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## Illness Dwelling in Currené: Fleshing through Education, Pragmatism, and Spirituality

Leigh Rogers Medders

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ILLNESS DWELLING IN CURRERÉ:  
FLESHING THROUGH EDUCATION, PRAGMATISM, AND SPIRITUALITY  
*JOANNA'S JOURNEY*

by

LEIGH ROGERS MEDDERS

(Under the Direction of Marla B. Morris)

ABSTRACT

The purpose of this dissertation is to create a merging of illness, education, pragmatism and spirituality. The dissertation argues the pragmatist views of the lived experience propose a need for spiritual awareness when facing adversities such as illness. *Curreré* and creation spirituality are woven together as a means of discovering a path to recovery. Perceptions of reality and education are approached, and an *educational malignancy* is suggested whereas unforeseen occurrences and entities are breaking down the current educational system. Finally, death is approached not as an end, but rather as a beginning. Education, spirituality, pragmatism and illness are united by fleshing through pathographies, literature, and pragmatic views to shed light onto the lived experience of life in the ill body.

INDEX WORDS: Cancer, Creation Spirituality, Curreré, Death, Education, Illness, Pragmatism, Spirituality

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*JOANNA'S JOURNEY*

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DOCTOR OF EDUCATION

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## DEDICATION

This work is dedicated to those people who have encouraged, motivated and nurtured my journey. To my major professor, Marla Morris, who modeled scholarly intellect and gave me the freedom to write about my passion. To my committee, Bill Reynolds, Delese Wear, and John Weaver, who supported my work, and encouraged my writing. To my family in Statesboro, the Medders and the Rushings. To the McAfee boys, Jeff and Paul. To my brother and friend, Tom Rogers, and his wife beautiful wife, Gynger. To my heroes, my mother, JoAnne Rogers, and my sister, Misty McAfee. To those who own my heart, give my life meaning and brighten my day....my husband, Michael, and my precious children, Trip, Emmy and Bense.

And *most especially*, to my dear Joanna Rae McAfee.

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## CHAPTER 1

### Curriculum Theory and Cancer:

#### Conceptualizing a New Cataclysm in the Educational Realm

We have believed that we are experts, at least experts in our own lives, related to our own families and life experiences. We comfort ourselves in knowledges that we have spent years perfecting. Then life happens- our children, our parents, other people, our world, we ourselves – life changes in seconds, in years, and even in messy new experiences that we never dreamed that we would share with each other. (Cannella & Viruru, 2003, p. 4)

My writing opened a door which allowed me to journey through an experience that has been mind-altering, life changing, and at times unbearable. I have written out of frustration, in search of information and knowledge that will help me understand and conceptualize the ambiguity of cancer. Throughout this pursuit, I have sought solace that would allow me to work through cancer's adversity as an outsider, virtually helpless in fighting off the disease that dwelt within Joanna. Years filled with joy, hope, dread and agony were spent watching my niece boldly meet the challenges of cancer, then quietly and peacefully succumbing to the undeniable grip of this dreadful disease. I write to reveal my own thoughts of how this disease infiltrates throughout a body, a society, and an educational system. Sumara states "for we know that once we have had an experience with another person...we cannot leave that experience unchanged" (p. 86, 1996). It is my hope that as the reader engages in the text, he/she will be moved, comforted, challenged, and changed.

I approach my dissertation as a *witness*, giving personal testimony to the trials that my family faced upon Joanna's diagnosis and throughout her journey with illness.

Derrida (1994/1997) states that testimony is based on faith and trust, being essentially a promise, that what is revealed is true. Each time one addresses "the other," an underlying request is made to "believe" what is being shared. In Derrida's words, "addressing the other" signifies "trust me, I am speaking to you" (p. 22). What I reveal within this work for me is truth, or more accurately, what I interpret as truth. This dissertation begins my storytelling of the ordeals, the hardships, and the lessons learned as Joanna embarked on the greatest challenge any of us have had to pursue...the fight to win back her life.

Arthur Frank (1995), claims that the storytelling of an illness is not "just the topic of...[the] story" but rather, it is "the condition of...[one] telling the story...*through* a wounded body," such that the body speaks, allowing for intimacies about the journey to be shared (p. 2). Storytelling is two-fold, according to Frank, approaching both personal and social aspects. By sharing about illnesses, Frank suggests that in addition to stories being told to assist those with illnesses in working through "their own changing identities," stories should be shared "to guide others who will follow them," not as a means of creating a course for someone to follow, but rather, as a means of "witness[ing] the experience of reconstructing one's own map" to assist others in creating their own (p. 17).

My dissertation will walk the reader through the stages of Joanna's illness. Each chapter will address a significant stage of her illness which altered not only the ill body, but the body of family and friends, the kindred spirits who loved and supported her. Chapter 1 will revisit the phases of Joanna's diagnosis, as I explore perceptions of reality.

Education will be discussed, and dissected as having what I have termed an *educational malignancy* whereas unforeseen occurrences and small entities are breaking down the educational system. Chapter 2 will further examine the educational dilemma by providing a brief historical background to our current system. I will delve into *carreré* as a means of discovering a path to recovery. The pragmatist views will be discussed as addressing a systemic problem which silences children and the ill. Spirituality will be introduced as a way to move forward in a world facing adversities. Chapter 3 will build on this notion by suggesting a return of the spiritual dimension in the educational arena. A pragmatic theme will be woven into this chapter as well. Chapter 4 will explore Creation Spirituality as a means for working through illness, especially in the face of death. And finally, Chapter 5 will approach death, not as an end, but rather as a beginning. The chapters will unite education, spirituality, pragmatism and illness by fleshing through pathographies, literature on illness, and pragmatic views in an effort to shed light onto the lived experience of life in the ill body.

It is my hope that witnessing will open and initiate a desire to refocus on reality and life. For those who choose this reclaiming, life can be living, existing, interacting today and everyday henceforth. "Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience" (Frank, 1995, p.115). Each human life whether or not in our view as being lived to fruition, is a journey, an exploration, an experience.

Dewey (1958b), drawing on James' notion that experience is "double-barreled" states that experience "includes *what* men do and suffer, *what* they strive for, love,

believe and endure, and also *how* men act and are acted upon, the ways in which they do and suffer, desire and enjoy, see, believe, imagine” (p. 8). For Dewey, experience is defined by all occurrences, from the onset of one, to fulfillment of the other, from complimentary relations to opposites. Dewey (1958b) offered examples of experience such as “the planted field, the sowed seeds, the reaped harvests, the changes of night and day, spring and autumn, wet and dry, heat and cold” (p. 8) He further defined experience by stating that it signifies “the one who plants and reaps, who works and rejoices, hopes, fears, plans, invokes magic or chemistry to aid him, who is downcast or triumphant” (p.8).

According to Dewey, experiences entail the results of activity, and validate the education in life. In recounting the overall goal of education, Dewey (1938) claimed that “education in order to accomplish its ends both for the individual learner and for society must be based upon experience – which is always the actual life-experience of some individual” (p. 89). Dewey believed, like Rousseau, that learning for a child is a “part of self-preservation” and “a necessity” (1915/1962, p.2). “The child’s first business is self-preservation....not...barely keeping himself alive, but preservation of himself as a growing, developing being” (p.5). This statement, although aimed at the healthy, thriving child, is as pertinent to the child facing her own mortality. To live, when threatened with death, can become the primary and ultimate goal of existence. In this case, learning to endure pain, learning to take medication which causes additional sickness, and learning to adjust to an alternate lifestyle are lessons that self preservation may teach in the life of the ill.

*Life as a Lived Experience*

“Then life happens...*then life happens...*” (Cannella & Viruru, 2003, p. 4). *Life* can be defined in a multitude of ways, from mere existence to the signification of an onset of the trials, the obstacles, and the unexpected mishaps which inadvertently affect the *quality* of life. Life, in relation to living in and of itself, is daily, hourly, every minute of every day from the time one inhales the first breath, until the last breath is exhausted. The beating of the heart, the constriction and expansion of the lungs, the blood’s oxygenation of the organs, all function involuntarily, automated, diligently completing tasks that are concealed, silently hidden away from the scrutiny and analysis of others. The body, programmed to maintain life, operates vulnerably depending upon each minute component to complete a specific job that adds to the functioning complexity of the whole. This miraculously intricate creation, the body, is far too often taken for granted, admiring the overall appearance, hardly aware of the wealth of inconceivable entities which lie below the surface. Unaware, unknowing, and unquestioning, life persists as normal until something emerges and the undisclosed is revealed.

Illness, which at one time was seen solely from a medical perspective, is no longer one-dimensional having only a medical voice whereas medical personnel possess the one true story; rather, illness expands into other dimensions, having a voice from the patient, and branching out further, having a voice from a bystander, one physically disconnected from the illness, but connected through the spirit, the soul, the bloodline. The effects of illness, although embedded within the ill, spill over onto the disconnected through the senses. What is seen, heard, and felt settles within the conscious/unconscious

being to linger as the journey moves on. Different perspectives of the illness and the ill allow for different voices to be heard, different stories to be told.

Cancer begins its story long before it can be seen, heard or felt. The disease, as depicted in numerous personal testimonies, is absent, yet present. Drawing on Grumet (1988), the presence is there, deeply rooted, lurking, thriving, mutating, silently contaminating the body, visibly concealing its presence. To one's conscious being, it is absent. The presence is there as it strengthens, causing minor aches and pains, which are easily blamed on other, less serious ailments; but its absence is assumed. The presence is there collecting, reconfiguring the bodily functions as time passes. Unexpectedly, without fair warning, cancer begins to speak through undeniable terms. The presence of cancer is there, and finally, is identified as such. The illustrations in the story of cancer uphold the irony that the recognizable obvious is not always the significant presence, and the unseen is not always an absence.

Schools are not sheltered from the visible and unseen. Students, teachers, administrators, and staff, all exist with the same susceptibility to illness that lurks outside of the school walls. Illness dwells in various forms on school grounds as we claim witness to increased cases of juvenile diabetes, asthma, allergies, and cancers invading the lives of students, just as cancers, heart conditions, and bodily ailments invade the lives of many adults that manage, operate and supervise the schools. Although illnesses are not always evident within the lives inhabited, the presence affects one's performance, attitude, stamina, and perseverance, which is of utmost importance in reaching the expectations of "*No Child Left Behind.*" The presence of illness, known or undisclosed,

consciously or unconsciously ignored, is prevalent in all facets of life, all arenas of existence, schools being no exception.

Presence and absence, although adversely related, find common ground in relation to one's conscious being. Interpretations of life can become confusing, distorted, clouded so that reality is blurred. In this case, perceived presences, common, less dangerous symptoms and illnesses, do exist, but the presence, many times, is provoked by a misconstrued absence, cancer. There exist absences and presences within the educational realm, as well, on the school grounds, within the four walls of the classroom, which function outside of the human body. Grumet writes of curriculum as "the presence of an absence" (1988, xiii). The educational presence consists of "the curriculum, the course of study, the current compliance...computer literacy, master teachers...reading readiness, time on task...the window." Present is the regiment, the pen to paper documentation that appears whole, the obvious. Consequent to the theoretical manifest, absent is the life behind the curriculum, "the laugh...the whimper, the song" (Grumet, 1988, p. xiii).

