biology and meaning as early on as the pregnancy: *maternal passion de-biologizes* the link to the child, *without becoming completely detached from the* biological, yet already the emotions of attachment and aggression are on the way towards sublimation.

I cannot think of any one thing I would not do for either of my children. As Bradley lay in his bassinet, his violated body bruised and swollen from the affects of surgery, I desperately wanted to change places with him. I wanted to be the vessel for the pain his innocent body was enduring. The helpless hopeless feeling that overcomes a mother as she observes her child suffering is overwhelming. *He's an infant. He won't remember any of this.* These phrases were offered as words of comfort. However, I question the impact this preverbal experience will have on Bradley's psyche.

The Grieving Mother

Living a life which teeters on the edge is common for those suffering from some illnesses. A cancer patient endures chemotherapy treatments which cause side effects equal in magnitude to the cancer itself. Her family yearns to take her pain away, to give her one more day free from pain so that she may taste the saltiness of the ocean's waters. Her medical chart describes her form of cancer as manifesting from "unknown etiology," thereby making it nearly impossible to cure without the aid of a miracle. Her family clings to the hope that the chemotherapy will provide this miracle. However, reality is that her future looks bleak; her body

will eventually succumb to cancer's destroying pressures. Her family begins psychological preparation now, anticipating the grief that they will endure when their beloved matriarch is no longer with them.

Oftentimes the diagnosis of the dreaded "c" word is received as a death sentence to those who are affected by its destruction. Susan Sontag (1978/1989) clearly illuminates this issue as she describes cancer as

the disease that doesn't knock before it enters...that fills the role of an illness experienced as a ruthless, secret invasion—a role it will keep until, one day, its etiology becomes clear and its treatment effective as those of [tuberculosis] have become. (p. 5)

Illnesses such as cancer or AIDS that have long-term effects on the ill body can alter the psyche as the ill person is confronted with the notion of dying. And, while illness' psychological effect on the ill person is a noteworthy topic for discussion, I am most interested in how illness affects the caregiver's psychological state. I was first introduced to the notion of "anticipatory grief" by my pastor during a weekly church service. He shared a personal story describing his depressed state when his son received orders for overseas deployment with the United States Army. He admitted to feeling a sense of loss, although he could not determine why he felt this way even after his son's safe return home. My pastor explained that he was encountering "anticipatory grief"—a psychological state in which the psyche prepares for the loss of a loved one before the loss occurs. However, this mental preparation can backfire, sending one into a deep depression, as was the case with my pastor. In his mind, he had mentally prepared for his son's death, even to the point of planning what to say at his funeral.

I suppose that families of cancer patients (or other patients suffering from terminal illnesses) encounter a similar type of anticipatory grief. However, I do not think that this

psychological state is limited to those who encounter terminal illness. In considering my own illness, I cannot help but wonder if part of my depressed state stems from the ever-present notion that Bradley's heart may fail him and he could die. It is possible that I did not allow myself ample time to bond with him when he was a newborn because I was attempting to psychologically prepare for the possibility of losing him. I was anticipating losing Bradley which resulted in my feeling as if he had already died. My depressed state not only affected (is affecting) my relationship with Bradley but also affected my relationship with my husband, my oldest son Tyler, and others in my circle.

Harriet Hodgson and Lois Krahn's (2004) *Smiling through your tears: Anticipating grief* has been of comfort as I have struggled to put a name with the entrenched emotions I have encountered as a mother with an ill child. They state:

Early grief is almost worse than post-death grief because you don't know when death will come. Distant relatives and friends, people you thought you could rely on, may not expect you to feel distress. Why are you grieving if no one has died? Some family members may become short-tempered with you, while others may accuse you of "borrowing trouble." (p. 7)

It is partially due to this notion of "borrowing trouble" that encouraged me to remain silent about my illness for so long. *Why am I so upset? Bradley is a healthy, happy child. Things could have been much worse than what they are.* These thoughts plagued my mind as I have openly acknowledged my illness and even more as I have begun to develop this pathography. I have frequently questioned if I have anything of value to contribute to the conversation, that possibly I am "making a mountain out of a mole-hill," so to speak. But the very fact that I am questioning the worth of my contribution illuminates the need for this sort of complicated conversation.

Elisabeth Kubler-Ross (1969) recognized the need to complicate the conversation when she strived to give voice back to ill persons experiencing death. In her book *On Death and Dying*, Kubler-Ross (1969) discusses the five stage theory of the death experience: denial, anger, bargaining, depression, acceptance. Caregivers who are faced with the possibility of losing a loved one often experience a similar complex emotional state. In their book *On Grief and Grieving*, Elisabeth Kubler-Ross and David Kessler (2005) further expand on Kubler-Ross's first book, addressing how the five stage theory relates to the caregiver. I do not specifically believe that the ill person or the caregiver pass through these stages in chronological order, nor do believe that it is impossible to wander amongst many stages simultaneously. Nevertheless, I am intrigued by Kubler-Ross and Kessler's stage theory as it applies to my own illness.

As with many caregivers who learn of a loved one's an unfavorable diagnosis, I first subscribed to the *No, not my child* denial. They had to have gotten my child mixed up with another. Bradley was perfect, not like his older brother who required special attention from the neonatal team immediately after birth. The news of Bradley's heart defect was delivered in stages by three different individuals, none of whom I had ever met prior to this day. Along with Bradley's diagnosis, I was handed a stack of paperwork which required my signature so that my child could be flown to a hospital in Atlanta, over 200 miles away from home. I have no idea what those papers said; I only trusted that the nice looking man in the white lab coat and blue tie knew what was best for my child.

Driving to Atlanta, I drugged myself with Ibuprofen so that I could deny my conscious from contemplating Bradley's future. I awakened to the sounds of my Ford Explorer struggling to make it up the steep ramp in the hospital's parking garage. Floor after floor the Explorer moaned, searching for a parking place so that it could rest after the long and weary trip. My

struggling Explorer was synonymous with my own struggling body, tired and weary, looking for a place to rest for awhile. But unlike my SUV, I could not remain in the parking lot to rest; I had to keep moving, keep climbing the steep ramp, because my journey had only just begun.

The two weeks spent in Atlanta were no doubt the longest of my life. I lost almost all concept of time, often not knowing the day of the week. In retrospect, I feel that this was possibly another way that I could deny that Bradley was ill. By not being able to place a date or time with events, I could almost erase the experience from history. The online journal I kept during our stay did allow me to date and time stamp events as they occurred. However, it has been years since I have read the journal's entries. I had promised to print out the one hundred plus pages and have them bound as a remembrance of Bradley's first few weeks of life. Alas, I have never found the time to do so, possibly because having a coffee table book of those entries would prohibit me from denying that the events ever occurred.

It is no doubt that the majority of our time in Atlanta was spent in the hospital. However, I purposely planned lengthy outings each day so that I could have a break from reality. Kubler-Ross and Kessler (2005) suggest that denial can be a healthy way for the psyche to deal with loss:

The first stage of grieving helps us to survive the loss. In this stage, the world becomes meaningless and overwhelming. Life makes no sense. We are in a state of shock and denial. We go numb. We wonder how we can go on, if we can go on, why we should go on. We try to find a way to simply get through each day. Denial and shock help us to cope and make survival possible. Denial helps us to pace our feelings of grief. There is a grace in denial. It is nature's way of letting in only as much as we can handle. (p. 10)

I have continued to resort back to the denial stage, this time in light of Bradley being different from other children. As an educator, I see how children who are “different” are treated by their peers and teachers. Before Bradley began speech therapy, I denied that he needed services. I assumed that he would progress when he was developmentally ready without the aid of outside support. And he may have done so on his own. However, denying that he needed the extra support does not eliminate his illness. I fear that I will struggle with denial in some form throughout Bradley’s life.

When Bradley was a little more than two weeks old he had to be rushed to the emergency room because his skin appeared blue, indicating that he was not receiving enough oxygen. The doctors were baffled by what we had observed because his tests showed that his heart was functioning sufficiently. However, it was recommended that he remain in the hospital overnight for observations. As I sat alone in the hospital room, the denial about Bradley’s illness evolved into anger. I sobbed uncontrollably for the longest time, angry at God for giving me a baby that was less than perfect, angry at Bradley for bringing such chaos into my life, angry at myself for being angry at a helpless infant that I should be nurturing instead of neglecting. Nearly four years since the onset of the Bradley ordeal, I still harbor extreme anger at God, Bradley, and myself. There have been many times I have asked *Why me? Why couldn’t this have happened to someone else?* My sister has given birth to two healthy children, the first of which was born four months after Bradley. Although I was overcome with joy in becoming an aunt, I was envious that my sister was given an opportunity that I was not afforded. Because Bradley and my niece Allie are so close in age, they are frequently compared to one another, if not verbally at least silently. It angers me that he is different from Allie and I find myself getting angry with

her, despite the fact that I love her almost as if she were my own child. Oftentimes the anger expressed by the ill person is not caused by the target to which the anger is projected.

As I stood in the narrow hallway watching my four-day old infant being wheeled through the double doors to the operating room where the cardiothoracic surgeon was to perform open heart surgery, I recall thinking *Okay, he'll have the surgery, and then he will be a normal little boy*. I felt guilty that I was granting permission for strangers to mar my child, but felt even more guilt in the possibility that I could have been the cause of his defect. Surgery became my bargaining chip, the hope that the aftermath would prove favorable and remove me from wrongdoing. Bradley's further complications with his heart, feeding, and speech only serve as a reminder that I lost this hand of cards. I could not fix Bradley, even after I showed the dealer my hand. Thus, the guilt remains.

Although I have previously denied the fact (Yet another *denial!*), I do indeed believe that most of my dwelling with illness can be attributed to depression. For reasons I have already discussed, it is possible that I feared admitting my depressed state. Writing about my illness and working through my emotions has been therapeutic yet troublesome. I have been overcome with grief, oftentimes sobbing as I continue pushing through the pain, continue typing on the keyboard soaked with tears. I am beginning to learn how to accept my new reality, a reality in which I will forever dwell with illness. I am not content with the notion that my child required heart surgery to correct a congenital defect. I am also not content with knowing that I cannot turn back time, to return to a place when Bradley was an infant where I could care for him as a "good enough" mother should. However, these facts have become a part of my reality. Writing about my illness has, in some ways, given me the closure I have needed on a situation that I cannot remedy.

Drawing Strength from M/others

As I have begun to open up to others about my illness and my anxieties regarding how Bradley's illness will continue to affect him, I have found encouragement from other mothers who are managing similar concerns. Through several casual conversations I have discovered that four friends from my adolescent years are each struggling with similar trials and complex emotions as my own. When the subject of illness was initially brought up in our conversation, it was almost as if all of the air in the room had been sucked out. My friends each held their breath as they tried to answer my question when I asked *How is your child?* But when I began to reveal my own struggles of raising a child who was slightly different from normal, the volume of the room's air increased ten-fold. There seems to be a uniting bond between us, this group of mothers who are concerned with how she compares to the "good-enough" mother. Illness can destroy the body, oftentimes to the point that it is unable to be restored. But illness can also foster community among individuals who are dwelling with chaos, creating a bond that will endure.

It is possible that this pathography will be met with criticism by those who do not feel Bradley's illness and my illness warrant a place in the conversation because our illnesses are not "severe." In other words, Bradley does not suffer from severe life-long complications, such as one diagnosed with cerebral palsy. Likewise, my illness may be cast to the side as being common because many individuals suffer from depression. I acknowledge that I am fortunate to still have Bradley with me; many mothers have lost their children to illness. Mothers who no longer have their children in their arms may scoff at my pathography as they ask *What does she have to complain about?* This fear of criticism is what prolonged my silent state.

One mother who has been of great encouragement to me has been my colleague and friend, Era Hall. Not only has Era acknowledged my anxieties pertaining to Bradley's illness, she has never made me feel as if my experience with illness was any less valid than if I had been dwelling with illness of a more serious nature. Considering Era's personal encounter with illness, one might assume that she would criticize my account. Era's only child, Will, was born with a rare genetic condition called Joubert Syndrome which affects brain development. Most children affected with the condition do not live past the age of two. In order to better explain Will's illness to family and friends, Era wrote a letter in which she provided the following description:

The prognosis for Joubert Syndrome is developmental delays such as sitting, head control, crawling, walking, and talking; however, health and growth are not usually affected. Commonly there is a degree of mild or moderate retardation...[T]he severity has a wide spectrum. (Hall in Tompkins, 2001, p. 113)

Will spent much of his life in a wheelchair because his lower muscles were never strong enough to support his own weight. Will was fed through a tube in his stomach so that he would not risk aspirating (or, getting food into his lungs) when he was trying to eat. Will could not see. Will did not talk but found other ways of communicating through special noises and moving his arms and legs. Will surpassed all expectations regarding his life expectancy; where many of his physicians did not think that he would live past the age of two, Will delighted those who knew him for fourteen years and eleven months.

I am fortunate to have met Will at his home just after he had turned fourteen years old. There was an obvious bond between mother and son; as soon as Will heard Era's voice as she came into the room, he turned his head in her direction and started to swing his feet rapidly.

Era's strong arms would scoop Will from his chair and place him awkwardly on her lap as she sat on the couch talking to her guests who had come to visit. No doubt, caring for Will was a huge responsibility. I cannot imagine the physical, mental, and emotional exhaustion that must accompany caring for a child with special needs such as Will. But Era never considered caring for Will to be a burden. She comments:

[W]e are thankful for everyday that we can be together. We also know that there have been many blessings to count and special persons that we have met because of our experience. We do not feel persecuted by God or fate. We feel blessed. Along with many other parents of children with disabilities, we feel that we would not have chosen this to be, but can not [sic] imagine that our lives would be any richer had we not begun our travel down the road with a child of special needs. We do what we have to do, and we take each day one by one, and often, minute by minute. (Hall in Tompkins, 2001, p. 117)

I have often wondered how Era was able to do what she did for as long as she did it. Era's testimony serves as a daily encouragement. I draw strength from her. It is likely that, being colleagues, we would have begun a friendship. But illness has united us on a deeper, more intimate level. I value our connection and view her testimony as encouragement as I continue to derive meaning from my dwellings with illness.

Kristeva (2005) describes these mothers of children with disabilities, such as Era, as "courageous." She states:

Everyone knows that in most cases it is primarily the mother who "manages" and "cares for" the child. However *worn down* the mother of the "disabled" or "troubled" child may be, she remains a *fighter*. She only despairs about what will happen to her child "after

her death.” As long as she’s alive, the mother is there to guarantee life to the best of her ability, whatever the conditions. And since the famous “crisis of values” we’re going through really upholds only one value which seems to garner overall support—“life” as a value itself—courageous mothers are considered the cornerstone of today’s civilization, a civilization which has lost its point of reference. (date, reference).

In reviewing narratives of mother’s of disabled children, I have gained “a sense that a woman must justify her continued investment in what is publicly perceived as a defective commodity” (Landsman, 2004, p. 109). To some, a child with special needs may be viewed more as a burden than as a blessing. In the July 1983 journal *Pediatrics*, Peter Singer made profound and controversial statements regarding the value of a disabled infant’s life. In summary, Singer justified killing an infant with a disability because the disability often creates financial and emotional hardship on the family. Additionally, if the family had pre-determined the number of children they wished to raise, eliminating the child with disability/ies could allow space for another child to enter the family that would be healthy and go on to live a productive life. Singer’s (1983) statements reduce the infant’s life, specifically the infant with disabilities, to a commodity. In this light, a life is a “thing” that can be discarded, like a pair of shoes that do not fit as comfortably as one might like. The disabled infant is no longer a person; the individual has been removed from the conversation. Also removed from the conversation is how killing the infant would affect the mother. I am not specifically referring to how abortion affects the mother, although this is a noteworthy discussion that demands attention, because Singer’s (1983) statements seem in favor of killing the child after s/he has been born. Although the patriarch may have reduced the infant to a commodity, I imagine that it could be more difficult for the mother to respond in the same manner.

Mothers of children with special needs experience a roller coaster of emotions. However, the mother is not the only family member on the roller coaster ride. In *Ian's Walk: A Story about Autism*, Rolland and McGuire in Lear (1998) acknowledge that “[s]iblings of children with disabilities...have extra challenges in their lives.” I would like to broaden Rolland and McGuire’s statement by replacing “disabilities” with “illness” as a general way of including illnesses, disabilities, disorders, and the like. Like the individuality of the ill person, illness comes in a variety of shapes and sizes, so to speak. Some illnesses, like Joubert Syndrome, have more pronounced effects. With other illnesses, like autism, the ill person may look normal but s/he responds to ordinary environments in very different ways. Under this description, some developmental delays, like the ones that Bradley experiences, could be included in this cluster. Siblings usually have responsibilities taking care of these siblings and may not fully understand why their brother/sister acts “different” but looks “normal.” They may experience negative feelings of embarrassment about their sibling, feeling alone because their friends do not have siblings with similar disabilities, or anger because their family is living with the disability. But through caring for a sibling with special needs, these siblings also learn positive feelings of loyalty, responsibility, and love for someone who is “different.” “The healthy siblings learn valuable lessons of responsibility, compassion, and toleration of differences. They grow to understand that while life is not perfect, it is still good.” (Rolland and McGuire, 1998, front matter)

My oldest son, Tyler, was three years and eight months old when Bradley was born. Tyler was an active part of my pregnancy with Bradley. He was with us when we learned that he would be having a little brother. Given a choice between two names, Tyler felt that “Bradley” was well suited to be his brother’s name. Tyler eagerly called friends and family to announce

that we were having another son. Each time we visited a baby section of a store, Tyler would pick out an outfit or toy or book for his little brother. Tyler made an orange cat at one of those “make your own stuffed animal” stores so that he could present it to Bradley at their first meeting. Tyler eagerly took mental notes as we instructed him on what to expect when his baby brother came home. He looked forward to taking care of Bradley, giving him a bottle, soothing his cries, or even helping to bathe him. We told Tyler that we would be at the hospital for a day or two, and then we would be home. It was difficult for Tyler’s three year old mind to understand why our prescribed plan had been altered. He did not understand why we had to spend time away from him in another city or why his little brother was not coming home. He did not understand why he could not give him a bottle or the purpose of the tubes taped to Bradley’s cheeks.

Admittedly, I have been self-centered in this examination of my Self. Bradley’s illness has affected members of this family other than me, although in different ways. This notion is evident in some of the recent conversations I have had with Tyler. Although the onset of Bradley’s illness began almost four years ago, the events are still very fresh in Tyler’s mind. I have seen several pictures that Tyler has drawn, some for class assignments others at leisure, that depict something that elude to the fact that his little brother had a broken heart. Recently, in Tyler’s presence, I was discussing Bradley’s illness with a colleague. Tyler became very retreated and dismissed himself to another room. After the conversation with my colleague, I found Tyler sitting at a desk, tears streaming down his face. It took quite some time to coax from him what was bothering him. I played a guessing game for some time as my mind rewound the conversation with my colleague. When I asked if he was upset because I was talking about Bradley’s illness, I did not need to wait for verbal affirmation because Tyler’s face provided the

answer I was seeking. Despite the time that has separated all of us from the main ordeal, wounds are still very raw for some. As I continue to seek healing through my writing, I hope to discover ways that I can also help Tyler and others who have been affected by the Bradley ordeal heal from the affects of illness.

CHAPTER 6

ILLNESS, MOTHERHOOD, AND EDUCATION:

REDEFINING “NORMAL”

When those in my circle inquire about the topic for my dissertation, I describe it simply as the “Bradley ordeal.” They often nod in apparent agreement as if they understand the subject of my study yet offer a perplexed expression as they ponder how I have been able to spend so much time writing about a topic as seemingly simple as illness. For me, the Bradley ordeal has been anything but simple; it has been a time of chaos and complexity, a time of psychoanalytic inquiry through autobiographical means, a time to investigate my Self as a mother dwelling with illness. I must credit Delese Wear (personal communication, November 8, 2010) for pushing me to complicate the term “ordeal” within the context of my study. When developing an earlier paper on the subject of illness, “ordeal” was the only word that came to mind that could summarize my encounter with illness. Although the term initially served as a placeholder, it illuminated an area of my Self that demanded attention. In alignment with Webster’s definition of the word, this experience has undoubtedly been a “severe trial.” Additionally, I continue to uphold that I am responsible for Bradley’s illness. I feel as if the additional trials that I have/am experienced/ing are indeed some way of determining my guilt or innocence. Although, unlike the accused subjected to the decree of the American judicial system, I am not innocent until proven guilty. The Others within have determined my verdict: I am guilty—guilty of causing Bradley’s heart defect, guilty of his subsequent delays, guilty of manifesting this illness within me, guilty of taking time away from my family to write about my illness. Charon (2006) states:

[I]llness seems to induce irrational guilt in patients who search for something they may have done to cause their lymphoma or breast cancer or multiple sclerosis, almost as if

identifying something concrete in their experience as the proximal cause of an illness is preferable to accepting its random unfairness, even at the cost of assuming some of the responsibility for their illness themselves. (p. 31)

Bradley's heart defect was random. It is unfair that neither Bradley nor I will ever know his life free from illness. Placing the blame on myself for Bradley's illness gives me an outlet, a reason for this unfair randomness, despite the psychological damage the excessive guilt is causing. The chapter allowing me to grapple with my feelings of extreme guilt has not been written. Fleshing out my feelings of guilt created by Bradley's and my own illness is complicated. This examination into my Self does not end here with my final chapter; there is still much work to be done.