Life lessons and experiences occur as circumstances unfold. Quite contrary are the lessons to be learned in the school setting which have traditionally been taught by the presentation of concepts through a step-by-step procedure. This methodology of teaching has dominated our educational system, persisting through numerous pendulum swings, then ironically, returning stronger than before. I must carefully articulate my belief as to how our current educational system operates, and under the conditions I assert are symptoms of a greater complication, an *educational malignancy*.

In 1976, Huebner stated,

The curriculum field of the past one hundred years is not just moribund; for all practical purposes it is dead. It did not die because it depended on theory rather than practice, although its sickness might have been diagnosed sooner if there had been greater correspondence between its rhetoric and its performance. It died because the increasing diversity of interest it tried to carry during those hundred years could no longer be held together by a single focus. (Huebner, 1976, p. 253)

Moribund. Dead. Huebner spoke of a perceived termination of curriculum which ultimately transpired during an educational era which emphasized a “how to” methodology of curriculum development. The dependence on “theory rather than practice,” coupled with the “increasing diversity of interest” in which given procedures attempted to encapsulate, seemingly failed the students for which the principles were based. Huebner was not alone in his assertion. Schwab (1969) was first to note the curriculum field as “moribund....unable, by its present methods and principles” to sufficiently “continue its work” (p. 1). Pinar (1999) followed 30 years later by stating, “It is obvious that the curriculum field is now...in a period of breakdown” (p. xxvi). He continues, the curriculum field “has been near death for at least ten years” (xxvi). The declaration of a dying field was evidenced over three decades by symptoms of digression and disaccord.

One is able to dwell within the school, harboring illness, as the symptoms of the body fail the individual who seeks refuge in the shell. And all the while, the systemic body of education suffers deficiencies which seemingly terminated a field of curriculum. I will not argue the matter of whether or not the curriculum field at any given time was



actually suspended, or disabled; however, I will argue the educational dilemma today for which I interpret as a restoration of the curriculum field for which Schwab declared moribund. The pendulum swing has returned to an era where the behavioral sciences, outcome assessments and accountability issues have coalesced into a national rhetoric. Life experiences, the essence of existence, are isolated, and ultimately ignored. The preparation for life is systematic, disconnected, and abstract. The voice of the child is neglected and ignored.

Curriculum theorists are aware of the dis-ease permeating current-day education where uniformity, efficiency and compliancy govern the educational precept. The methodology criticized over thirty years ago is still to a large degree intact. I assert that the experience of illness is not limited to ill individuals, or to the medical community which intervenes, but rather the experience of illness is felt within the reigns of education, whereas the systemic pursuit of educating our young suffers from dis-ease. I must state at this point teachers, the dedicated and the devoted, are not blamed for the progression of this debility, for just as the intricate components of the body function as they receive signals from entities created to manage, so too, do the teachers in the body of education perform the tasks specified by those dictating these decisions. Frankly, blame cannot be thrust in any one direction, for when dealing with *malignancy*, too often, the point of origin and the cause for the effect cannot be solely identified. The symptoms of dis-function are evident, as well as the dis-content; however to identify the sole determinant is improbable, thereby rearing the road to recovery as a treacherous and long journey. Oppression, silenced voices and illness merge to triangulate expanding beyond the educational borders, spilling over into realms of society. This notion of needing

systemic restoration is based on the pragmatic view. Meanwhile, the *educational malignancy* is a quite rage.

My work on illness entails a journey, a journey through time, whereas one progresses down life's path encountering obstacles, savoring victories, and making choices in earnest to enable one to press forward. The affects of illness emanate to the *other(s)* through the onward progression of life. I argue for children's voice, insight, and rights to be children both in and out of the classroom. I stand firm in my belief that children, even when facing mortality, need time to be children, to draw from life's experiences, and learn the essence of life as it is lived. My focus on illness approaches this ever-changing movement through time enveloping life and schooling as experienced by the ill.

In this capacity, life, which is shaped, molded and fluid is spent preparing to live as if it is futuristic, "*then life happens*" (Cannella & Viruru, 2003, p. 4). Life is living, both being synonymous, both being present. The absence, however, lies in the interpretation of the living where quality of life comes into play. Our conscious being becomes cognizant of the absence, the cancer.

### *Revealing the Malignancy*

For many, the term *cancer* implies more than an obscure disease that randomly invades the innocent; rather, the term *cancer* exemplifies mystery, deceit, and the confirmation of one's humanness. *Cancer* subjects one to the reality of the falsehood that life is guaranteed, that tomorrow will proceed just as today. *Cancer* brings into consciousness the frailty of the body, and then awakens one to the notion that time for intimate conversations, for loved ones, and for relationships is limited, finite. *Cancer*

thrusts to the forefront the future as fluid, constantly changing, unforetold, and unforeseen. Cancer interrupts the normal functions of the body, thereby interrupting present life as it is lived.

My mother was in surgery, a simple mastectomy as a result of breast cancer, when I first observed Joanna's breathing. A somewhat labored inhale, then exhale, inhale, exhale. Joanna slept on a down comforter that was brought from home due to her need for frequent naps. My sister, Misty, and I discussed her breathing, but it was reasoned that it was the result of the sinus infection and congestion she was experiencing following a cold. I remember watching Misty look at Joanna, puzzled, concerned, unaware, and yet apprehensive. The obvious was unsettling, and the motherly intuition began to probe for answers over the weeks to come. Weeks following trial and error solutions, Joanna was admitted into the hospital to administer medication and perform techniques to clear her bowels. During this time, the specialists ordered x-rays to be taken of her abdominal cavity which clearly identified the obstruction. The tumor was unmistakable. It was the size of a football in her tiny three-year-old body.

How could this have been overlooked? Numerous visits to the pediatrician, and never blood work, never an x-ray. Resentfully, I recall the time Misty questioned whether the problem could be related to a tumor, and the pediatric gastroenterologist smirked confidently and said no. Alan Shapiro (1997) recounts his sister's diagnosis of metastasized breast cancer followed "weeks of searing headaches," diagnosed as sinus related problems, and "erratic behavior," diagnosed as depression (p.7). When confronting cancer, there is no time for mistakes. CANCER? Time stands still. The word, repeated over and over with various intonations in the mind, was detestable. Cancer,

when fused with Joanna was emotionally incapacitating. The reality was incomprehensible. Raphael Campo (1997) shares his initial reaction to being told he may have cancer, by stating “‘cancer’ is only a word, like any other....I gripped it in my mind’s fist like a hot stone, unable to throw it from me, letting it burn into my skin. I was angry, I wanted to hit people with it” (p. 242-243). The reality of facing one’s mortality, whether it is the self or the *other*, can prove to be perplexing, and complicated.

The body itself is complicated, and somewhat mechanistic with specific programs that regulate the overall performance. When analyzing childhood cancer, an examination of the human cell is necessary. Within the nucleus of each normal cell, a genetic code is stored within 23 pairs of chromosomes. This genetic code is made up of units known as genes, which monitor the cell, and define its very existence. The genes consist of the material DNA (deoxyribonucleic acid) which is broken down into nucleotides (Steen & Mirro, 2000). The chromosomes, which are made up of a program coded within the DNA prompts cells to divide and grow. When ample cells are created, a signal to stop cell division is received. (American Cancer Society, 2003a). These components functioning together normally create a particular protein specific to each gene, and it is the protein of each cell that enables the cell to function properly. (American Cancer Society 2003a; Steen & Mirro, 2000). When there is a malfunction, an abnormality in the genetic code, the cell is unable to complete the job of producing the unique protein for the cell, thereby becoming unable to function properly. This abnormality, or mutation in the genetic code is currently responsible for “approximately 4,500 diseases” and is “associated with various cancers” (Steen & Mirro, 2000, p. 51).

Several scenarios exist that trigger the malfunctioning of this program, and the onset of such diseases. For instance, if the signal to cease cell division is not received, then the cells will continue to divide and collect, causing a mass. Even those cells with damaged DNA have the capacity to continue to thrive and divide, hence causing further damage to other genes which help stabilize cell growth. Another problematic situation arises when the program within the cell's DNA is rearranged or translocated. Theoretically, the sequential order is shuffled causing chaos in cell production, thereby resulting in cancer. Hypotheses have been made that these defective processes cause many types of childhood cancers and leukemias (American Cancer Society, 2003a). One such childhood cancer is rhabdomyosarcoma which is the most common soft-tissue sarcoma found in children (American Cancer Society, 2003c; El-Sherbiny, El-Mekresh, El-Baz & Ghoneim, 2000; Janes-Hodder & Keene, 1999; Merlino & Helman, 1999; Pediatric Oncology Resource Center, 2002; Steen & Mirro, 2000). This was Joanna's cancer, a very aggressive, highly malignant, fast growing cancer. Generally, the first recognizable symptom of rhabdomyosarcoma is a lump (Pediatric Oncology Resource Center, 2002), which in Joanna's case was a mass, a mass that was hypothesized to have originated from abnormalities within the genetic code, and uncontrollable cell growth (Steen & Mirro, 2000).

John Gunther (1949), in writing about the cancer which invaded his son, Johnny, best summarizes this catastrophic occurrence in layman's terms stating,

Cancer is rebellion – a gangster outbreak of misplaced cells. Extremely little differentiates a normal cell from a cancer cell. One theory of the origin of cancer, is that during pregnancy a cell may be displaced in the embryo and may lie

dormant for many years....Then it may get kicked loose,...and break out with savage violence....The cell, its energies thus fiercely released by some unknown eruptive force, tries insanely to catch up. But it is a foreign environment and hence destroys relentlessly what it is surrounded by.” (p. 78)

As Gunther noted, some data suggests that the majority of cancers result from one abnormal cell (Steen & Mirro, 2000), which ultimately, when left in isolation, can slowly and painfully destroy an entire human body. The scenario of one mechanism affecting numerous others is not a new concept within society. Hitler altered the thinking of many, and as a result, a multitude of innocent people were destroyed, murdered, sacrificed as a result of his mission, his corrupted plan. An illustration of how society's cancer is absent, yet present, focuses on companies, corporations, and conglomerates that alter the thinking of millions through advertisement and propaganda thus constructing new thought processes, new avenues of action, and new tactics for consuming products out of desire of a lifestyle rather than the satisfaction of a need. Giroux (2003) asserts that the conjuncture of popular culture and the advertisement industry has “redefined the very nature of identity, needs, desire, and democracy itself,” where citizenship in our consumer oriented society has been “reduced to the obligations of consumerism” (p. 56). Capital globalization appears to ignore the strife present throughout the world, and the gap is widened between nations that are wealthy, and those that are not. Giroux illustrates, in my opinion, how global America perceives an ‘absence of a presence.’ The presence is there...starvation, homelessness, poverty, suffering; however, because it is distant, disconnected, and tolerated, its absence is accepted. This is a cancer, society's cancer, where the conscious being is unaware, incognizant, directly unaffected/ indirectly

affected. Society's cancer is symptomatic of greater evils yet to come, where the eyes on reality are deceiving. Differentiation arises, differentiation influences, and fundamentally, differentiation rules.

In many aspects of life, the human conception of reality as it exists can pose grave difficulty. Bits and pieces can be synthesized, but quite contrary to the obvious, the magnitude of the whole is overwhelming, complex, even destructive. Dewey (1958b, p. 54) defines reality as being "what existence would be if our reasonably justified preferences were so completely established in nature as to exhaust and define its entire being and thereby render search and struggle unnecessary" (p.54). Considering Dewey's definition, reality for each individual is based on what one wants to perceive after dissecting the imperfections, then determining what would dismiss these imperfections. Reality, then, is an awareness of what one wants to see, with a satisfactory explanation for the distorted other. Dewey's explanation of reality illustrates the examples of blurred reality when chronic or terminal illnesses are looming, whereas the symptoms are linked to less serious ailments, providing a satisfactory explanation. When escalated to a broader scale, society has become comfortable with accepting, the more approachable, aesthetically appealing side of life in an effort to lessen the sting of more serious, life-threatening issues.