This pathography about the Bradley ordeal and my illness which has stemmed from his illness has been an ordeal to write. I have spent countless hours typing hundreds of thousands of words on my pink laptop computer's keyboard making the letters on the keys unrecognizable and abusing the space bar so that now it has begun to stick. Words that I type are often imprinted on the page inaccurately juxtaposed, forcing me to pause so that I may insert a pause between words. But during these times of pause, I have been forced to slow down my progress as I reflect upon, analyze, and synthesize my experience as a woman, a mother, an educator dwelling with illness. Writing about illness is physically exhausting. Writing about illness is also emotionally exhausting. Throughout this process, I have allowed my Self to be exposed, scrutinized, stomped on, and ripped apart hoping that I would begin to understand how illness, specifically illness that is ignored, affects one's psyche and relationships with others. It has been painful to subject my Self to such an ordeal.

In a recent Chemistry class I was describing the formation of elements through nuclear reactions occurring in stars. As my students and I discussed the article “Where do chemical elements come from?” (Ruth, 2009), I came across a passage that struck a different chord than one relating to our study of chemistry:

A star is a balancing act between two huge forces. On the one hand, there is the crushing force of the star’s own gravity trying to squeeze the stellar material into the smallest and tightest possible ball. On the other hand, there is a tremendous heat and pressure from the nuclear reactions at the star’s center trying to push all of that material outward. The iron nucleus is the most stable nucleus in nature, and it resists fusing into any heavier nuclei. When the central core of a very massive star becomes pure iron nuclei, the core can no longer support the crushing force of gravity resulting from all of the matter above the core, and the core collapses under its own weight. (Ruth, 2009, p. 7)

A young star is primarily composed of hydrogen atoms, the most simplistic of all the elements. When the nuclei of two hydrogen atoms within the star collide, a helium atom is produced and energy is released. The releasing of energy helps to keep the star alive. Two helium nuclei could collide, producing a beryllium nuclei and releasing energy. These successive fusion reactions continue forming new elements and releasing energy until the iron nuclei is formed. At this point, the process ceases because the creation of nuclei heavier than iron requires an input of energy from the star. If the star were to make nuclei heavier than iron, it would eventually use up all of its energy and cause the star to implode.

As I discussed this article with my students, my mind drifted away from nuclear chemistry and toward my work in understanding how illness has shaped myself as a woman, a mother, and an educator. I was once like the young star, filled with simple hydrogen nuclei,

trying to maintain a balance of forces. Learning of Bradley's illness was an outside force creating chaos in my life, prompting me to search for inner stability. I continued to synthesize my emotions so that I could gain stability. By doing so I was simultaneously repressing my heavy emotions deep into my core. My core became a dense metallic mass, ultimately reaching a point at which I could no longer repress my emotions. The imposing, crushing pressure of the outside forces of illness threatened to destroy my inner Self as it pressed my core deep into a depression. In some ways, writing about my illness has perpetuated my depression. I have not only spent this time dwelling with illness, I have spent countless hours reworking, rethinking, reliving every facet of this illness which I fear has pushed me into a deeper depression. My hope is that as I have pressed deeper into this depression, searching the Self as I seek to understand illness, I am in some way like a supernova, ejecting a shockwave of new material into the system. The immense radiation from this supernova explosion, partially detected in the form of visible light, may not be seen for many light years. However, the effects of my work are indeed present at minimum within my Self but hopefully within the illness community. My work will become my legacy.

It is not my intention to mislead one in believing that I have a feeling of bitterness toward this time I have spent understanding my illness dwelling. Indeed, I feel quite the contrary. It is true that this time of Self discovery has been tremendously difficult; however, I have gained much insight into how illness has affected my Self. I have found great personal healing in working/writing through my emotions which were not previously articulated. I am not disappointed with my discoveries; although, there is much more to discover. While one goal of writing about my illness dwelling has been therapeutic, an equally important desire is to interject an underrepresented voice in order to complicate the conversation. At the conclusion of this leg

of my journey, I hope that I will have developed something that is both understood by those who read my text and worthy of their complicated conversation.

I have always longed to have a deeper connection with those who attend to my medical wellbeing. When I worked as a medical assistant in a cardiology office, I strived to make personal connections with my patients in hopes of facilitating a healthy doctor/patient relationship. Likewise, I have strived to attain the same ideal within the teacher/student relationship. Yet, doctors are discouraged from becoming emotionally attached to the patient for fear that there may be lapses in judgment when determining the most appropriate methods of treatment. Similarly, many teachers are cautioned of crossing the “invisible line” (Silin, 1995, p. 39) that would distort the teacher/student division. This seems to be an odd practice for professionals who claim to be in the business of helping people. I have often wondered what impact this mind/body disconnect has had on doctors/teachers who maintain this separation of intellect and emotion. Intellect and emotion should not be isolated from one another because it is in the unification of this dichotomy that practical meaning is derived from personal experience.

This pathography has been an account of three illnesses: Bradley’s congenital heart defect and its a/effects, my illness which has developed because of Bradley’s illness, and society’s illness of excluding the ill person’s voice from the conversation. I have sometimes thought of my illness as a parallel illness to Bradley’s, an illness that is occurring simultaneously with another illness. This parallelism makes me think of Rita Charon’s (2006) elaboration on a type of “parallel suffering” (p. 32-33) between patients and their doctors. She uses an example from child psychology, where young children play alongside each other but do not engage in interactive play with one another. Similarly, she suggests that patients and doctors are both

suffering from the a/effects of illness. However, both parties are suffering alongside each other as opposed to with each other. She elaborates:

What power would devolve on our medical care if these two could take stock of one another's emotions and engage fully in their joint suffering. The intersubjective recognition of doctor by patient and patient by doctor would deepen knowledge, steady presence, and prove commitment. Such mutual recognition, transcending parallel suffering, would enable them both to reflect on their common journey and, by virtue of being "together" on it, would lessen one another's suffering. (2006, p. 33)

I think that part of the reason that the voice of the ill person is not heard is because s/he may feel alone on her/his journey. For over a year, I remained silent about my illness because I felt that no one would be willing to listen, especially as time distanced those in my circle from the initial events of the Bradley ordeal. Even now that I have begun to open up about my illness, there are still many times that I feel alone. Writing about my illness has offered companionship, but I long for the conversation that I can exchange with an other that will travel alongside as I dwell with illness. It is possible that my feeling of aloneness stems from my longing to appear normal, to assimilate with the larger crowd. Vocalizing the a/effects of my illness would isolate me from normalcy. I would not be a "good enough" mother if I acknowledged to others my repressed feelings of resentment toward my child and his illness. If there is some way for doctors and patients to join voices on their journey with illness, it is possible that this feeling of aloneness would diminish. At the same time, I feel that Charon's (2006) notion of collaboration can reach into the classroom, joining teacher and student on the educational journey. In order for this collaboration to occur, oppressions created by the institutions of illness, motherhood and education must be revealed and acknowledged in the conversation. Thus, as I finalize this leg of

my illness dwelling, I find it appropriate to examine how the institutions of illness, motherhood, and education contribute to the de/construction of normalcy.

De/Normalizing Illness

In *Birth of the Clinic*, Michel Foucault (1994) questions the metanarrative to which so many individuals subscribe that uplifts the doctor to some sort of nobility status. According to Foucault (1994), many endorse the myth that doctors are omniscient, possessing a certain “gaze” (p. xi) that allows her/him to see all and reveal what is hidden from view. This “gaze” that Foucault describes is not acquired through the accumulation of knowledge from textbooks; instead, it is developed through wisdom and the observation of patients. There is a universal understanding within the confines of the myth that assumes that the doctor’s words are ultimate and cautions one of questioning her/his directives.

Foucault (1994) argues that this metanarrative regarding the doctor was created around the time of the French Revolution, when the hospitals were no longer under the direction of the church but instead became ruled by the government. In *The Greatest Benefit to Mankind*, Roy Porter (1997) describes the Revolution’s impact on medicine:

The medical revolution was the work of a cadre of physicians seizing the opportunities afforded by salaried appointments of Paris’s vast public hospitals....French hospitals had traditionally been pious foundations devoted to tending the sick; elite physicians were to turn them into scientific machines for investigating diseases and for teaching the vast numbers of students...flocking to the capital for medical training. (p. 306)

Although many continue to view doctors as a type of nobility, as I have in some regards viewed Bradley’s physicians for their remarkable ability to correct his heart defect, I must agree with

Porter (1997) that the pendulum has swung away from the doctors and toward scientific investigation and discovery. The common physician, despite their remarkable skill and expansive knowledge, is not regarded in the same light as those scientists who devote their lives to finding the cure for disease or developing the most advanced medical procedure. Put simply, scientific inquiry drives the money train. Medical humanity has been pushed to the side in the name of scientific discovery. My concern is that “science demystifies, dehumanizes, creates impersonality, clinical detachment and modes of mechanization, all of which may seem remote and uncaring” (Porter, 1997, p. 671).

I must pause here to admit that when I first began my study on the relationship between doctors, patients, and illness, I placed much of the blame on doctors (and the medical profession in general) for dehumanizing illness, for silencing the patient’s voice. As I have delved deeper into medical literature, reading personal accounts written by doctors who describe their feelings of diagnosing and treating the ill person, I have had a change of attitude. While there are undoubtedly doctors who lack bedside manner, I do feel that the majority have the patient’s best interest in mind when they are contemplating treatment options. My students often say that they want to become doctors because of the substantial salary that accompanies the profession. But in recent conversation with Bradley’s pediatrician, I was encouraged to believe that I should encourage my students to embrace areas of scientific research instead of the medical profession if they are seeking monetary value. Undoubtedly, governmental and private funds are being poured into scientific research to develop cures and to advance medical technologies for plaguing illnesses. While my students believe that becoming a physician promises a hefty paycheck, if it is truly money they seek scientific research may provide a better pathway to reach their monetary goals.

Unfortunately, as the government continues to gain a tighter grasp on the medical realm, I feel that the level of humanity will continue to decrease. While I am interested in the notion of socialized medicine for reasons such as the availability of healthcare to all people, I am concerned with the lack of power bestowed upon the physicians. By “power” I specifically mean the physician’s ability to freely use her/his judgment in treating the ill person. As it stands currently, the scientific research companies and other large corporations with deep pockets are already steering the ship. Placing ultimate control in the hands of the government only further removes the physician from power.

Largely due to the emphasis placed on monetary gain, the realm of medical care has become an institution. Porter (1997) states, “The medical machine has a programme [sic] dedicated to the investigation of all that is objective and measurable and to the pursuit of high-tech, closely monitored practice. It has acquired an extraordinary momentum” (p. 629). Medical institutions have become synonymous with expansive buildings, state-of-the-art facilities, high-tech procedures and advanced practices. While I was in Atlanta during Bradley’s hospitalization, I visited the campus of Emory University and the adjacent hospital. I felt as if I had stepped into the Holy Land, insisting for a moment that the carefully manicured green spaces were singing melodic hymns as I approached the imposing medical collage. I am fearful of the patient’s role in the midst of this scientific advancement, questioning whether the ill person’s voice will be heard above the noises of the laboratory equipment.

Previously (in Chapter 2), I discussed Frank’s (2005) “restitution narrative” of illness which maintains that there is a way out of illness, that there is hope, that circumstances will get better. The medical institution helps to perpetuate this hopeful thinking. I am reminded of a local hospital’s television commercials that can be summed simply: patient presents with illness,

chooses to seek treatment from a certain doctor who has exceptional skills, and shortly thereafter the ill person is “as good as new,” returning to life as normal before illness attacked her/his body. Similarly, Frank (1995) elaborates on television commercials which depict the ill person seeking remedy from over-the-counter medications. Once the advertised product is taken, the ill person’s symptoms are relieved and s/he can continue about her/his daily routine. Restitution narratives suggest that the ill person is some way in control of her/his illness, the s/he has a choice in who to seek for treatment or what type of medication can be used to alleviate the ailments. But not all have a choice in the type of care s/he desires. Ill persons who cannot afford healthcare or those that treatment is not possible cannot subscribe to the restitution narrative. Nevertheless, “[i]nstitutional medicine is asserting its preferred narrative. This assertion goes beyond hospitals to the strategies that more powerful interest groups use to shape the culture of illness” (1995, p. 79). While restitution narratives undoubtedly have a place as a means of conveying the ill person’s story, to endorse this type of narrative as a way of shaping cultural attitudes about illness is oppressive to the very people the institution is claiming to serve.

Frank (1995) states, “Restitution requires fixing, and fixing requires such a mechanistic view. The mechanistic view normalizes the illness: televisions break and require fixing, and so do bodies” (p. 88). If the institution of medicine strives to look at the optimistic side of illness, “...that for every suffering there is a remedy” (Frank, 1995, p. 80), then this could be a possibility as to why the emotional aspect of the patient is not always recognized. Charon (2006) suggests that emotional topics such as shame, fear, blame, and guilt are often avoided in the doctor/patient relationship because either or both party(ies) is/are uncomfortable in broaching the subject. However, avoiding the patient’s emotional wellbeing can ultimately cause additional damage to the patient’s physical health. When my obstetrician called me a week after Bradley

was discharged from the hospital to ask how I was doing, I told her that I was “fine.” This was nothing short of a lie. I was not “fine” in any sense of the word. Yet, I made the assumption that she was too busy to really listen to “how I was doing,” to hear that I wept uncontrollably for most of the day, that I resented my child and the fact that he was not “normal,” that I felt guilty for somehow causing all of his medical problems. It is not my intent to mislead; my obstetrician is a wonderful, compassionate, caring, skilled physician. Having been her patient for over ten years, she has consistently provided the most attentive care and has never given me reason to believe that she was not sincere in her inquiry regarding my status. On the other hand, knowing her popularity as a physician, I am sure that she had an office full of patients demanding her attention. I speculated that she did not have the time to listen to me drone about the multitude of problems plaguing my current situation. Admittedly, I was not in the right mindset to acknowledge that I needed to divulge my feelings of insecurity and inadequacy, and most likely would not have discussed my feelings with her had she encouraged me to be transparent. Yet, as a courtesy, I provided a sufficient answer to her question so that she could focus attention to the “paying customers.”

The notion that my physician did not have time to listen to me was not placed in my mind by anything of her doing; this idea stems from capitalism’s influence on medicine. In my mind, my physician was losing money, so to speak, by taking time to talk to me when she could have been treating, diagnosing, testing other patients that would help boost revenue. News stories describing the inadequate funding for healthcare are in abundance. Patient quotas must be met and procedures must be scheduled in order to secure financial stability. Because of the overwhelming need to generate monetary funds, the current conditions of most doctor/patient relationships do not afford the required time needed to embrace the emotional component of the

relationship. I am not one to typically lash out against America's capitalistic ideals. However, I suggest that it is unethical when the doctor/patient relationship is compromised, and consequently "quality care" of the holistic individual, for the sake of monetary compensation.

Because of the incessant focus on monetary value, the personal side of the ill person can be overshadowed by test results and dictation notes plaguing the medical chart. Rita Charon has devoted her life's work to the field of narrative medicine which strives to identify the ill person as an individual rather than a medical case. Charon (2006) defines narrative medicine as "medicine practiced by the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness" (p. vii). Charon (2006) recognized that her medical students were not being afforded the opportunity to express the personal impact their patients, and the treatment of their illnesses, had on their psyche. After years of supervising medical students, she became concerned of the potential harmful effects this lack of expression would have on the medical students' psyche. The patient's medical record has ample room for the doctor to transcribe test results, plans for treatment, prescribed medications. However, no place exists for a doctor to transcribe personal thoughts and feelings. Charon (2006) "was unhappy that [her] students did not have a routine method with which to consider their patients' experiences of illness or to examine what they themselves undergo in caring for patients" (p. 155). In response to this concern, she implemented the "Parallel Chart," a tool in which medical students could record personal feelings and concerns about the treatments of their patients' illnesses. Several times a week, the medical students would convene to discuss entries in the Parallel Chart. Charon and her students identified stories' similarities, common themes that each medical student was experiencing in her/his own way. Bringing these personal thoughts and feelings to the forefront allowed for community to occur among a marginalized group.

Charon (2006) states, “Without the narrative acts of telling and being heard, the patient cannot convey to anyone else—or to the self—what he or she is going through” (p. 66). Charon encourages doctors to listen to their patients’ stories, because this could possibly be the window to healing and restoration. She recounts the story of an elderly African American woman who suffered from a plethora of illnesses. The woman insisted that her health problems began when she fell off a horse at a young age. After treating the woman for twenty years, Charon was deemed trustworthy enough to be privy to the real pain that was plaguing the woman: she had been raped by a neighbor white boy. Charon claims that after revealing this horrifying event, one in which the patient had kept compartmentalized in her soul for some seventy-plus years, the woman’s health began to improve.

I reflect back over my own illness. For almost a year and contained all of my emotions, my anxieties, my fears. When Bradley first became ill, I had hordes of individuals who offered their help and some even a shoulder to cry on. However, at the time I was not sure what I needed; the influx of chaos had rattled my psyche. By the time I figured out how I could be helped, most of the individuals had vanished. A few remained; however, I felt awkward calling out to them after so much time and distance had separated us from the events. My mom frequently says that time is one of the best healers. Maybe. But time can also cause one to push the feelings further out of sight, compartmentalizing emotions which should be dealt with.

Throughout my study I have come to appreciate the symbiotic nature of the doctor/patient relationship. I previously viewed the relationship as parasitic, one in which the doctor robs the patient of dignity and personal attachment. However, I have recognized the mutualism associated with both parties. The doctor needs the patient just as the patient needs the doctor. Each fulfills something that the other lacks. The patient comes to the doctor seeking prevention

from or treatment for illness. In turn, the doctor needs to have reciprocity from her/his patient to feel validated. The utilization of narrative medicine is essential within the confines of a “health care system that places corporate and bureaucratic concerns over the needs of the patient and that leaves patients feeling abandoned and unheard” (Charon, 2006, front matter). For these reasons, narrative medicine and pathography are vital lifelines for valuing the individuals within the realm of illness.

De/Normalizing Motherhood

One of the most significant works describing motherhood as an institution is Adrienne Rich’s (1986) *Of Woman Born*. In this influential piece, she details the pressures placed on women by the patriarch to be mothers upholding specific ideals:

Patriarchy depends on the mother to act as a conservative influence, imprinting future adults with patriarchal values even in those early years when the mother-child relationship might seem most individual and private; it has also assured through ritual and tradition that the mother shall cease, at a certain point, to hold the child—in particular the son—in her orbit. Certainly it has created images of the archetypal Mother which reinforce the conservatism of motherhood and convert it to an energy for the renewal of male power. (Rich, 1986, p. 61)

According to Rich, the aim of the institution of motherhood is to ensure that society remains under male control. She insists that the patriarch depends on women as mothers to carry out the patriarch’s agenda; without the aid of the woman, the patriarch will fail.

Being a mother is complicated. It is more than a job, more than a responsibility. It is an emotional investment which carries significant weight. Rich (1986) insists that motherhood

cannot be compared to slavery or forced labor because the laborer can hate his master/boss and despise the work, but a mother can simultaneously have both love and anger for her child. Some women have to go beyond the limits of being the emotional stronghold for their family; some may also be the physical and financial providers as well. Rich (1986) refers to motherhood as a “powerless responsibility” because “it is recognized in some quarters, at least, that economic forces, political oppression, lie behind poverty and unemployment; but the mother’s very character, her status as a woman, are in question if she has ‘failed’ her children” (p. 52).

It is unnerving to constantly worry about failing my children. I am fearful of not spending enough time with them so that they might feel loved and nurtured. At the same time, I am fearful that if I am overbearing I am not giving them opportunity to gain independence. I am charged with a great responsibility of being a “good-enough” mother to my two sons. Society persuades me to raise my sons so that they will be “manly,” rough and tumble, sports fanatics. This depiction is what the patriarch views as “normal.” However, I want my sons to feel comfortable with their “feminine side,” as my students would say. I want my sons to feel comfortable expressing their feelings, enjoying fine food, and appreciating the arts. But Rich (1986) gives me encouragement when she says, “The ‘son of the mother’ (the mother who first loves herself) has a greater chance of realizing that strength and vulnerability, toughness and expressiveness, nurturance and authority, are not opposites, not the sole inheritance of one sex or the other” (p. 209-210). These quality traits do not have to be mutually exclusive. However, Rich (1986) cautions that before my sons can learn from my teachings it is imperative to first learn to love myself. Sometimes it is easier to love another than it is to love my Self. Is not this notion essentially the reversal of the Golden Rule—To love your neighbor as yourself? Freud (1961) did not believe that it was possible to love another as oneself. Loving the Self can be

quite difficult. There are so many aspects of my Self that I find great difficulty in loving, parts that I choose to sweep under the rug so that they are not obvious to Others. However, Kristeva (2005) states that the “‘good enough’ mother succeeds in loving her child as herself, and then as another self.” If I am not completely at the point where I can say that I love myself, then can I completely love my children? And, furthermore, does not loving myself exclude me from the “good enough mother” club? I am not sure, but I am perplexed by this notion.