General health related issues are no exception to this conversation. From an aesthetic point of view, infomercials advertise equipment that sends a clear message that the user will inherit the perfect body modeled in the ad simply by purchasing the product. Cosmetic surgery is on the rise to provide a happier lifestyle by improving physical features, and even for illnesses, commercials, advertisements, and billboards sing the

praises of medications available to improve one's standard of living by offering a lifestyle which will alleviate anything from allergies to high blood pressure if one consumes this or that particular product. The illness is portrayed in light, with the ill performing acts as vibrant as running, smiling, laughing, as if the illness is non-existent. David Morris (1998) recognizes the emphasis on the aesthetic in observing that in "any suburban mall" one is unavoidably confronted with "seductive displays promising miracle cures, ageless bodies, and perpetual well-being" as though overcoming mortality was life's goal (p. 1). The portrayal of illness, namely cancer, is only witnessed in commercials which depict hospice as a five-star hotel. Publicizing the favorable side of illness and concealing the truths which take place within, reveal acceptable societal perceptions of illness, and reality remains approachable.

Macdonald (1981) stated,

We know that there exists a reality 'out there,' and we know that as human beings that reality is known to us by the limits and creativeness of the human imagination. What we 'know' is as much or more who we humans are: as it is what is there! (p. 175)

Macdonald testifies that our perceptions are as true to reality as what actually is there. One's truth of reality marks the lived experience for that individual, thereby influencing the past, present and future. Consequently, the interpretation of the reality is not misunderstood in the present. The only manner in which one recognizes reality as blurred and misconstrued is in the return to the past experiences. Only in this light, may one understand the significance of returning to our past to analyze our current conditions. When confronting illness, to live, to allow life to happen, an intentional decision must be



made to contend with the past and present, considering the course of action to confront the truth of reality as it is perceived.

### *Treatment of/for the Ill*

The reality of coping with illness, and the treatment of illness can prove to be almost as repulsive as the disease itself. Chemotherapy, in relative terms, is referred to as medications used in the treatment of cancer. (American Cancer Society, 2003b; National Cancer Institute, 2002; Steen & Mirro, 2000) The purpose of chemotherapy is to damage the abnormal cancerous cells so that division and growth is no longer possible. The treatment is not restricted to a certain area, thereby allowing the medication to reach parts of the body where cancer cells have metastasized in locations other than the site of origin (American Cancer Society, 2003b; Steen & Mirro, 2000). Several drugs are commonly combined for the chemotherapy in order to hinder the cancer cells from mutating, and building a resistance to the medication; however in doing so, normal, healthy tissue is also damaged. (American Cancer Society, 2003b; National Cancer Institute 2002; Steen & Mirro, 2000). In an effort to ward off this life threatening disease, normal, healthy cells will be sacrificed so that the corrupt can be halted, an ironic twist in cancer treatment.

Most pediatric cancer patients are treated through prospective clinical trials referred to as treatment protocols. The chosen protocol can provide advantages in that the most recent peer-reviewed therapies are administered. The frequency for which the protocol has been used “is an important reason why there has been remarkable progress made in curing children with cancer” (Steen & Mirro, 2000, p. 21). One specific protocol used in the treatment of metastatic tumors and the most aggressive types of cancer is

called VACIME. This treatment, VACIME, combines six different drugs, vincristine, adriamycin, cyclophosphamide, ifosfamide, mesna and etoposide, which are given every 3 weeks (Thomson et. al., 1999). The use of this protocol, as witnessed with Joanna, comes at a price, not a monetary price, but an expense whereas the body must suffer additional ailments to forcefully decrease the aggressiveness of the cancer. The intensity and degree of side effects, as well as the overall effectiveness of the treatment for cancer patients differs, depending upon numerous variables, both visible and unseen.

The success of any treatment is multi-dependent on the individual considering that “no two people are exactly alike.... malignancy differs from one person to another....[and the] response to treatment is not precisely the same for any two patients” (Steen & Mirro, 2000, p.187). The body’s response to the treatment, and the body’s capability of overcoming complications that may arise from the treatment are integral in the healing process of the patient. Reactions within the body vary among individuals, as well as stimuli outside of the body. In addition, and equally important to the effectiveness of the treatment, is the patient’s exposure to various agents such as “bacterial, viral, protozoal and fungal agents” which may cause infections and can also alter the course of the treatment process (Altman & Wolfe, 1997, p. 1). Infectious diseases are potentially detrimental, and may cause a massive setback for the patient, particularly if the patient is experiencing a drop in white blood cells (WBCs), which is one of the body’s most significant defenses against infection. The onset of neutropenia, a condition experienced when the neutrophils, a specific type of white blood cell which defends the body against bacteria, are low in number, can be life-threatening and require that the treatment be postponed and additional treatments be administered to boost the growth of blood cells

(Steen & Mirro, 2000; Wolfe, Ablin, Altman, & Johnson, 1997). Therefore, the rate at which the treatment takes place is heavily dependent upon the patient's body in relation to the medication, other infectious diseases, and the rate of restoration of blood cells. In the cancer treatment process, it is apparent that the relationships between the body and the medication are monitored, examined, and closely supervised for possible changes, variations, and complications.

In an effort to coherently state my assertion, several parallels must be drawn between the medical and educational approach to the individual, most specifically the child. Two critical areas must be examined to demonstrate the differing approaches to the individual in terms of the acknowledgement of the individual response, and the guarantee which accompanies the intended intervention of the teacher and the doctor. The two fields, both assist the child or the individual, progress with distinguishable variations.

From the medical perspective, the treatment of any illness is intensely focused on the individual, the starting point, the analysis, and the plan for how to proceed. The recognition of the individual with emphasis on the relationship between the body, the environment and the self is necessary for anyone dealing with advancing the individual beyond the current condition whether it is in terms of health or education. Teachers and doctors analyze the status of an individual based on observations, tests, and symptoms. To assist in an accurate path of progression, the two may refer to documents of past history in determining a treatment or plan which is believed to increase the likelihood of positive development. The effectiveness of the proposed action primarily depends upon the relationships of the individual's response. It is here that the lines between the roles of

doctor and teacher sharply divide, whereas the individual response is either deemed critical, or insignificant.

The doctor's expertise in the field weighs heavily in the sense that he/she must be receptive, attentive and knowledgeable about symptoms, reactions, and the overall health of the patient. The doctor follows the individual's progress, reducing the strength of the medication if necessary, increasing the dosage if needed, providing additional medications as need arises, and allowing for the patient to regain enough strength before continuing forward. The '*in-between*', the time between diagnosis and recovery is full of uncertainty, and it is the *in-between* that paces, and ultimately determines the logistics of the treatment process. Teachers struggle to match this example. What becomes problematic is the teacher works on a political timeline. The expectation is to not only to successfully transmit given information through an individualized plan, but in essence, make up for lost time, having the child function at a particular level within nine months with no account for home life, past experiences, or performance level upon entering the particular grade. Teachers are expected to diagnose, treat and cure students with given deficiencies, so that all students function the same, retain the same information, and test at or above a given level based on a grade bracket. Society has come to determine the quality of a teacher based upon this mastery of ensuring that all children intellectually reach the same benchmarks based on identical criteria so that no child is functioning below a given level at a particular age.

Let me clarify that I do not intend to insinuate all children are incapable of learning, just as I do not contend that all children will or will not recover from a given illness. Quite contrary, all children are capable of learning, but just as some children's

bodies react differently to environmental stimuli, physical challenges, internalized medications, or simply capacity to respond to given situations, so, too, the realization must be made that children do not learn at the same rate, learn in the same way, retain the same quantity of information, and most importantly, all children do not test with the same proficiency. In addition, the relationship between the teacher and student, the alliance, the vested interest in schooling is not always positive, encouraging, and motivating thereby altering the results in the life-long learning process. The *'in between'* is detailed encompassing the school year with a given set of objectives and a specific number of days, and in many cases, scripted lessons which dictate the conversation and teaching approach.

The *'in between'* and Sumara's 'hap' can be closely woven. Sumara speaks of the hap in relation to textual reading; however, the hap filters through in everyday living. The medical field far too well understands "the hap...what remains after method...what occurs beyond what we predict" (Sumara, 1996, p. 176). A protocol is used as a basis of method, a set of directions to follow, a research-based procedure; however the *'in between'*, the unforeseen, the deviations are somewhat anticipated, although the definitives concerning the *'in between'* are obscure. Numerous variables alter and sway the proposed outline of the protocol possibly stalling, slowing the pace. It is the meshing of happenstance along with the ailing individual that determines the rigorous compliance to the protocol. Possible complications unveil themselves and require additions to be made, supplements to be given and obstacles to be overcome in an effort to create a new course for getting back on track, back to the plan, the protocol.

Curriculum too often focuses on the method, the plan, the research-based procedure to follow with little consideration of the ‘*in between*’ the unpredicted, somewhat anticipated, situations that arise as a result of or in concordance with the outlined scheme of educating. Expectations are mandated to successfully progress throughout the sequenced plan, outline, within a certain time frame for outputting products, e.g. students, accomplishing like goals, attaining equivalent amounts of information, and successfully regurgitating the information in a particular format. This is due in part to the supposed guarantees our society has placed on the education of youth.

The medical community recognizes each individual as different and unique, physically, genetically and mentally. It is clear that guarantees are excluded from the medical field where chronic and terminal illnesses are concerned. Discussion of side effects and alternate complications generally precede any action. Adverse reactions between what can make the body well, may in essence, put the body in serious jeopardy. These risks are discussed, again, reiterating that there are no guarantees for positive results in the medical profession.

Education is sold within our society as somewhat implicating guarantees. George W. Bush’s education bill “*No Child Left Behind*” sends a clear message that his intent is to guarantee parents, society and students they will not only succeed, but reach a measurable goal, the same for all students within a given age bracket regardless of the ‘*in between*’ that arises or the discrepancies that exist prior. The proof of this goal attainment will be evident in standardized test scores. Along with the success of students, teacher quality will also be measured based on this assumption. Giroux (2003) contends that Bush’s plan is packed with rewards and punishments. Parents whose children attend

schools, which do not perform to expectations, have the option “to take their children out” (p. 77). In addition, the choice is given for low-income parents to have their children transferred “to better public schools, including charter schools” with the use of federal money (p. 77). I assert this plainly suggests a guarantee, with alternatives if the guarantee is not met. If the child or school performs below an expected gain, then as a parent, the child may be pulled, may bail out, leaving the school, or in the terms of Giroux, “disengage” (p.77). Presented is an educational guarantee, which again, fogs the realistic thinking, happy children, a happy society where each member is compliant, motivated, and performing efficiently and effectively.