While trying to keep up with the demands of the patriarch, I have realized that there is no area for what I refer to as “me time.” Oftentimes, I forsake my own emotional wellbeing for the benefit of tending to my multiple responsibilities. I frequently neglect my needs, my Self; I feel this is the only way I can fulfill all of my duties. I am rarely in solitude. I do not mean to grumble; indeed, I enjoy my responsibilities as both a mother and an educator. Likewise, it is not my intent to mislead others to believe that I have not been offered help during chaotic times. I have not made it this far on my journey independently. My dilemma has not been the lack of people asking, “How can I help you?” The issue has been trying to determine exactly what kind of help I needed at the moment. This problem was especially evident during the beginnings of the Bradley ordeal. Frank (1991) says,

Except for the need to hear that it is all a mistake...the ill person does not know what she needs, though the needs are very real....All you can do is let yourself discover these needs, and all others can do is give you the time and space to make this discovery. (p. 47-48)

Time is required to work through the psychological pain caused by illness. Raffa (1992) refers to this pain-dwelling time as “island work.” She states, “Our island work usually begins when our psychic pain is so intense that we are forced to acknowledge our need for help” (Raffa, 1992,

p. 109). Sometimes this “island work” can occur in solitude, although it doesn’t have to. Delese Wear (1993) says that we know our self by our interactions with others. However, she is cautious of becoming too interdependent on others. She explains:

I want not just a room of my own; I want figurative space in my life. I’m slowly finding that my view of myself is not solely in relation to others, but is one that emerges in moments of impenetrable, profound silence, moments in which I am alone, moments in which I am no longer mother, daughter, teacher, wife. (p. 4)

I can relate to Wear’s (1993) need for solitude. I have often commented on my struggle to balance the demands of wife, mother, daughter, teacher, church member, friend and the excessive amounts of energy spent to “keep up an appearance” (Frank, 1991, p. 64). I can also identify with Nettles (2001) who wrote, “Being all things to all people—at home and on the job—leaves little time for being oneself” (p. 38). It is through my writing that I can create this place of solitude, “a room of [my] own” (Woolf, 1929/2007, p. 2).

De/Normalizing Education

In *The School and Society*, John Dewey (1915/2001) describes the institution of schooling:

[T]he school as itself [is] an institution, in relation both to society and to its own members—the children. It deals with the question of organization, because all waste is the result of the lack of it, the motive lying behind organization being promotion of economy and efficiency....[T]he primary waste is that of human life, the life of the children while they are at school, and afterward because of inadequate and perverted preparation. (p. 40)

One of Dewey's primary concerns was that the curriculum to which students were being exposed during the school day was not representative of the lived experience. He believed that one of the greatest "wastes," as he phrased it, was that students were not afforded the opportunity to bring outside experiences into the classroom, nor allowed to transfer what was being learned in the classroom to everyday experiences. He firmly believed that a continuous flow should occur between a student's school and non-school lives. In other words, keeping these two realms separate is an "isolation from life" (Dewey, 1915/2001, p. 46).

William Reynolds (2003) is one curriculum theorist who has personally encouraged me to find ways to bridge the school and the lived experience. Having had the privilege of studying with Dr. Reynolds throughout my doctoral program, I have felt challenged to examine the hidden curriculum and to find ways in which to enhance dialogue within my own classroom. In his essay "Critical Pedagogy within the Walls of a Technological Institution: Toward a Reconceptualization of Classroom Practice," Reynolds (2003) describes a class in which he tried to "define, initiate, refine, and maintain a degree of critical pedagogy" while "reconceptualiz[ing] traditional classroom practice" (p. 14). Reynolds was met with mixed sentiments regarding his attempt to infuse unfamiliar and sometimes taboo subject matters into the classroom conversation. In order to facilitate this type of learning style, Reynolds (2003) had to find a "common language" (p. 15) in which the students could engage in dialogue. I am reminded of Virginia Woolf's (2002) statement that there are no words to describe the ambiguity of illness. As ill persons continue to describe, both verbally and textually, their experiences as one dwelling with illness, a common language will begin to form that will help to alleviate Woolf's (2002) concern. Reynolds (2003) comments that as students engaged in reading and rereading of the texts, they were united as a "community of readers" (p. 15). Similarly, as ill

persons continue to write and read pathographies and discuss illness, community within illness is created. Dewey (1915/2001) might even describe this community as a society, “a number of people held together because they are working along common lines, in a common spirit, and with reference to common aims” (p. 10).

Reynolds (2003) also notes that some of his students were hesitant about discussing the texts in class, and rarely, if at all, contributing to class discussion. Concerned, he “made...resistance a topic of discussion” (p. 15). As students began to divulge their reasoning for not engaging in class discussion, he learned of their “stories of pain and dehumanization. They discussed the fact that a majority of their educational experiences were ones in which silence, obedience, and ‘playing the game’ were encouraged and self-expression, meaning, and discussion were for the most part discouraged” (p. 15). I find great similarity in comparing the resistances of these students’ classroom discussion and the ill person’s discussion of illness. Like the students, for quite some time I felt the need to remain in silence about my illness, to hide behind a façade so that I appeared normal, discouraging any attention that I may have attracted by expressing my concerns about my illness dwelling. One way Reynolds (2003) found to encourage those hesitant students to engage in discussion was through the use of dialogue journals. As students embraced the dialogue journals, conversation began to flow, first textually and then verbally. Using dialogue journals to record thoughts and feelings in order to stimulate conversation makes me acknowledge how writing about my own illness has helped to stimulate conversation among other members of the illness society. Writing my pathography, similar to the students’ dialogue journals, provided a “room of my own” (Woolf, 1929/2007) where I could begin to find a common language to describe illness that could be used to communicate with other ill persons.

Society, generally speaking, does not accept the ill person into its circle. Illness is taboo, the Other. When one is ill, s/he must not speak of it so not to appear vulnerable. Instead, one is encouraged to embrace an optimistic approach to life. I often feel this way within the field of education. An administrator once warned me that I should only engage in uplifting dialogue with my students. It was suggested that the students regularly struggled with trials and tribulations and desired to foresee a more positive alternative to their circumstances. I was appalled by this administrator's suggestion. I question the validity of my role as a teacher if I were to engage in such false, optimistic dialogue with my students. I do not suggest that my role is to be as a dreary raincloud, showering my class with pessimism and gloom. However, education must not limit its curriculum to that which is joyous; it has a responsibility to address the solemn curriculum as well. I agree with Dewey's (1915/2001) suggestion that "school...[should] be made a genuine form of active community life, instead of a place set apart in which to learn lessons" (p. 10). Most students spend more time in school during the early formative years of their life than in any other place. Therefore, should not the school community be representative of the community the students will be members of when the last school day has dismissed?

If, within the classroom, I choose to ignore such relevant pieces of "normal" society, such as illness, I am only "[mis-educating] students through dishonesty" (Morris, 2008, p. 123). The sharing of personal stories within the classroom, specifically those regarding illness, often validates what others are experiencing (or have experienced). To expect that we ignore illness in our lives is to demand that we adorn a façade in which to hide behind. In this case, I am not sure if I could consider myself a "real" teacher. I am not an expert in my classroom. I feel that my students and I are on an educational journey together as students of curriculum, learning from

each other as we travel these winding roads through life. Collaboratively, we jump through the necessary hoops designed by the institution while infusing opportunities to engage in meaningful dialogue.

Oftentimes, the personal impact that the teaching profession has on the educator is neglected. However, much can be gained from studying the lives of teachers and how their lives influence their work. Curriculum theorist William Schubert (1991) uses teacher lore as a means of uniting the personal with the practical. He defines teacher lore as

the study of knowledge, ideas, perspectives, and understandings of teachers. In part it is inquiry into the beliefs, values, and images that guide teachers' work. In this sense, it constitutes an attempt to learn what teachers learn from their experiences. (Schubert, 1991, p. 207)

Schubert recognizes that the personal experiences of the teacher indeed influence the practical application within the classroom. Teachers are often accused of taking their “work” home. (Here, I refer to the emotional investment of teaching, not the literal paperwork.) However, Schubert has a converse view, suggesting that it is the personal story of the teacher that actually influences her/his work. Assuming that teachers are influential in students' lives, learning more about the personal lives of teachers will provide insight into how students are being influenced.

The teacher's role in the classroom is similar to that of the physician in the medical office: each should strive to holistically understand the patient, both as an individual and as a person to be educated/treated. Likewise, the student/patient comes to the teacher/physician, whether by choice or force, seeking guidance. I am a mother who fills both roles: as a teacher (and thus a physician) and as a patient (and thus a student). Using personal stories within the educational realm can foster stronger teacher/student relationships and make meaningful

connections among those engaged in complicated conversation. Similarly, the sharing of personal stories within the medical realm “will more ably recognize patients and diseases, convey knowledge and regard, join humbly with colleagues, and accompany patients and their families through the ordeals of illness” (Charon, 2006, p. vii). It is my desire that one day I can share with the health professionals involved with the Bradley ordeal what has transpired throughout the past four years since its onset. Using shared knowledge through personal stories “will lead to more humane, more ethical, and perhaps more effective care” (Charon, 2006, p. vii).

Searching the Self for Normalcy

Institutions can serve to oppress because they insist that its members conform to a norm. Institutions do not allow for vulnerability, which is necessary for personal growth. But allowing oneself to be vulnerable is not necessarily easy to do. In reflecting over my own illness, I recall the miserable, gnarling, empty, aching feeling I had in the depths of my stomach when I insisted on keeping my complex emotions to myself. To expose such private thoughts is to allow one to be vulnerable. I could not afford to be vulnerable, because I had to uphold the image of the “good enough” mother. Charon (2006) says, “The healing process begins when patients tell of symptoms or even fears of illness—first to themselves, then to loved ones, and finally to health professionals” (p. 65). I believe Charon’s statement is accurate. Admitting the core of my illness was no easy task; on many occasions, I wrestled with emotions late into the night. Yet, when I began to write about my illness, to join thoughts and feelings about the Bradley ordeal, my pain was validated. I felt comfortable behind the shield of my pink laptop computer, knowing that what I wrote was confidential. I experienced further vulnerability when I turned in

my first paper which outlined my pathography. I remember being nervous as I handed in the manuscript, unsure of how my story would be received. I am fortunate that my account was well-received, thus validating my emotions from a secondary source. This validation prompted me to write additional papers, each carefully critiqued in such a way to strengthen the meaning to be gained from my text. I find it ironic that, before the early work of my pathography, there are only two whom I had allowed to read my story, neither of which were directly involved with the Bradley ordeal. I have been anxious to share my pathography with those in my immediate circle, for fear that they will discredit my account of the ordeal. Although I desire to publish my final manuscript, this threatens the ultimate vulnerability. My words will be exposed for all to criticize. On the other hand, it is possible that my story will be recognized by others who are also dwelling with illness, that “the disease that sets the body apart from others becomes...the common bond of suffering that joins bodies in their shared vulnerability” (Frank, 1995, p. xi).

“I don’t know how you do it” is a phrase I often hear from those in my circle. I assume the “it” they are referring to is my ability to multi-task. I am the picture-perfect example of an overcommitted woman. Between the interactions of teaching full-time, finishing doctoral coursework, volunteering time with my church, chauffeuring my two children to practices and appointments, and trying to keep up with my husband’s hectic work schedule, it is a wonder that I have not experienced a significant emotional breakdown. I often feel like a street performer I once saw who was balancing one hundred wine glasses on a serving tray. One slight movement in the wrong direction, one unexpected gust of wind would send the glasses shattering to the ground. I am not seeking pity; this over-scheduling is of my own doing. Moreover, I suspect that there are other women who can relate to my chaotic lifestyle; indeed, I am in good company. Yet, I question why I feel I must elegantly balance these wine glasses while attempting to ignore

the panging anxiety that stems from those threatening to jolt my poised serving tray. Why do I feel it necessary to maintain the image of a “good enough” mother and wife?