The division between the fields of education and medicine is evident in the acceptance of the unexpected, the happenstance. Life resonates at the core of both fields. Education, a field geared toward life preparation, is structured, with a clear path, plan from beginning to end, a set of given objectives and expectations, where the healthy child fits the mold of advancing the rungs on the ladder until reaching adulthood. The medical field, a field whose mission is to maintain life, is open to the flexibility of the unforeseen, the complications that arise as life is lived, as life is experienced. One field, blinded by aspirations for the future is incognizant of the present, whereas the other field, preoccupied with today, tends to abandon the notion of a long-range future. Dewey (1938/1964a) spoke of this comparison in stating, “The educator more than the member of any other profession is concerned to have a long look ahead. The physician may feel his job done when he has restored a patient to health” (p. 375). He continued that the physician had the “obligation of advising” his patient how to go about living “so as to avoid similar troubles in the future,” knowing that the patient has the option of heeding

the advice or ignoring it (p. 375). Upon offering the advice, according to Dewey, the physician “takes upon himself the function of an educator” (Dewey, 1938/1964a , p. 375).

According to Dewey, doctoring, when extending beyond the illness, looking further into the patient’s future, spills over such that the doctor “function[s] as an educator,” whereas the educator’s concern is based on the “long look ahead” (p. 375). It matters not whom illness invades, a child, youth, adult, or the elderly, the “long look ahead” should never stop one from reaching for dreams and aspirations; however, one must take notice of the obstacles, and barriers, and create new life lines for the path in living. Educators must be cognizant that the “long look ahead” may be interrupted, halted, and therefore, must take an active part in nursing one through the journey. I find fault in the educational system for those falling to illness, most especially, terminal illness. I will even argue that the system fails those students whose teachers, family members, loved ones, and friends become ill. I base my argument on the eliminated realm of education which allows one to find solace in the confrontation with mortality, the spiritual realm.

Spirituality allows one to turn inward, to bond with that which lies within, to acquaint oneself with the *other*. A connection with the inner being teaches one much about the self, and how the self situates within the broadening capacities of life. Grumet (2005), not speaking of spirituality per se, spoke of the inner and outer worlds by stating that one aspect of *carreré* was to open the door for a “method of reflection on educational experience” which would identify the potential and inhibitions on “inner and outer worlds” and allow for easier access to them both (p. 49). Elaine Riley-Taylor (2003)



shares that education and learning for her is “a spiritual journey. It is *creation* itself,” where the individual is free to seek-out the self which meshes with a “community, society, world” (p.46). She addresses the child and spirituality in stating,

It is also about the children and about those who would guide them toward a “becoming” of their own – into the fullness of life, the richness of relationships, the strengthening and broadening of skill and abilities. It is about nourishing their capabilities for negotiation, discernment, and fairness, so that they may come to recognize their own responsibilities as members within a larger matrix of life.... (2003, p. 46)

Illness spawns an urgency for spirituality in the educational realm to initiate direction, helping to clarify the meaning of life. Not only does the ill child need to seek purpose and meaning, but the child witnessing illness through the *other* needs reassurance and comfort. Working through illness by confronting feelings and emotions encourages healthy relationships between life, the lived experience, and the mind’s perception of the merging of the two. Dewey (1956a) states,

The only significant method is the method of the mind as it reaches out and assimilates. Subject-matter is but spiritual food, possible nutritive material. It cannot digest itself; it cannot of its own accord turn into bone and muscle and blood. The source of whatever is dead, mechanical, and formal in schools is found precisely in the subordination of the life and experience of the child to the curriculum. (Dewey, p. 9)

Content matter, as described by Dewey (1956a), is only useful when the mind “reaches out and assimilates” making sense of the information, and relating it to life.

Schools cannot ignore the life one lives, nor can it ignore that children need continuity, balance and a connection between the content and life (p.9). Fox (2006) states that spirituality led him to “reinvent forms of teaching so that we may educate more than just the head in our learning institutions” (p. 8). Intelligence is short-lived when there is no application to life. Children need guidance in dealing with life’s adversities, upsets and downfalls. I contend that spirituality coupled with faith can assist one in confronting perceived obstacles of life. This notion will be examined as an approach to confronting illness in Chapter 3, and will explore the relationship between spirituality, transcendence and faith, a triad which I argue gives strength to approach chronic and terminal illness.

### *Afterthoughts*

“Then life happens...*then life happens...*” (Cannella & Viruru, 2003, p. 4).

Educating through living, while living, for living is the premise behind learning. The conclusion of this chapter is only a beginning. This chapter is only a beginning of thought processes that unfolded as a precious life was threatened, the beginning of a story of a child invaded by cancer, and the beginning of life through the eyes of one who had to unwillingly give back a gift. Chapter 1 has set the stage for argument of this dissertation. I have unveiled my arguments intertwined with the story of Joanna’s diagnosis. Writing this paper was not easy. The gruesome loom of cancer, the reality of cancer’s deceit was hanging over me. My emotions were and still are jumbled, churning.

By sharing about illnesses, Frank (2000) suggests that in addition to stories being told to assist those with illnesses in working through “their own changing identities,” stories should be shared “to guide others who will follow them,” not as a means of creating a course for someone to follow, but rather, as a means of “witness[ing] the

experience of reconstructing one's own map" to assist others in creating their own. (p. 17) It is my hope that witnessing will open and initiate a desire to refocus on reality and life. For those who choose this reclaiming, life can be living, existing, interacting today and everyday henceforth. There is no given time that life will happen...life is happening now.

Life is not fair. Education is not fair. Yet we struggle for fairness, equality, balance. Whether based on race, gender, sexuality, power, even health, our endeavors will not cease. "Then life happens....*then life happens*" (Cannella & Viruru, 2003, p. 4). Windows will continue to open as doors are shut, allowing just enough light to penetrate to lead us forward, but the obstacles will continue to appear and block the paths chosen. Determination must dwell in the hearts of the ill, as well as the *other(s)*; for it is through the support of the *other(s)* that the ill draw strength, motivation, encouragement, power, hope, a yearning to muster the energy to press forward in search of that which attains fairness, or in the least a fairness that one can tolerate, that one can bear. The quest for restored health is a mission, a confrontation with reality. It is my contention that we must adhere to a final quote from Dewey (1897/1973) as he stated, "*I Believe that* – education therefore, is a process of living and not a preparation for living" (p. 445).

## CHAPTER 2

### Diagnosing Curriculum:

#### Redefining Dewey's Pragmatism through the Eyes of the Ill

A step towards understanding the curriculum field encompasses “remaking both experience and its discursive representations” in an effort to “see the past and present more clearly,” and by doing so, determining “where our seeing might lead us” (Pinar, et al., 2000, p. 868). I interpret Pinar as meaning when one revisits the educational past, one is better able to see the present, and thereby better able to project and understand the future. In keeping with Pinar's assertion, retracing the past philosophical beliefs and methodologies in education will shed new light on the present predicament. The past will address the present quandary, bringing pragmatism to the forefront as a manner for approaching a society being comprised of curricular discrepancies and childhood illnesses.

Dewey (1938) stated, “All social movements involve conflicts which are reflected intellectually in controversies. It would not be a sign of health if such an important social interest as education were not also an arena of struggles, practical and theoretical” (p. 5). Dewey continued that it is the duty of “an intelligent theory of education” to determine the origin of the existing inconsistencies and conflicts, then “instead of taking one side or the other, to indicate a plan of operations” for which to proceed, stemming from “a level deeper and more inclusive than is represented by the practices and ideas of the contending parties” (p. 5). Dewey acknowledged the dilemma surrounding educational theory, and suggested an approach for how to begin to refine, and redefine theoretical thought and practice of the day.

The battle over educational issues has been ongoing throughout America's history. From the Classical Humanists to the Social Meliorists, rising groups have attempted to solve educational matters based on various philosophies. Although many attempts have been made to revamp and rectify the current educational system of the day, the controversial debate is ongoing, not only due to educational issues, but due largely to differing beliefs about life, living, and how education fits between, amidst, or synchronous with human existence. It is important to trace the events leading up to the reconstruction of curriculum, known as curriculum theory, pointing out not only the influential works that impacted and continue to affect education today, but also the works of curriculum scholars that fuse the trials, challenges, and obstacles faced in running the race of life. This recognition of battles that alter lives is often absent from traditional views of education, thus creating a gap, a dis-connect within the continuity of life and learning. It is this space of unapproachable ground that I intend to visit by examining not only the mind in relation to what is/is not, but rather the mind, the body and the spirit in relation to what is perceived to be.

The mind, the body and the spirit come together not only to create one's actions and responses, but the feelings and voices behind the acts, the life philosophies which spawn thought, inspiration and progress. The purpose of this chapter is to briefly retrace the steps of how the reconceptualization of curriculum theory evolved, bringing to the forefront the continual evolution of the field as new themes come forth, such as illness. By pinpointing specific components of Dewey's pragmatic thought, I will illustrate the relevance of pragmatism in schools today, and explore illness and the implications brought forth when coupling pragmatism and spirituality.

### *Retracing the Diagnosis of Curriculum*

The varying philosophies concerning American Education have long existed, and in doing so, have introduced various beliefs about what the priorities of education should be. From 1828 to present, numerous groups have been competing for dominance in the field of education, formulating their own definitions of curriculum in terms of the school, the subject matter, the teacher, the student, and the lived experience. Emphasis shifted and transposed from various perspectives, chiseling away philosophical ideas each deemed unnecessary and inappropriate while building and defining new concepts, themes and conditions. The Classical Humanists, the Herbartians, the Developmentalists, the Social Efficiency group, and the Progressives all played an integral part in shaping what is known today as education.

According to Kleibard (1995), the Classical Humanists, emerging in the late 1800s, believed that the mind worked as a muscle, and in order to improve the mind, education must practice mental discipline, or memorization. Emphasis was placed on the classics, in an effort to problem-solve in current day by relying on the “windows of the soul” as coined by William Torey Harris. Specifics such as course lengths, grade levels, and ages of students in relation to subjects became topics of discussion.

In contrast to relying on the classics and concentration of grade level criteria, the Herbartians, influenced by Johann Friedrich Herbart, a German philosopher, brought in ideas of lesson plans and cultural-epochs, with strong opposition to the Humanists’ ideas of mental discipline (Pinar et al., 2000; Spring, 2001; Kleibard, 1995). The Herbartians believed that instruction should be directly linked to the students’ interests and prior knowledge, with consideration for the stages of development. Primal thematic teaching

and unification of the curriculum drove much of Herbartian thought, whereas lessons entailed and emphasized the relationships between known material and new material being introduced. In addition, the Herbartians emphasized character building as opposed to mental discipline. The rising debates among Herbartians soon began to reflect the curriculum rather than the method (Pinar, et al., 2000). Interdisciplinary concepts of the curriculum prevailed in Herbartian thought, and was the segue to child-centeredness.

The Developmentalists, interested in the development of the child, believed that the curriculum should be organized around the needs, interests and abilities of the child. The educational philosophy of the Developmentalists was based on the “assumption that the natural order of development in the child was the most significant and scientifically defensible basis” from which the curriculum should be determined (Kliebard, 1995, p. 11). The Humanists, led by William Torey Harris, were in direct opposition to the Developmentalists, which was headed by Granville Stanley Hall; however, the two groups led the way for Dewey’s own curriculum theories and thought, which began to emerge at the turn of the century (Kliebard, 1995; Schubert, 1986).

Around 1900, during the Industrial Revolution, the Social Efficiency group came forth. Members of the Social Efficiency group believed that education should become more efficient, following a task analysis whereas the job should be broken into parts, and the parts should be taught separately. This factory model functioned under that assumption that within the schools, there are products to yield, those products being productive citizens.