Similarly, I feel expected to uphold a façade of the perfect teacher within the classroom. It seems that education encourages teachers to believe that curriculum comes in nice, neat packages. Test scores, textbooks, programs never implemented are efficiently packed in cardboard boxes, taped shut, and stored away. The emotional dimension of the teaching experience, also part of the curriculum, is similarly compartmentalized and stored away. At the onset of the school year, the teacher must rid her/his classroom of unattractive, unneeded paraphernalia in order to prepare for Open House, a snapshot of what is to be maintained over the upcoming months. Teachers are instructed to make the classroom “look good” for visiting parents and students. The subliminal message conveyed encourages teachers to also make their personal lives “look good.” Any lingering personal problems not attended to over the summer break must remain private to be dealt with at a later time. Compartmentalized, boxed off. Anything other than what “looks good” should be pushed away.

Compartmentalizing the emotions perpetuates the Cartesian mind/body dualism. I am not suggesting that the classroom should be used to facilitate a political agenda or to air dirty laundry. However, a deep, intimate connection is made between individuals who choose to be vulnerable and share personal feelings about the lived experience. Bonnie Meath-Lang contends that “curriculum study based on lived experience becomes pedagogically crucial in the face of a popular culture that devalues the life story and appropriates it through the tabloid impulse and political inauthenticity” (quoted in Pinar, et. al., 2004, p. 530). She encourages students to use dialogue journals as a way of helping students find their voice. I have always viewed my classroom as a medium for discourse. I have gotten the vibe that most students feel comfortable

sharing their personal thoughts, feelings, and concerns in my classroom. Students are told what to do by teachers, administrators, parents, and employers all day long; most are looking for someone to listen to them for a change.

Compartmentalizing has also become commonplace in the medical facility. Patients are triaged and then moved from room to room as vital signs are recorded and symptoms are noted in preparation for the doctor's evaluation. There is little opportunity for the patient to engage in dialogue that could provide insight into how the patient is coping with illness. Perhaps it has become "normal" for doctors to spend as little time as possible with a patient while still managing her/his illness. The concept of "family medicine," where one physician has treated generations of the same family for medical conditions ranging from chicken pox to prenatal care, is essentially obsolete. Going to see a "Doc in the Box," (or "Urgent Care Clinic") for treatment of common illnesses is on the verge of becoming the "norm." I envision primary healthcare in the future of a capitalistic society being orchestrated somewhat like a fast food restaurant: you order off the menu, pay at the first window, and drive around to pick up your prescription. Where is the humanity in this type of care? In many ways, I see similarities between this type of healthcare and education. I resist the temptation to conform to the "norm" of teaching to the test, depositing unattached, meaningless knowledge into my students with hopes of them regurgitating facts in order to improve test scores. I hope that I can help my students find individual meaning in their lives. I want to be like the old "family doctor" that ultimately knows and understands my students as individuals. But getting to know my students on a deeper level could require addressing the taboo subjects that are omitted from the curriculum.

My students often accuse me of going against the "norm." They comment that most of their teachers are focused only on the standards needing to be addressed during the day's lesson

and that opportunities to engage in meaningful dialogue is scarce. Charon (2006) was going against the “norm” by encouraging her students to discuss their personal feelings about the patients that they were treating. Likewise, it is not the “norm” to discuss illness in the classroom. The state mandated curriculum standards afford little opportunity for discussing the affects of illness on both student and teacher. Thus, curriculum theorists strive to recognize those that have been left out of the curriculum and, most importantly, identify why this has happened. Apple (1975) emphasizes the need to not only identify those that have been left out of curriculum, but to understand the implications of such wrong-doing. He states:

The hidden curriculum in schools serves to reinforce basic rules surrounding the nature of conflict and its uses. It posits a network of assumptions that, when internalized by students, establishes the boundaries of legitimacy. This process is accomplished not so much by explicit instances showing the negative value of conflict, but by nearly the total absence of instances showing the importance of intellectual and normative conflict in subject areas. The fact is that these assumptions are obligatory for the students, since at no time are the assumptions articulated or questioned. (p. 99)

I often hear my colleagues comment that they wish their students would “think for themselves.” However, I question if the educational institution really desires for students to “think for themselves.” It seems that it would be much easier to maintain the status quo, upholding the “hidden curriculum” if such was never questioned. This type of curriculum is what curriculum theorists strive to dismantle because it serves to oppress. Pagano (1990) states, “Knowledge is power. Those who have it are more powerful than those who do not. Those who define what counts as knowledge are the most powerful” (p. xvi). Defining knowledge suggests that there is universal truth, prohibiting deviations. Curriculum theorists recognize that there is not one

universal truth but instead many truths. Therefore, differences are celebrated, recognized as attributes of individuality rather than shameful characteristics of the “other”. Stories of illness, not typically viewed as the “norm,” can find refuge in the field of curriculum studies.

Daily, I strive to infuse individuality into my classroom as I tip-toe the line of standardization enforced by traditional educational curriculum. I encourage each of my students to look beyond what society defines as “normal,” conversely embracing what makes her/him unique so that s/he may make a meaningful contribution to society. This ideal encompasses my teaching philosophy. Yet, I am perplexed as to why I cannot transfer my passion to de-normalize individuals from my professional to my personal life. I yearn for my child to be “normal,” to no longer be followed by a horde of medical professionals who expose the traits that single him out from the others. I long for my child to be grouped with the others instead of labeled as the boy whose excessive saliva rivals any dog’s slobber. I am terrified of the label my child will bear if he is not promoted to the next grade level.

It is unsettling to think that my child may not be classified as “normal.” I am not faring well with this recent possible diagnosis. I feel alone. I assume there are other parents who share similar anxieties because medical problems and developmental delays are not limited to children in a particular social, economic, or racial class. I feel as if I am fighting the same battle as others, yet with an army of one. Individually, parents of ill children are encouraged to find ways to connect their child and their lives to the realm of the norm. At each doctor’s visit, Bradley’s current medical status and developmental milestones are compared to a set of norms. Bradley’s case manager periodically questions how Bradley’s behavior is adjusting to the demands of a normal daily routine. Maybe all of the medical experts have gotten to my head. Maybe our world has become obsessed with “normalizing;” anything that does not fit into the cookie-cutter

mold is othered, different, strange, outcast. After all, what does it mean to be “normal?” It has become “normal” for some to have ultra-white teeth and plastic surgery. It has become “normal” for the majority of my students to wish to enroll in college after high school. It is “normal” for many people to engage in more textual communication with others than verbal communication.

On the other hand, at times I wonder if some people use illness as a way of defining themselves in order to assimilate with a particular group. A few years ago, I recognized that a number of my female high school students suffered from some sort of physical ailment. Knee braces and crutches commonly accessorized the school uniform. Physical therapy clinics became popular after-school hangouts. I often questioned the legitimacy of their ailments. To me, it seemed as if having some sort of knee or ankle problem made one more “normal.” I reflect on past conversations I have with my colleagues. At lunch we share stories of mothers with Alzheimer’s, husbands with cancer, children with learning disabilities. It is almost “normal” to bring some sort of illness to the table, as if traveling through the land of the ill in some way secures one’s place in society. I pause here to impress that I do not intend to make light of illness. It is not “cool” to be ill and does not make one noble. However, there is apparently some sort of superficial community among some people with some types of illness. Although not all illnesses are included in the conversation; illnesses such as AIDS, mental illness, and autism are oftentimes excluded from the discussion. There is such a desire for one to fit in with society that “people do not know how to be honest with one another [and] have forgotten how to be genuine” (Morris, 2008, p. 123). The battle between wanting to be accepted and wanting to be genuine is dizzying. Having lived a life behind a façade for so long, allowing myself to be vulnerable to others threatens my norm. I fear rejection. Society does not

traditionally accept that which is different from the norm, othered. Illness and lived experience may be viewed as Other, and therefore ignored in attempt to normalize.

It has been interesting to observe how my pathography has morphed over the past four years. Reading back over old papers I have written for other courses, I am intrigued by how my thoughts and tone in my writing have changed. My writing was once very sullen. My bitterness over the entire Bradley ordeal was clearly etched onto every page. Even though I once denied the suggestion, I do believe that I did suffer, and perhaps still suffer, from depression. At the beginning of the ordeal, my so-called “normal” life had been stripped from me, sending me into a tailspin in which I had little control. However, I have noticed a more optimistic turn in my writing as I have strived to find ways in which my pathography can help others. I do not mean to have a Pollyanna approach to my situation; I am no more “fixed” than Bradley’s heart is. There is much more “soul work” (Morris, 2008) to be done. Perhaps I have begun to embrace a “new normal.” I have a plaque in my house that says “One shoe can change your life...Cinderella.” On a shelf under the plaque I have a glass slipper that I purchased on a recent trip to Disney World. These two pieces serve as constant reminders that “normal” is not universally defined. Just as Cinderella’s foot was the only one that could fit into the glass slipper, I cannot expect my topsy-turvy life to be contained inside my neighbor’s white-picket fence. When I finally came to this realization and decided to stop trying to cram my foot into the glass slipper, I was able to walk a little better on the journey. Besides, a glass slipper is very rigid, inflexible, not at all suitable for traveling long distances. Similar to the façade I have tried to uphold, a glass slipper may look pretty on the outside, but what good is it really? I’m learning that I would rather wear an old worn out shoe if it’s comfortable, if it’s mine. Outside appearances can be misleading; it is the uniqueness of the individual that should be recognized.

The Wholeness in Brokenness

For some time, I could not put my finger on the exact etiology of my illness. I wondered why I felt depressed, although I use this term only because I have no other way to equate what I was (and still am) feeling. I tried to pin my emotions on one thing or another, but nothing seemed to fit. It was while reflecting on my writing that I discovered the reason for my bitterness: I suffer from loss. Throughout my pregnancy, I longed for those first precious days to bond with my new baby, the alien-child who had taken form in my womb. To have this time stripped from me makes my heart ache. I am not sure my husband shares my sentiment. It is true that Bradley is a part of him, but not in the same physical way that he is to me. I could possibly equate my experience with one who has lost a limb, only to be reconnected to a prosthetic some time later. “Here you go---a new leg. Good as new,” the doctor sings. True, this new appendage resembles a leg and functions as such, but is very foreign and the body must re-learn how to maneuver it. The patient is grateful for the new limb but longs for once was, in the same way I long for my perfect child before chaos disrupted my plan. By exploring my pathography, I have begun to come to terms with my repressed emotions. They are woven together in the form of an ugly monster that resides in the depths of my soul. It has been painful/therapeutic to allow these emotions to emerge. But knowing why I am depressed does not relieve me from its affects. Unlike a tumor that can be zapped with radiation, or a chemical imbalance that can be corrected with the aid of medication, the etiology of my disease is originated in the realm of time. And time stands still for no one.

I suffer from a loss of time, a time which I cannot regain. But Taylor (2009) reminds me, “[I]n the beginning—before the beginning—there is loss” (p. 19). Loss is part of the origin. Loss is both part of control and chaos. The butterfly has become a symbol for chaos, in part due

to Edward Lorenz's lecture titled "Predictability: Does the Flap of a butterfly's Wings in Brazil Set off a Tornado in Texas?" (Lorenz, 1993), and in part from John Gleick's (2008) opening chapter, "The Butterfly Effect," in his book titled *Chaos*. The term "chaos" has acquired a negative connotation, despite the fact that it is from Chaos that Cosmos was formed. Some choose to precede the term "chaos" with "organized," in possible attempt to defend its meaning. However, Winnicott (1971/2005) comments, "Organized chaos is a denial of chaos" (p. 74). It is acceptable that chaos is chaotic; there is no need to make excuses! The institution of education is frequently concerned with organization and control. However, this overemphasizing of the control ideal can stifle. "To live between chaos and form is to be alive" (Eigen, 2005, p. 58). Learning and living take place in the presence of chaos; it should be welcomed rather than rejected. Salvio (2006) says that "a student cannot become immersed in educative inquiry without experiencing conflict, and a loss of equilibrium" (p. 84). I believe that Salvio is not only referring to students within the confines of the classroom, but students of life as well. Being chaotic, having a chaotic life is acceptable, because it is within the realm of chaos that learning occurs.

While chaos has been a prominent companion in my dwelling with illness, I cannot pretend that it has been a welcomed traveler. Chaos has caused me great pain. It has disrupted my façade of the "good enough" mother. It has made me lose control. Furthermore, Chaos has shattered my life into a million pieces. I am broken because of the effects of chaos. This time of illness dwelling that has been accompanied by chaos has been traumatic. However, this time has helped me discover parts about my Self that I was previously unaware. In a way, chaos has given birth to a new concept of my Self. The birthing process is traumatic: onset of labor pains which demand attention; rush of endorphins as the body is overcome by a supernatural force;

administration of the epidural which numbs the body of the pain, but not of the imposing pressure; deep, heavy breathing accompanied by eyes tightly closed allowing for better focus on the all consuming rush of pressure, floodwaters, cries, relief. In a literal sense, the mother's body endures the chaos of the birth experience as a baby, the symbol of new life, is expelled from her body. Eigen (2005) elaborates on Bion's notion of the baby as an "annihilating force...[drawing] on a background of real danger attached to birth, but most pointedly [referring] to psychic annihilation" (p. 23). Eigen (2005) further defines the annihilating baby as "psychoanalysis, an idea, a feeling, a work of art exerting pressure to be born" (p. 37). Similar to literal birth, psychic birth is traumatic as parts of the Self are made vulnerable in the realm of illness: pain of illness; endorphins that have allowed me to cope; repression of emotions which numb the body but not the mind; time spent in solitude in order to gain focus; pressure from others, and Others, and my Self to finish this exploration of my Self as one dwelling with illness.

As I have previously stated, writing about my illness dwelling has provided a source of therapy that could not be replicated by other means. Although I grieve for the lost time with Bradley that I cannot regain, I have embraced the opportunity to delve deeper into my Self by reading the accounts of others who suffer from illness. I credit Frank (1991) who encouraged me to write about my illness, not in attempt to recover what I once was but to "discover what else I might be" (p. 2). I believe that this is the reason, although subconsciously, I maintained record of my experience while Bradley was in the hospital in Atlanta. I agree with Broyard (1992) that when I initially began writing about my illness dwelling that I was probably attempting "to confine my perfect catastrophe" (p. 19). I recall wanting to record my experience in its entirety, but found that I kept procrastinating. Autobiographical writing often finds its way to the back shelf, ignored for a period of time as more important pieces take precedence. This avoidance

only serves to further repress my emotions for fear of what would happen if I allowed them to emerge. Now, I am able to write about this chaotic time in my life because I have allowed distance to separate me from the events. I recognize that I am dealing with multiple times which overlap, and while there are truths to my pathography, there is no absolute Truth. However, I feel that it is important to share my pathography as completely as possible. “The value of telling one particular story in detail is that it shows how unique each of us is” (Frank, 1991, p. 42). It is not fair to compare my experience, or Bradley’s condition, to illness of others. True, others have experienced worse situations; this was evident during our hospital stay. An eight month old little girl, who had been in the hospital since she was born, was able to receive a heart transplant. Another patient near him passed away less than 48 hours of her arrival to CICU. I recognize that, by medical standards, my child had a much better prognosis than many others around him. However, this does not make my pathography any less valid or my emotions less real.

Bradley’s surgery was bitter-sweet. I knew that his heart defect was corrected, but his body had been violated and would never be the same. Like Frank (1991), I did not dread what Bradley would become, but needed to grieve what he had lost. “Recovery has different meanings...I wanted to return to a place in the healthy mainstream as if nothing had happened. Cancer does not allow that version of recovery” (Frank, 1991, p. 2). Neither does heart complications. Early in the duration of our hospital stay, I was informed that Bradley would be followed by a cardiologist for the remainder of his life. It was difficult for me to digest that he would be forever labeled as a “patient.” His heart defect may have been corrected, but he will never fully recover from this ordeal.

Taylor (2009) speaks of his brother who had to be hospitalized for a severe abdominal condition when he was only a few weeks old. His brother spent six months in the hospital. As

an adult, his brother, Beryl was fascinated with genealogy. “Having been sent into exile a few days after he came home for the first time, it seemed as if his entire life had become a search for the home he had lost as a newborn” (Taylor, 2009, p. 40). Taylor believed that by filling in the missing pieces of family history, Beryl felt that he could restore what he had lost as an infant. However, sometimes when you go searching for the lost pieces, you uncover things that you did not know even existed. Such was the case with Beryl. He discovered a deep family secret regarding his great-grandfather’s suicide that was common knowledge in their small town, but had never been revealed in the family. Likewise, as I have searched for ways to fill in the missing pieces, I have uncovered areas of my life that I did not even realize were there.

Epstein (1995) speaks of an encounter with a Buddhist monk who gives the following analogy:

You see this goblet? For me, this glass is already broken. I enjoy it; I drink out of it. It holds my water admirably, sometimes even reflecting the sun in beautiful patterns. If I should tap it, it has a lovely ring to it. But when I put this glass on a shelf and the wind knocks it over or my elbow brushes it off the table and it falls to the ground and shatters, I say, “Of course.” But when I understand that this glass is already broken, every moment with it is precious. (p. 80-81)

I blame illness for bringing chaos into my life. But chaos has always been there. Before the beginning, there is chaos. Before the beginning, there is loss. The cup is already broken. It was never whole. All things will eventually come to pass. Everything is temporary. Recognizing these facts somehow lessen the sting of loss, although does not diminish the grief. But it does keep me from focusing on the “if” and “when” loss will occur, because I know that loss is inevitable. Instead, I can focus on enjoying the moment and not worrying about the future. This

is sort of in line with *currere*—focusing on the journey and not the destination. The only problem with this notion for me dwelling with illness is that I never got a chance to enjoy Bradley before he was broken. I guess if I had acknowledged from the beginning that Bradley was always broken (whether I knew of his heart defect or not) then maybe I could have been okay with the fact that I was losing him to illness because I would have comprehended that all things are already broken. But, I did not comprehend this notion of predetermined brokenness at the time and so in my mind, I have lost something, which elevates the grief.

Contemplating the notion of everything being already in a state of brokenness, I am reminded of a memory from childhood, specifically when I was seven years old. For Christmas, I received a bicycle. It was beautiful---a white and purple bicycle with rainbow accents, a basket on the front and tassels on the handle bars. I loved that bicycle and was so proud of it. For two weeks I kept my bicycle in my room. (I do not know why my parents let me do that!) Every evening before I went to bed, I would take an old rag and polish my bicycle, carefully wiping off the dirt I had accumulated on my rides that day. I was not very steady on my bicycle and one day came face to face with my neighbor's mailbox. I was upset that I had run into the mailbox and bruised my face as well as my ego, but was more upset that I had scratched my new bicycle. My dad comforted me by saying that this was probably not the last time that I would scratch my bicycle. After this day, I did not polish my bicycle anymore or keep it in my bedroom. There was no need for trying to keep up with a perfect appearance. My bicycle had a noticeable scratch on it. Over time I did indeed accumulate more scratches, as my father had predicted. But maybe this is not such a bad thing. While the initial scratch bothered me greatly at first, I hardly noticed the subsequent scratches. Instead, I enjoyed riding my bicycle for many years later.

Maybe, if I could employ the lesson I learned from my bicycle to life, then I would not be so concerned with appearing “good enough,” or making sure that my child is “normal.” If I could subscribe to the idea that everything is already broken, then I would not have to try to keep up with appearances. Maybe this would take the pressure off of me. Maybe I could relieve some of this guilt that I feel. Reflecting back to Epstein (1995), Bradley is a cup that was already broken before he came into my arms. As we learn to cope with his illness by surgery, or therapy, or whatever other measures lie ahead of us, these are all just methods of gluing an already broken cup back together again. But there will come a time when the glue will fail and the cup will fall apart again. Maybe it will be when Bradley enters school and does poorly. Maybe he will not get into the college that he wants to. Maybe he will commit the unthinkable somewhere down the road. Of course, I only desire the best that life has to offer for Bradley. But in the end, no one knows what the future holds. My point is that I cannot keep blaming all of Bradley’s shortcomings on his illness. Bradley’s cup, like all cups, is already broken; there is not anything I did to break it, nor is there anything I can do to change the fact that it is broken. Epstein (1998) explains:

When we seek happiness through accumulation, either outside of ourselves---from other people, relationships, or material goods—or from our own self-development, we are missing the essential point. In either case we are trying to find completion. But according to Buddhism, such a strategy is doomed. Completion comes not from adding another piece to ourselves but from surrendering our ideas of perfection. (xviii)

If I surrender my notion of ultimate perfection and instead embrace Epstein’s (1995) notion of brokenness, I could possibly relieve some of the guilt I harbor, if only a little bit.

To become whole, I must be broken. Motherhood has initiated me into the broken/whole duality. I was broken, physically and spiritually, through pregnancy, labor, and delivery. Stretch marks, aching joints, and warped stomach muscles are my physical war-wounds of the battle. Having had two children who were taken from me due to complications before I could properly bond with them has scarred my psyche. However, I did not know my full capacity to love until I became a mother. Physical flaws now seem trivial. In many ways, my children have allowed me to become whole. Work cannot be done on the body without working on the soul as well. This mind/body duality can be examined in a variety of ways. While illness physically attacks the body, it damages the soul of the ill person. Similarly, when the illness is treated to restore health the soul may also be restored if the outcome is optimistic. When one's soul has been damaged, outward physical signs are often observed. Likewise, if the soul is rejoicing an inner light shines through the physical body. If the body and soul share similar fluctuations, how can one argue that the two are disconnected? (see Descartes, 1996) The Greeks as well as religious leaders have persuaded us to believe that the mind is superior to the body, teaching "us to suspect and even hate our physical selves" (Raffa, 1992, p. 113). No, the mind and body are not disconnected; instead, they are harmoniously confused.