In 1929, John Dewey and others stated that Social Efficiency was not sufficient, and that educational reform was in order. From this belief, the Social Meliorist, or

Progressives, emerged. This group was interested in the journey of learning, and inquired as to why the destination, rather than the journey, was deemed as more important. The Progressives believed that education was more about transformation, the transforming of people and society. A split among the Progressives, initiated by George Counts, was enacted in response to his book, *Dare the Schools Build A New Social Order?*, which inferred that the dominant ideology of education was of the dominant class. In addition, Counts asserted that teachers could bring about some social change by becoming a “militant force” (Kleibard, 1995, p. 168). In the 1940s and 1950s, education’s pendulum began to swing back towards Social Efficiency, an act of preparing students for life by teaching home economics and industrial arts, and other subjects directly related to the work ethics of living. The tug of each group’s handle on education began to come into focus as social events took place within the forties.

It was towards the end of this decade, 1949, when a monumental document would emerge, profoundly influencing education to the very foundation of purpose and method for which it existed. Ralph W. Tyler wrote a paper entitled “The Organization of Learning Experiences,” which later became a chapter in his book *Basic Principles of Curriculum and Instruction*. This paper, which discussed learning objectives, learning experiences, methods to implement in order to better organize these experiences, and finally, methods of how to evaluate the experiences, mapped out a systematic procedure for teaching any and all students. Tyler encouraged behavioral goals rather than extreme emphasis on child-centeredness (Pinar et al., 2000, p. 50). During this era, the empirical/analytic form of inquiry dominated with emphasis placed on technical interests,



or rather scientific knowledge. Significance was placed on studying and designing the curriculum (Schubert, 1986).

According to Shane (1980), Tyler's book, which targeted curriculum thought and practice, and emphasized method, was ranking among the top two most influential books approaching curriculum. By emphasizing or "misreading" this work as a curriculum book, which, in essence, focused on instruction, Clandinin and Connelly (1992) assert that the teacher in this text is implied as the "curriculum maker" (p. 366). The significance of teachers in relation to the curriculum proceeds when in 1960, Joseph Schwab claimed that for a statement concerning curriculum to be sufficient, it must make reference to the teacher. A paradigm shift occurred at this point, which was referred to as practical inquiry. According to Schubert, Schwab's interpretation of practical inquiry was concerned with the "continuous interpretation of lived experience;" however, the primary focus involved more of an "instrumentalist, problem solving flavor" similar to the philosophy of pragmatism (Schubert, 1986, p. 317). By labeling the curriculum field as "moribund" or a dying entity, Schwab "signaled the decade of Reconceptualization" (Pinar, et al., 2000, p.193). Hence, hermeneutic inquiry sprung forth under the umbrella of practical inquiry, whereas the individual would search for meaning and understanding within a given situation. It is my contention that at this point in time, the emphasis on one's feelings and experiences began to take on meaning for insight into a better understanding the self and the surroundings.

The critical paradigm then broadens to encompass more than the individual and his/her surroundings. Rather, critical theory envelops ideology of social constructions, social organizations, and the understanding of the reproduction of the structures. Schubert

(1988) appoints Dewey as the “original critical theorist...he was a paragon of a philosopher, a sensitive practitioner, a social critic, and a radical activist” simultaneously (p. 331). Within critical praxis the teacher and student together determine the learning experiences, following intuition rather than a specified curriculum outlining methods and procedures. The emphasis in critical inquiry on the voice and intuition of the individual spawns a new era, an era where stories about the past, present and future provide information pertinent to understanding how groups or individuals are situated within the social structure, a direct opportunity for critical narrative inquiry to develop.

The reconceptualization emerged as a way of confronting and challenging the traditional processes of the educational field, which held true to the premise of Tyler’s work. Critical pedagogy, according to Sleeter and McLaren (1995), predominately grew out of Latin American struggles for liberation. Paulo Freire, a Latin American educator, focused on life in the classroom and discrimination within social classes, drawing similarities to criticalists in North America at the time. By the early 1980s, American scholars such as William Pinar, Madeline Grumet, Michael Apple, Henry Giroux and others began to write openly about experiences, thereby broadening the field of education in a theoretical breakthrough that closely examined race, gender and class. These curriculum theorists questioned and debated that curriculum should not be based on the managerial and developmental aspects of educating, but rather, that curriculum focus on the experiences of individuals that encompassed life and living. Variables and facets of life specific to individuals such as the “political, cultural, gender, and historical dimensions” began to guide the search towards the understanding of the educational experience (Pinar, 1988, p. 484). The existing field of education had become “static and

limiting,” and the first phase of the reconceptualization criticized learning objectives, the bureaucracy of education, and the subject matter concentrations (Pinar, et al., 2000, p. 184).

Over the next 30 years, reconceptualized educational views would shift from a concentrated critique of and professed opposition to the Tyler Rationale, to diverse themes identified by the curriculum theorists themselves. These topics had and continue to have an impact on the lives of all members of the human race, searching for answers as to how lives and lived experiences play an integral role in what is recognized as education. The search for “understanding – not curriculum development” has driven the curriculum theorists into the 21<sup>st</sup> Century (Pinar, et al., 2000, p. 213). The push for understanding, and the search for unveiling truths that guide our learning, require one to delve deeper into the premise behind one’s existence. The reconceptualized curriculum field “is a knowledge-producing discipline, with its own method of inquiry, and its own area of investigation. *Curreré*...is the study of educational experience” (Pinar, 2000, p. 400). This concept moves one from course objectives within the curriculum to “complicated conversation with oneself...an ongoing project of self-understanding” which prepares one for “engaged pedagogical action” (Pinar, 2004, p. 37).

In keeping with the educational experience derived from an emphasis on autobiography, curriculum theorists continue to parallel anticipated and necessary curriculum reform based on individual life experiences. Grumet (1988) identifies curriculum as a “moving form” which complicates efforts of “capturing it, fixing it in language, lodging it into our matrix.” This movement, according to Grumet, weaves together both the “ideal and actual” (p. 172). Sumara and Davis (1998) reiterate this

notion by contending *curreré* focuses on movement, rather than progress. With this in mind, Sumara and Davis state that with “the running of the course” one must be cognizant that “resistance, difficulty, ambiguity, surprise” and other difficulties arise, possibly initiating a rethinking of what was, what is, and is to be (p.85). *Curreré*, seen in this light, is the way one approaches the flow of life which confronts the complexities, and uses the past and present experiences to determine how to proceed. Mary Aswell-Doll (2000) approaches *curreré* by suggesting a “backward, downward move” so that individuals may journey “into their own depths” of “‘course’[ing] through time, through memory, through dream, through culture” (xiv).

To know the self, to journey “backward, downward” to the inner depths, while continuing in forward progression as uncertainties arise, to learn from the present to continue in the future, all highlight major concepts of *curreré*. Each component plays significant roles in the merging of understanding the self. It is *curreré* which summons illness, spirituality, pragmatism and education to common ground. Working and learning through chronic and terminal illness, that which brings about “resistance, difficulty, ambiguity, [and] surprise” exposes one to a new progression of experience between the inner and outer. Life is in “moving form” and approaching the illness; however, “capturing it, fixing it in language, lodging it into our matrix,” our world, our lives, brings about new complications. Through *curreré*, one may acquaint oneself with the ill body, and by “coursing” into the “depths” of one’s inner world, may find a beaten path for which to journey through new life experiences, drawing on the spiritual dimension to assist in learning to live in the ill body.

Pinar (2004) states,

The method of *curreré* – the infinitive form of curriculum – 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)

Pinar eloquently acknowledges that *curreré* will not provide immediate resolutions to the current educational system; however, as Dewey (1902/1956a) stated

Profound differences in theory are never gratuitous or invented. They grow out of conflicting elements in a genuine problem—a problem which is genuine just because the elements, taken as they stand, are conflicting. Any significant problem involves conditions that for the moment contradict each other. Solution comes only by getting away from the meaning of terms that is already fixed upon and coming to see the conditions from another point of view, and hence a fresh light. (p. 3)

The individual educational experiences which help describe and define *curreré*, are the very experiences which teach and spawn learning. In the following section of this chapter, I will examine the significance of the educational experience as it exists within the lives of individuals, most profoundly those who are ill. Through examining one's philosophy of life, and contemplating one's spirituality coupled with the unraveling of life, the conscious fusing of education and the lived experience become evident. As I

examine Dewey and Macdonald, the necessity for a return to the self in a spiritual and educational sense allows one to embark on the journey of coming to know.

### *Redefining Curriculum*

By knowing myself, I am better able to come to know *the other*. Enveloping all capacities, my philosophical beliefs take form, knowing that experiences have played an integral part in the shaping and molding of thoughts, and ultimately my outlook on life. I have identified myself primarily as a pragmatist, an educator immersed in much of the same theoretical beliefs as William James, Charles Sanders Peirce, George Herbert Mead, George Santayana and most profoundly, John Dewey; however, in addition to these philosophical stances, I feel that it is important to couple pragmatic theory with James B. Macdonald's transcendental development theory, in an effort to illuminate spirituality, a component of education that has been ignored, neglected and eliminated. I deem it important to promote not only the growth within an individual for thinking and living, but also to infuse the spiritual dimension which was purposefully omitted from the pragmatic viewpoint, as well as the majority of most philosophical positions.

Dewey's pragmatism, an ever-evolving philosophy, is an entanglement of ideas rooted in various philosophical perspectives such as romanticism, radicalism, naturalism, and Darwinism. According to Schubert (1986), John Dewey, a student of Charles Sanders Peirce, elaborated and validated the philosophy founded by Peirce and William James, and notably publicized and forwarded the philosophy of pragmatism further than any others (Pulliam et al., 1999). By accepting and rejecting concepts that defined the other philosophical viewpoints, John Dewey established a branch of philosophy which educators today still deem as important and as a premise for social change.

In formulating his personal view, Dewey examined philosophers that preceded him, such as Rousseau, Peirce, James and Darwin. These four philosophers along with others shaped and molded his pragmatic theory in diverse ways to create what we know today as Dewey's pragmatism. One such philosopher was Jean-Jacque Rousseau. Although Dewey developed a denial for forms of the supernatural and any formalized religion, contrary to romanticism, he agreed with many of Rousseau's naturalistic thoughts, especially the notion that nature and experience play an integral part in education. (Ozman, et al., 1986, p.103). Both Charles Sanders Peirce and William James had a tremendous impact on the evolution of Dewey's pragmatism. Charles Sanders Peirce's case against dualism, carried over into Dewey's writings, and his groundwork on pragmatism (Ozman, et al., 1986) in arguments such as "the false dichotomy between means and ends" (Peters, 1977, p. 107). In addition, Peirce's significance placed on science through experimental procedures, as well as his reference to the laboratory is evident in Dewey's philosophical beliefs concerning education, as well as life (Kurtz, 1966). William James further shaped Dewey's thinking with his assertion that truth and experience were inseparable, and to obtain truth, one must study experiences (Ozman, et al., 1986). James' applications of moral and social consequences also appeared within Dewey's concepts of pragmatism. And like many philosophers of the day, Charles Darwin's theory of evolution influenced Dewey's views in terms of how habitants solve problems in relation to a changing environment. Each of these philosophers Rousseau, Peirce, James, and Darwin had an impact and influence on Dewey.

Just as traces of several philosophies blended to fuse as Dewey's idea of pragmatism, I too, must be selective in the components of Dewey's philosophy that help

to define who I am amongst a sea of varying beliefs. James Macdonald's proposed transcendental development theory has similarities to Dewey in that it states that there is no "predetermined path" by which the process of human development takes place; more accurately, this process is a "transactional relationship" between the individual and "his environment" (Macdonald, 1964, p. 16). Woven into this association between the individual and the environment are intricacies such as "individually unique choices...unpredictable circumstances", growth and learned social patterns. Macdonald (1964) argues that what has been ignored or better yet, what must be considered is the "personal responsiveness" to the binding connection between individual and life. It is through these perceptions of the lived experience and self that the human potential can expand, escalating, at times, beyond comprehension.

I contend that this display of human potential is due to faith, a faith that I believe would tap into the spiritual dimension of an individual, which encompasses experience and interests, the relationship between the two, and the environment, and allow one to transpire from the spiritual experience. Dwayne Huebner (1985) shares a similar belief in that he believes faith alters life by "infusing...transforming...[and] sanctifying" the "schemas and structures of our being" (p.372). Keeping in mind that Dewey's pragmatism shunned transcendentalism, formalized religion, and belief in the supernatural, the underlying parallels between Macdonald's foundational premise and Dewey's beliefs in experience are that experience is the concept that formulates or triggers thought. I believe that there are two definite threads concerning the individual that bind these theorists, those being the responsibility of the individual, and the



experiences of the individual which play a significant role in how the individual interacts with the environment.

To better explain the role of the school in the individual's environment, Macdonald (1971) contends that "school is not the center of a child's learning" but rather is "one of his environmental situations" experienced within the confines of "his own unique historical, biological, and total environmental fabric" (p. 52). This realm of the environment is expanded to the world outside of the classroom. Dewey (1902/1964b) explains that the "somewhat narrow world" full of "personal contacts" is where most experiences consist of those which "touch, intimately and obviously, his own well-being, or that of his family and friends" (p. 340). Life outside of the classroom, then is a major source of one's learning environment. This being the case, it is important to examine the school, society and the family within the pragmatic views of the lived experience.

### *Reconsidering Pragmatism*

School, societal, and family interactions are crucial in portraying this lived experience. Over the past several decades, society's general notion of *a family* has been redefined, modified, and altered. Garrison (1997) identifies two major feminist criticisms of Dewey's pragmatism concerning the family structure as being outdated and inattentiveness to care. Martin (1992) debates the validity of Dewey's position in terms of the family unit in today's society arguing that homes no longer revolve around "a place of work...[where] occupations of home [could] be transplanted into school" (p.126). What is missing, Martin asserts, is caring. Although Dewey did not mention caring as such, I argue that he did approach a changing educational system, a changing society, and

embedded in each, changing family structures with implications for care, concern and nurturance, all of which are of utmost importance when experiencing illness.

Dewey (1899/1964c) stated that as society and “social life” change, so, too, education “must pass through an equally complete transformation” which will evolve slowly and steadily (p. 309). When a small community is established within a school preparing children for roles within society, “the deepest and best guaranty of a larger society” progresses in harmony (p. 309). It is evident in Dewey’s writing that he identified change as good and society’s proposed benefits of change. He defined society as an association which invoked a “coming together in joint intercourse and action for the better realization of any form of experience which is augmented and confirmed by being shared” (1900/1967, p.7). Multiple family units or family structures, however defined, create a society, so that society directly reflects the entities in which it is established. My rebuttal here acknowledges that society, education and the family have changed since Dewey’s original work; however, it was the recognition of change that spawned Dewey’s writings advocating what was practical and useful, rather than a *fix it* philosophy whereas we sought “to superimpose the new on the old” (Dewey, 1931, p. 40). I must return to the premise of Dewey’s argument that learning is life, and however life changes, and in whatever realm that implies, the schools, too must change.

Life changes and responses for the individual, are not only contingent upon the external, physical nature of existence, but rather, are contingent upon a convergence of the internal, the external, and the experience perception of the individual.

Dewey (1934/1958a) stated,

...life goes on in an environment; not merely *in* it but because of it, through interaction with it. No creature lives merely under its skin; its subcutaneous organs are means of connection with what lies beyond its bodily frame, and to which, in order to live, it must adjust itself, by accommodation and defense but also by conquest. (p. 13)

The relationship one shares with the environment is essential. One must interact with the external to meet internal needs. The hungry child, the student in search of knowledge, and the suffering child heavily rely on the external to meet needs. The inner, out of sync with the outer, must restore equilibrium in order to continue to thrive as an individual. In the case of the ill child, the internal, external, and *other* come together to create an environment specific and unique to the individuals which interact.

The other(s) is responsible for caring for, nurturing, and tending to the ill, whether it be the physician, the guardian, the teacher, or any other caregiver. Another criticism of pragmatism, raised by Martin (1992), refers to care and nurturance. Arguing in defense of pragmatism, I turn to what may be viewed as the philosophy's greatest weakness, that is, the emphasis on the individual. My background in Early Childhood Education recognizes the importance of nurturing the individual in all facets implied. This attention sets the stage so that reconstructivist ideas and poststructuralist notions can be instated; that is, social issues and social concerns can be addressed to initiate social change. But quite contrary to the critics of pragmatism, I argue that it is of utmost importance for a firm, healthy, positive foundation to be laid so that problematic social injustices do not

deplete the individual of all conceived possibilities. Children must be recognized as children, and as Dewey states:

If we seek the kingdom of heaven, educationally, all other things shall be added unto us-which, being interpreted, is that if we identify ourselves with the real instincts and needs of childhood, and ask only after its fullest assertion and growth, the discipline and information and culture of adult life shall all come in their due season. (1899/1964c, p. 69)

I interpret Dewey as meaning that meeting the needs of the child enables him/her to conceptualize and digest social issues with maturation in a manner that the conceived need or recognition for social change is understood. In this light, it is unquestionable the validity of Dewey's pragmatism in relation to its child-centeredness. It is my contention that denying a child this attentiveness is unethical and immoral. Dewey (1899/1964c) expounded on this reciprocity in expressing the crucial significance of the school's responsibility for "being true" to the development of all individuals who make up a society, which he deemed as "being at the disposal of its future members" (p.295). He believed that it was only through this commitment that society, in turn, could be "true to itself" (p. 295). To trace the roots of what fosters a harmonious society, I argue that the family unit is meeting the individual needs of its members, that care is evident, and that this critical part of nurturance is present.

Noddings (1992) raises thought provoking issues concerning care about the "who" behind the development of schools and school systems by stating,

Suppose education had been planned and school systems constructed by people whose interest and responsibilities focused on the direct care of children, the

elderly, ill, disabled, and otherwise dependent. Suppose education was planned by people primarily concerned with the kinds of relations we should establish. (p.44)

I believe these to be interesting topics of conversation. Relations at the core of education? Caring for the elderly, the ill, the disabled calls for an acute awareness of the individual. Care for these individuals would require one-on-one conversations, considerations for feelings, progress and well-being. Attentiveness to needs would guide daily occurrences, which I find to be very much inline with the pragmatic philosophy. I consider it ironic, yet appropriate that Noddings included the child among this list, a dependent still coming to know of his/her world. An individual, whom Dewey (1930/1940) states, “is not something isolated; he does not live inside himself, but in a world of nature and man....To fail to assure them guidance and direction...promotes the formation of *habits* of immature, undeveloped and egoistic activity” (p.218). The child, a stranger in this world, looks to the *other(s)* for “guidance and direction” as he interacts with the world. That “guidance and direction” stems not only from family and friends, but from teachers, as well. A child, one needing one-on-one conversations, considerations for feelings, progress, and well-being, as well as an attentiveness to needs is one needing care and nurturance. An unspoken care and nurturance which resonates through the selection of activities and experiences, stimulating interests for the child is a profound part of the pragmatic view.

Another criticism concerning truth and absolute Truth is problematic in any and possibly all philosophies. Bertrand Russell (1912/1967) has criticized the definition to the pragmatic meaning of truth in terms of what truth ‘*means*’ and from a standpoint of satisfaction. Dewey (1920/1957) states that what is true emerges when a hypothesis

works. truth, then, acting abstractly, is a “collection of cases, actual, foreseen and desired” whereas the consequences and confirmation of the acts are recognized (p.156). This notion of truth is contingent upon the “the correctness of the prior account of thinking” reflecting on why it is objectionable (p. 157). The reference to satisfaction is clarified by Dewey by stating it is not “merely emotional satisfaction...a meeting of personal need,” rather, it is “a satisfaction of the needs and conditions of the problem out of which...the purpose and method of action, arises” (p. 157). In reference to truth as utility, Dewey asserts that frequently, it is interpreted as meaning a “utility for some purely personal end” (p. 156). Quite contrary to this assumption, Dewey clarifies that truth as utility is illustrated when an initial supposition of the inquiry is confirmed by the other.

I agree and strongly support the notion of empirical truth being guided through utility, satisfaction and need; however, I am in opposition to Dewey’s denial of an absolute Truth. I believe that there are temporal truths in this life, and that through science, these truths may change, alter, possibly even become obsolete; however, it is the absence of supernatural truths that I differ greatly with Dewey’s definition of Truth in a spiritual sense. Dewey (1894/1971) states that when closely examining truths, “it is always implied that the inaccessible truths are really not truths, or are at least not worth finding out” (p.102). Furthermore, he continues “all truth which promises to be of practical avail...may be gotten at by the scientific method” (p. 102). Dewey’s call for action for us all to “form our faith in the light of the most searching methods and known facts;...to form that faith so that it shall be an efficient and present help to us in action” is exactly what I argue from a spiritual standpoint (p. 105). I believe that my sense of

inquiry and emotional satisfactions can allow me to accept temporal truths which fluctuate depending on proofs that I may come to know, and justifying my Truth in the same manner, through my daily experiences. I see evidence of God in the lives of those around me. William James (1955/1960) states that “the evidence for God lies primarily in inner personal experiences” (p. 78). In addition, James asserts that “the truth of ‘God’ has to run the gauntlet of all our other truths” (p.79). I, too, argue that my own realization and confirmation of the reality of God is found in my own personal thoughts and perceptions, and evident through my reality. In relation to Dewey, Truth as “emotional satisfaction” acts as a utility in my actions and experiences. Realizing that Dewey would argue my stance as being emotional rather than spiritual, I believe that spiritual dimensions stem from the emotional, as well as the emotional stemming from the spiritual. This partnership illustrates the denial of yet another dualism, an act which resonates throughout pragmatic thought.

The notions of truth/Truth play a crucial part in the lives of the ill. What is true for the ill patient may more authentically be answered through feelings of pain, anguish and suffering. The temporal truth of the disease may be revealed through conversations with medical personnel, through conversations with other patients, or some other confidant willing to listen and offer assurance; however, these temporal truths are temporal. Health may decline, or remain constant for periods of time. Pathographies testify to Truth in the lives of ill, and the integral role it plays in the daily lives, and will be explored further in Chapter 3.

The last and most profound criticism of the Deweyan philosophy stems directly from the realm of present day schools. Politicians and society at large have viewed this

philosophy as appearing to be too permissive, lacking limits and specificities, allowing the students to choose what information was to be learned, and in doing so, not learning needed information (Guttek, 1988; Chambliss, 1996; Ozman, 1986). What we have witnessed as a result of this “child-centered” opposition has been drastic measures to press forward in the opposite direction, a pendulum swing into the past, a direction that I believe not only stifles learning, but also confines growth, not in a physical sense, but in a mental, intellectual and social aspect as well. In *The Way Out of Educational Confusion*, Dewey (1931/1964) stated that methods are still practiced where the student “is a recording phonograph, or one who stands at the end of a pipe line receiving material conducted from a distant reservoir of learning” (p. 423). This focus of traditional education has seemingly been reduced to emitting ‘knowledge’ like a mother bird feeding her chicks- a ‘pouring in’ or ‘spitting out’ as students sit idle absorbing the regurgitated material as if it would permeate into the brain verbatim, there to stay, and at any given moment be thrust back if the need would arise. According to Dewey (1938), this methodology and pool of information catapults from the past thereby defining the role of the school as transmitting information pertinent to the past through a methodology created in the past “to the new generation” (p. 17).