I am not better because I have/am suffered/ing, but I am changed and different. Taylor (2009) states, "We come closest to the real, I believe, in moments that are profoundly unsettling. If you are patient enough to linger with loss and ponder the most troubling moments, you will discover lessons that make life richer even if much more complex" (p. 19). This may be a Pollyanna way of viewing a dire situation. Surely many in my circle would suggest that there is some lesson to be learned from adversity. While I definitely do not believe that illness is a part

of some sort of divine plan, predetermined so that one is able to learn one lesson or another, I do believe that things can be learned about the Self from reflecting on the dwellings with illness.

The End of the Beginning

When I was a young child, I enjoyed reading what could be called “choose your own ending” books. As I read through the book’s pages I would come to a point where the story’s main character had to make a decision as to which “path” s/he would choose. My choice would ultimately affect the outcome of the story. There were multiple endings to the story which were dependent upon the decisions made or circumstances encountered along the journey.

Oftentimes, when I got to the end of the story, I would turn back the pages of the book to the fork in the road where I had made the decision that ultimately affected the outcome of my journey. From this point I would follow the path in the opposite direction to determine how the story might have ended if I had picked the alternate route. Even as a young child I recognized the impact that one small adjustment, or fluctuation to use a chaotic term, could impact the ending to the story.

Similar to these stories I read as a child, the ending of the lived experience is also dependent upon the choices made along the journey. Unfortunately, if one is not pleased with the ending there is no way of turning back the pages of life to return to the fork in the road so that one can choose an alternate ending. But the journey, and therefore the ending, is not only dictated by choices that the traveler makes but also circumstances that are out of the traveler’s control, such as illness. These unforeseen fluctuations, no matter how minor, can completely alter the course and the ending. In another light, maybe it is not so unfortunate that we do not have the ability to turn back the pages so that we can choose a different ending to life’s story.

Doing so places extreme emphasis on the destination and does not allow one to experience the journey in its fullest capacity.

Indeed, life's story could have multiple endings depending upon the paths taken along the journey. However, because of unforeseen chaotic fluctuations, it is impossible to completely predict the way that the story will end. Before becoming a student of currere, I strived to control every aspect of my life so that I could ensure the ending to my story. Yet, illness stood as an unexpected obstacle that could not be removed which has altered what I thought was a predictable journey. Embracing the lessons I have learned as a student of Curriculum Studies, I have changed my focus away from the destination and toward the journey itself. Life is not ultimately about how everything turns out, so to speak. If I am only focused on controlling the outcome I will miss the enjoyment of the lived experience.

Instead of focusing on the possible multiple endings of my life's story, endings of which I ultimately have little control over, I will turn my focus to the multiple beginnings encountered along the journey. Examining the past decade of my life, I can easily list several important "beginnings": beginning my teaching career, becoming a mother, beginning the doctoral program in Curriculum Studies, becoming a mother to a child with a life-threatening illness, becoming a resident in the "kingdom of the sick" (Sontag, 1978/1989, p. 3). Writing this dissertation, this pathography, has also been a beginning—a time for me to search my Self on a deeper level to expose parts which have been repressed. As I begin to write the final words to the ending of this pathography, I look at this section as more than a conclusion to my dissertation. Instead, it is more representative of the end of the beginning of my inquiry into the Self, a journey that will have multiple endings but more importantly multiple beginnings.

The purpose of my dissertation has been two-fold: to embrace the opportunity to examine my Self as a mother who is dwelling with illness which resulted from my son's illness and to complicate and advance the conversation of including the ill person's voice into the curriculum. Frank (1995) eloquently elaborates on my intentions for this study:

As wounded, people may be cared for, but as storytellers, they care for others. The ill, and all those who suffer, can also be healers. Their injuries become the source of the potency of their stories. Through their stories, the ill create empathic bonds between themselves and their listeners. These bonds expand as the stories are retold. Those who listened then tell others, and the circle of shared experience widens. Because stories can heal, the wounded healer and wounded storyteller are not separate, but are different aspects of the same figure. (p. xii)

Writing about my illness dwelling, recognizing the repressed emotions that I contained deep within because I felt alone in my dwelling, has made me more receptive to others who are also dwelling with illness. Noddings (2003) cautions me about describing myself as "empathetic," because the term suggests that I, in some way, fully comprehend what the other person is enduring. I do not project my own assumptions on their personal situation. God knows that advice offered by well-intentioned onlookers is in abundance! Instead, I strive to be receptive of the other person, meeting her/him where they are and walking alongside them through their dwellings with illness. Sometimes our journey together is short, such as the woman at my son's baseball practice who felt compelled to disclose her concerns regarding her daughter's developmental delays, despite it being our first time engaging in conversation. Others I share a more intimate relationship with; our journey traverses hills and valleys as we travel the roads dictated by illness. Such is the case with my close friend whose mother has Stage IV cancer. I

bite my tongue at times, refraining from filling the awkward silence with empty phrases such as *Let me know if there is anything I can do* or *I'm praying for you*. While these are nice sentiments, they have become clichés which only take up space in the silence. In actuality, it is precisely this space that the ill person needs to embrace. The ill person needs to be given the room to express her/his thoughts, fears, emotions—whatever they may be.

As I reflect upon my journey throughout the doctoral program, I am pleased with the diverse experiences that I have been afforded. Although my journey began nearly five years ago, I recall the day of Orientation as if it were yesterday: I am sitting in a large room with others who, like me, have answered the call to embark on this life-changing voyage. My sister sits at my left. Both of us position our crisp notebooks evenly upon our laps, pen poised and ready to scribble down any bit of information that is offered. As I stare at the Head Table looming before us, a flood of emotions washes over me: Intimidation-*They are looking at us as if they could eat us alive*; Nausea-*I am out of my league*; Fear-*What if I fail?*; “Them”-*Who are they?* Then, with a poised, confident air, Marla Morris takes charge of the introductions. Her argyle socks partially hidden by her black and white shoes reflect in her numerous rings, creating a sort of optical illusion that demands my attention. Ming Fang He scribbles something on a pad of paper. I wonder: *Is she jotting down notes, first impressions perhaps, about each of us?* Bill Reynolds sits at the far end of the table with John Weaver. Interrupting my fascination with the vivid scene, my sister whispers, “Dr. Weaver likes *The Simpsons* and Mountain Dew,” obviously excited that she has found one with whom she could identify. From the pit of my stomach, a pang of fear causes me to wonder: *With whom do I identify? None of “them” look like me.* Suddenly, I feel alone, despite the numerous people who introduce themselves around me. Timidly yet anxiously, my sister and I approach “them” at the Head Table, in hopes of

introducing ourselves. One of “them” comments, “Oh, yes. You’re the Sisters. We’ve heard about you.” Curiously I wonder: *They’ve “heard” about us? What does that mean? Do “they” have preconceived ideas about us based off of hearsay? Will I get my chance to prove myself as an individual?* In retrospect I am ashamed at my hypocrisy. I had already formed opinions about “them” based on first impressions, but was appalled at the thought that “they” might do the same with me. What is seen with the eyes is absorbed by the mind and categorized into the familiar/unfamiliar, normal/abnormal. Unfortunately, new experiences are sometimes purposely avoided on the sole reason that they do not fit into one of the more recognizable categories. Once I fully understood the red thread uniting the field of curriculum studies, the thread of individuality, my fears of being normed were relieved.

I began the doctoral program as a young, naive woman who thought I knew who I was, only to learn that I did not have the faintest notion of my true identity. I looked to my teachers for guidance in helping me discover my true Self. “They” did not promise to teach me anything because “they” did not claim to be experts, but “they” did promise to show me things. It was their hope that one day I would pass the flame to another when this leg of my journey had come full circle. I recall sitting down to begin writing my first paper of the program. I did not have any idea what to write, but I recalled Marla Morris encouraging me to write what I knew about. I knew a lot about myself, so this is where I began, from Home. Marla Morris accurately critiqued my paper as being too personal and lacking theoretical support. Having felt as if I had ventured down the wrong path, I took a detour, trying to reinvent my Self. I attempted to dabble in environmental sciences (my paper on Ossabaw Island), took a feminist/Marxist stance (my paper on the oppression of women physicians), and even entertained the idea of looking at the history of the South for my dissertation (my paper on the southern plantation system and the

patriarch). Each time one of my classmates suggested a potential dissertation topic, I made a notation in the back of my three-ringed binder. I was determined to choose a dissertation topic early in the program with intentions of writing each course's paper within the context of my topic. But sometimes, one does not choose her/his dissertation topic; instead, the topic chooses her/him.

I have faced many challenges over the past five years as a doctoral student, the greatest being the unexpected congenital heart defect of my son, Bradley, and the aftermath of caring for him. At many times I have felt alone, lonely. There are others who began the journey with me. Some have sped ahead while others have fallen behind. Serres (1997) reminds me that "no one really knows how to swim until he has crossed a large and impetuous river or rough strait, an arm of the sea, alone" (p. 4). My teachers warned me that others would abandon me on this journey and that there would come a time when they, too, would have to desert me. But it was not before they taught me to value the lived experience, the written word, and the individual. It is my hope that within my own community I am able to instill this same sense of value in others. I must keep swimming and resist the urge to be carried away by the current.

In the Preface to *On Grieving and Grief* by Kubler-Ross and Kessler (2005), Kessler writes:

There is a saying that if your writing doesn't keep you up at night, it will never keep anyone else up at night either. In creating this book I often felt that if it didn't make us cry, if it didn't help us heal our own grief, it would never help anyone else. (p. xiv)

Writing my pathography has been all-encompassing. No doubt I have stayed awake countless hours considering not only what I was being led to write about but how it should be written. I have poured my heart and soul into this pathography. In turn, through the tears I have shed while

writing my pathography my wounded heart has been examined and my soul has begun to find healing. Writing the final lines of this segment of my journey as one dwelling with illness is bittersweet. Gilda Radner's (1989) *It's Always Something* chronicles her quest narrative with ovarian cancer. She writes:

I had wanted to wrap this book up in a neat little package...I wanted a perfect ending....Now I've learned, the hard way, that some poems don't rhyme, and some stories don't have a clear beginning, middle and end. Like my life, this book has ambiguity. Like my life, this book is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next. (p. 254)

There are certainly parts of my Self that are eager to wrap things up, tie loose ends, and put a bow on top of the pretty little package that I will call my dissertation. Yet, there is a part of me that is saddened by the notion that this segment of my journey has come to an end. I do not feel that I am finished discovering the ways in which illness has affected/is affecting me. This is not the end of my illness dwelling. It is merely the end of the beginning. There is much "soul work" (Morris, 2008) still to be done.

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