Today, this new generation of students dwelling within classrooms seems fully aware of the education that dwells beneath the shined armor presented to the public at large. Ayers (1993) described children’s perceptions of school as having “little individuality” where “the schedule is in charge” and “what’s good for the group had better be good for me” (p. 52). Within the school, Ayers continues, children come to recognize that learning takes place in small increments where the “knowledge is cut up



into disciplines, disciplines into subjects, and subjects into units of study” (p. 53). Dewey (1902) expressed concern about how the school divided the child’s world by ripping away at the continuity of subjects from experiences, and then plotting them back into universal rules and principles. I propose that both Dewey and Ayers were cognizant of the fact that children struggled with the segmentation of life within the school walls, and this is the reasoning behind Dewey’s and Ayers’ emphasis on experience and life.

Illness is one component of private life which cannot be detached. Entering in and of the self, illness demands recognition, possibly exposing students to the hardships, the adversities others face in confronting illness. First hand experience of life’s challenges, to sustain life, to sustain relationships, to trust in these relationships, is a lesson to learn packed with a wealth of knowledge; unfortunately, few state mandated objectives address this. The chronically ill are experienced learners in what is involved in reaching the optimum human potential in every facet, to reach deep for inner strength, to look for sources to provide this strength, and to believe and trust that the effort put forth will be rewarded with another day. We, as a healthy society, must partake in the lessons these ill patients have to teach.

### *Afterthoughts*

Dewey’s pragmatism recognizes learning as life. Over the past century, the definition of education and curriculum has fluctuated. From memorization, to methods, to the lived experience, education has journeyed under the label of specific groups, and with an agenda pertinent to each. Through a careful examination of Dewey’s philosophy, I am naturally drawn to his educational themes. I believe that his writings are as pertinent today as they were when written, and that his notion of educating the individual stands

solid in today's predicament. The present predicament includes children that have been oppressed, marginalized, silenced. My study of children with chronic and terminal illnesses exemplifies the need to draw experiences into the educational field.

The *Reconceptualization* opened the door for personal experience to play a role in education. Because of the work of curriculum theorists who reconceptualized the field, I can raise issues such as, "Is it ethical to weigh the work and achievement of these children against healthy, 'normal' children? Why would these children have a desire to be in school?" I am capable of answering my own question, and the answer is not to learn a predetermined set of criteria. The answer lies in the desire to live life to the fullest with relationships, the desire for social interactions. Yes, the pragmatic philosophy is ever pertinent and solidifies my need to give these children a voice; however, in order for education to truly reform, conversations must be heard, deliberated, and studied so that as a whole, society is drawn into the present world of educating the youth and children with the appendages that accompany them.

"Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience" (Frank, 1995, p.115).

Each human life is a journey, an exploration of how a being interacting with others and things can ultimately change and alter the present, all the while, being vulnerable to the happenstance that life can change and alter the individual. What obstacles, twists, and turns each will confront is obscure, concealed; however, when ill-fate settles, claiming yet another, the individual possesses the means to boldly confront the adversity by turning inward, becoming reacquainted with what lies within, tapping

into spirituality, and through faith, progressing to make the very best of each day. As a curriculum theorist, I believe it to be of utmost importance to listen to our children, to take into account the lives they live, and to encourage the sharing of their stories. The merging of education, spirituality, illness and education resides in the lives of our children, simultaneously residing in our own. The time has come to share these experiences, and realize that life outside of school carries over onto the school grounds, within the school walls, and throughout the educational arena. Dewey (1900/1956b) stated,

...the great waste in the school comes from his [the child's] inability to utilize the experiences he gets outside the school...he is unable to apply in daily life what he is learning at school. This is the isolation of the school-its isolation from life.

(p. 75)

## CHAPTER 3

## Contemplating Spirituality: Nursing the Soul Through Illness and Education

John Dewey (1958b) once stated,

...life...is onerous and devastating...corrupt and harsh....a spirit which believes that it was created in the image of a divine eternal spirit, in whose everlastingness it properly shares, finds itself an alien...in a strange and fallen world. Its presence...in a material body...is a mystery. (p. 248)

I believe these statements to be profound. Aside from recognizing mere existence as a mystery, Dewey implies the connectivity of an individual to each and every aspect of life, to nature, to society, to the *other*, and the perceived consciousness and experiences one has. Dewey contemplates the spirit believed to be created in the image of “everlastingness” finding itself in a “material body” which assimilates, responds, thinks, and reacts, all the while being vulnerable to the life around it. This unity of existence exposes those within the ring of consciousness to the unforeseen circumstances that may arise as one journeys through life. The mystery, then, is the realization that the individual is influenced by life which is “corrupt and harsh” in a world which is “strange and fallen,” and the beauty and mystifying aspect of it all is this individual dwells within the surroundings, interacting and striving to overcome the obstacles, and make sense of his existence. Illness, an adversary, employs within, but through the perpetual transpiration of experience, affects all involved, not simply the victim. The consequences of illness disseminate to those in relations with the ill. For this reason, stories, not only from the ill, but from loved ones, medical professionals, teachers, *others*, should be shared. The unveiling of insight into illness in terms of emotions, physical challenges, relations, and

spiritual angst, requires a careful examination from various perspectives capturing the circle of connectivity each life emits to others.

Whether bound by the parameters of work, school or home life, living is learning. Schooling is merely an additional avenue to one's educational experience. Dewey (1915/1962) states "what is learned at school is at the best only a small part of education, a relatively superficial part," with the "real teachers" being "experience and emotion" (p. 52). As life endures through time, the encounters help prioritize and determine the importance of what is learned. In the face of illness and schooling, one initial lesson to be learned is how one lives with illness, both socially and independently. This chapter will examine the complexity of illness in terms of confronting the disease, and through spirituality and faith, living and learning through the ill body which confines an individual, as well as an ill body which educates.

Spirituality, the very essence of the word embodies intimacy, serenity, and completeness, resounding peace and tranquility, yet the word is twofold. Although appearing light and weightless, upon probing deeper into the meaning of spirituality, the inconceivable intensity of the underlying themes emerge, the private, the personal, the passion, and the desire to be in and of this world, with perseverance and determination. Yet, as Susan Sontag (1977/1990) points out, all of humanity "is born with dual citizenship, in the kingdom of the well and the kingdom of the sick" (p.3). Once one enters the world of chronic illness, the familiar becomes strange, the known suddenly becomes the unknown. Grumet (1978) using the term "estrangement," in discussing curriculum suggests that one should examine the possibilities of a situation rather than the reality (p. 308). By claiming reality, or taking ownership in the situation, then

“estranging” oneself from that reality, one can refocus, rethink, recreate. I believe that through “estrangement,” viewing the familiar in a new light, or viewing it as strange, one can nurse spirituality to new heights, or better yet, to a new depth.

Illness invades the human body, uninvited, trespassing within what is familiar, forcing the whole to become unfamiliar. Illness has the capability to “undo our sense of who we are” (Morris, 1998, p. 22) by experiencing life transformations, engaging in struggles with the pain, suffering and trauma associated with the onset. Throughout the inflicted journey, those associated with illness are confronted with choices, choices that ultimately can affect the quality of life, the healing process, and the day-to-day challenges of living with an illness. I believe that a deep sense of spirituality not only facilitates the decisions, but also promotes an outlook so that life is bearable, even when it is unbearable; an outlook that life is livable, even when full of suffering; and an outlook that life is a gift, even when that gift slowly slips from one’s grasp.

Spirituality allows one to turn inward, to bond with that which lies within, to acquaint oneself with the *other*. Being grounded within, yet resonating beyond religious connotations, “an individual’s personal philosophical beliefs” emerge as spirituality is explored, implicating various meanings for each individual (Carroll, 2001, p. 2) The quest for wholeness generates a return to the self, a pursuit of completeness, meaning and purpose. It is my belief that spirituality coupled with faith can guide humanity through adversity to attain a sense of totality and unity when hardships arise, whether it be in relation to illness, educational dilemmas, or societal perplexities. This chapter will illustrate how one can approach the human potential, maximizing it through reflections in spirituality and faith. I will draw on James Macdonald’s (1974) concept of ‘*centering*’ in

order to lay the foundation of how individuals in a personal sense, and society more collectively speaking, can “estrangle” themselves from present reality, and search for the other possibilities that restore spirituality. In this chapter, I will demonstrate how faith inspires these individuals to press forward, in search of totality, in search of the human potential. For it is when one loses sight of faith, that the perceptions of the world and the importance of life within that world become trivial, pointless, and insignificant. I argue that as illness sets in, whether within one’s own body, or within the body of loved ones, there must be a *centering*, a spiritual experience whereby one recognizes the physical, mental and emotional potential that lies within, seeking unity between mind and body. Working through horrific experiences consistently challenges the human potential; for that reason, a conscious notion of the inner self in relation to spirituality springs one forward.

### *Spirituality*

What is spirituality? How does one define it? Webster (2003) argues that by virtue of being a human, one is spiritual based on the fact that for him, spirituality is conceptualizing what “the meaning of life” and “one’s self-identity are understood to be” (p.1). Spohn (1997, ¶8) discusses several types of spirituality such as “lived spirituality” which bonds the individual with “reality’s deepest meanings” and “reflective spirituality” which examines the lived experience. I believe that defining spirituality places boundaries on a concept that engulfs human existence and the human experience. Spirituality is the contributing basis for behavior, beliefs, values, and way of life, escaping *no* entity, *no* thing, *no* one. Spirituality is much like a heartbeat, pulsating to maintain one’s existence, yet too often, the individual is oblivious to its presence. It is

for this reason that I argue that a consciousness of spirituality, and a consciousness of perceptions of self can lead to inner strength to nurture our physical and mental being.

In exploring spirituality, it is important to examine Macdonald's concept of transcendental developmental ideology, which was developed as a follow-up to the romantic, developmental, cultural-transmission, and radical theories (Macdonald, 1974). These ideologies, according to Macdonald, which recognize relationships between one's inner and outer experiences, fail to recognize that which lies within the individual, locked away from consciousness. In addition, these ideologies fail to thoroughly outline and specify how "personal" values play a role in one's perceptions (p.81). Macdonald (1974) suggests that the transcendental developmental ideology not only addresses values as exceeding "one's biology, culture, or society," but in doing so, also recognizes the awareness of human potential and how values play an important role in the process of striving for optimal human potential. This ideology encompasses the inner and outer experiences, and the experiences between the self and the *other*. In other words, the transcendental development ideology allows for transactions to occur within the individual, as in acquiring knowledge, whereas the outer world is made one's own "through the inner potential of the human being as it interacts with outer reality," which is contingent upon a relationship between the self, the other, and the environment (p. 83).

Understanding illness envelops this triad in terms of the individual and the surroundings. Arthur Kleinman (1988) refers to illness as "the innately human experience of symptoms and suffering" and how the ill person, family members and society at large "perceive, live with, and respond to symptoms and disability" (p. 3). Suffering and symptoms may begin within the sick, enveloping conscious recognition of aches, pains,



and physical ailments, the “lived experience of monitoring bodily processes” (p.4). David Morris (1998) defines illness as “a fluid process that changes as we change, enigmatic, insubordinate, subjective....capture[ing] bodies, minds, and emotions” which cannot be articulated through language. He continues by stating that when “examining the same illness” from multiple perspectives, the illness will be portrayed from “different aspects of its truth” (p.5). Both Kleinman and Morris recognize that although perceptions of a given illness unfold within the ill individual, these perceptions do not stem solely from the ill, rather, perceptions are gained from the broad associations of others connected with the ill. Illness, then, is socially constructed. This view supports Macdonald’s transcendental development theory in that illness and the perceptions thereof, are culminations of the lived experiences through the environment, the individual, the self, and reflections on how these create the individual’s outer reality. As I will discuss later in this paper, it is the reflection of the lived experience that delves deep into the realm of the human potential.

Taking into consideration the latter, the relationship between the self and the individual, it is the conscious reflection of experience that initiates the determination of what is good and bad, what is valued, and what is not valued. In effect, this merging of the self and individual suggests a recognition of the conscious being, or “explicit awareness of the individual” and unconscious being or “the nonexplicit nature of the individual” (Macdonald, 1974, p. 79). By a personal connecting with the inner self, Macdonald contends that the human potential that lies within can be experienced in the conscious self. Therefore, attaining knowledge, or in more educational terms, learning, suggests a more complex act instead of simply connecting with the external, but rather

and in addition to this external collaboration, a digestion of the external world, and a realization of how the inner self interrelates to this reality is necessary. It is this continual flow of interaction with the outer world spawning individual perceptions and capabilities that evokes the concept of *centering*, which Macdonald asserts is the aim of transcendental ideology, and in my belief, the aim of healing.

Drawing on the work of Mary Caroline Richards, Macdonald defines *centering* as a spiritual experience, acknowledging the possibility that the development could take place within a religious framework; *centering* initiates a “search to find our inner being or to complete one’s awareness of wholeness and meaning as a person” (Macdonald, 1974, p. 87). In other words, *centering* is an act of being cognizant of the inner being and an act of tapping into the potential which lies within. Macdonald, writing in terms of potential, inquires into the mysteries of human existence giving examples such as mental telepathy and unharmed bodies when walking on hot coals. He asserts that the human potential has not been reached, rather, that the optimal human potential may just now be emerging from what already lies within. I believe that in direct relation to Macdonald’s view, the potential for overcoming, or in better terms, living with illness dwells within an individual. Macdonald states that current achievements, testimony and history emerged from “this very source of the unknown,” which I assert provides the possibility for self-restoration through the process of *centering*.

Although I, too, agree that *centering* is the fundamental basis for an individual to reach and recognize the human potential, I argue that there must be an additional phase for this process to be complete. I believe that not only must one interact with the external world, perceive the external world, and then reflect upon how the two mesh initiating

personal response, but in doing so, one must determine his will of faith in order to grasp from whence the potential stems. This faith, throughout the course of life, may shift from one source to another, meeting the needs of the individual in pursuit of restitution, which provides comfort, possibly hope. Macdonald and I share the view that this faith does not have to be religiously connected, as in the case of Carl Jung, who searches for wholeness, contentment within the inner self. This faith can dwell within the inner self, within other individuals, or within the notion of a higher being; however, by determining where faith resides, the individual consciously recognizes where the source for human potential draws strength. I further argue that *centering* along with the recognition of faith, has a place not only in relation to illness, but also in the field of education. For it is when one loses sight of faith, that the perceptions of the world become cloudy, blurred, and spirituality declines. Spirituality, that which helps give purpose, direction and meaning to life, resonates within the soul, and by focusing on drawing an inner strength, one reveals from whence faith is placed.

### *Faith and Unity*

Faith can be defined in many ways, ranging from *belief and trust in God*, to *allegiance to duty or a person* (Merriam-Webster Dictionary, 1997, p. 273). The definition of faith that I will be referring to throughout this paper is defined as *one firm belief in something for which there is no proof* (Merriam-Webster Dictionary, 1997, p. 273). Faith defined in this sense allows for one to draw inner strength from anywhere or any *thing*. This broadens the scope, placing no limits on where individuals may turn for solace, completeness, wholeness. In order for transcendental development theory to be complete, I argue that faith must accompany the personal response to how the inner self,

individual and environment interact, and how these interactions affect the individual. This faith, this belief in something lacking proof, which may or may not imply religious connotations, I argue, is a necessary component to reaching the optimal human potential of which Macdonald speaks, whether individually, or collectively.

Faith, for Derrida (1994/1997), stems from a “promise,” an unspoken assumption that what is seen or heard is true. This promise is the basis for conversation, life, mere existence in that “faith is absolutely universal” (p.22). Derrida argues that communication cannot take place without faith in that “When I speak to you, I am telling you that I promise to...tell you the truth....Every speech act is fundamentally a promise” (pp.23). Derrida continues by stating that no society exists without faith, even if the trust is abused, “there is no society without faith” (p. 23). In terms of Derrida, faith is an everyday occurrence, an act that transpires involuntarily, instinctively taking place through various forms of communication. I do not argue that this form of faith is nonexistent, quite contrary, it is very much a part of the human presence; however, in terms of expounding and expanding one’s potential, mere belief in society, and members of that society is not sufficient. When survival is at stake, there must be more, there must be an avenue, a channel, a source from which truth and honesty elicits strength, motivation and desire. This unequivocal faith is the essence behind progressing towards the potential that lies within each individual, particularly those with illness, lessening the tendency for fear and anger to diminish inner strength in the process.

Larry Burkett (2003) states that “fear is simply the opposite of faith” in that fear gives rise to “worry, frustration and anxiety” (p.31-32). By consciously placing trust and confidence in *another*, or the *other*, one can decrease, if not extinguish fear. Although this

fear is not permanently eliminated, it allows the ill to work through the present, which according to Burkett, the future is that which is most often feared, because as situations arise in the present, a determination to endure also accompanies. In discussing the present reality, Audrey Lorde (1980) recognizes that “reality, however difficult, was easier to deal with than the fear” (p. 31). In other words, the present confrontation, the reality of the illness, is somehow less threatening than the fear of the future, that which is to come.

Lorde (1980) gives testimony to illustrate this battle with fear in order to focus on faith, intensifying the inner strength to press forward. Making reference to her battle with fear, she states, “And I began to recognize a source of power within myself that comes from the knowledge that while it is most desirable not to be afraid, learning to put fear into a perspective gave me great strength” (p. 20). And again she reiterates her self-affirming inner faith, “It was very important for me...to develop and encourage my own sense of power” (p. 73). She speaks of her struggle with despair as “teaching, surviving and fighting with the most important resource I have, myself, and taking joy in that battle” (p. 17). Essentially, Lorde, embracing spirituality and placing faith in her inner self, gains the strength to endure, making the most of each day. Lorde discovered that by facing her fear, she became empowered, and the fear seemed less constraining. By claiming the fear as her own, and recognizing the illness as a part of her, a unified merging of the body and mind, Lorde was able to proceed with life.

Upon the onset of illness, many patients give testimony to the segregation between the mind and the body. Sontag (1977/1990) speaks of illness as betrayal of the self whereas “one’s mind betrays one’s body...or one’s body betrays one’s feelings” (p. 40). Healthy bodies not faced with mortality, according to Frank (1995), simplify

“associating the self with the body...[however,] mortality complicates this association (p. 33-34). Oles (1999), suffering from breast cancer states “my body has unfriended me” (p. 96). In other circumstances, those suffering from illness are cognizant of the unity between mind and body, however, struggles between the foreign substances within the body which create the illness occur due to the fact that the harm is many times self inflicted, such as in the case of many cancers which can originate from abnormal cell growth, a result of the bodily functions going amiss.

Gordan Stuart, a cancer patient in his final days of life, spoke of cancer in terms of being a part of him and apart from him. He stated, “The feeling there is something in me, an ‘it’ eating its way through the body. I am the creator of my own destruction. These cancer cells are me and yet not me. I am invaded by a killer” (as cited in Kleinman, 1988, p. 148). Another patient, Carol Dine, describes cancer as having the “dreaded cell...loose in my bones like a live grenade” unable to “separate myself from the cancer. I was becoming the cancer” (Dine, 1999, p. 256). In relation to this coupling of mind and body, Derrida’s faith, contingent upon the unspoken promise, plays an important role in the life of the ill. Kleinman (1988) states that the ill-being no longer can depend upon the “basic bodily processes that the rest of us rely on.” The reliability of basic functions of the body are “so basic that we never think of it...Chronic illness is the betrayal of that fundamental trust. We feel under siege: untrusting, resentful of uncertainty, lost” (p. 45).

This exemplifies a loss of Derrida’s faith, a faith that allows one to believe in something that is logical, reasonable. As living beings, we make the assumption that the bodies which give life will sustain life, unmindful of the possibility that this body, at any

given time, could rupture, fail, fall short of one's expectations. In reference to Derrida's faith, Caputo's interpretation states that it is more natural to "proceed by faith...since the reasonable thing to do most of the time is believe" (1997, p. 165). Derrida asserts that the "universal structure of the promise, of the expectation for the future, for the coming," referred to as the messianic structure, solidifies this faith, and I contend that this directly relates to the faith individuals have in their bodies (1997, p. 23). One believes that all is well until given reason to believe otherwise, thereby triggering a loss of faith in that which fails the individual.

It is precisely this loss of faith, the faith in the body, which sustains and is essential to human existence, that initiates the human reflection on the self, the individual and the environment. The future is anticipated through different eyes, thereby perhaps shadowing the individual's perceived human potential with doubt, which may soon decrease, lessen, even deplete the inner strength that once was present. The personal response may consist of fear, anger and confusion. It is at this point that I contend that the individual must place faith in some *other*, some *being*, or some *one* in order to gain strength, refocus, readjust so that meaning and purpose are returned to an altered life. Focusing on spirituality, and having faith, a faith or strong belief in some *thing*, or some *one*, can alter not only the mind, but bodily functions as well.

The placebo effect is an example of how directed faith in some *thing* can alter the mind and body. Morris (1998) mentions that sugar pills, white coats or other indications of medical emblems can initiate this effect. "Ultimately, the placebo effect...depends in humans on the power of belief to initiate biological processes. When patients believe that it is medically effective, a sugar pill can relieve pain as effectively as

morphine.” In addition, Morris states that prayer “in some circumstances and for some people,” can produce results of the placebo effect “for alleviating symptoms and improving health” (p. 67). Faith placed in prayer, medicine, doctors, or others has the possibility of triggering changes in the body and mind of those that truly believe. I am not suggesting that one is healed by faith alone. I am cognizant that the individual with AIDS, and likewise, the child with cancer, needs more than faith to restore health; treatment must accompany illness. However, what I am proposing is a body of faith may lift the spirit to assist in the journey through illness.

Faith has the potential to restore a vision of the health, encouraging individuals to reach for the optimum, whether through objects, such as medicine, or others. Life unfolds, unpredictably, as both the ill, and the unknowing ill participate in formulating his own destiny through the self and the environment. Macdonald states that there is no “predetermined path” by which the process of human development takes place; more accurately, this process is a “transactional relationship” between the individual and “his environment” (Macdonald, 1964, p. 16). Woven into this association between the individual and the environment are intricacies such as “individually unique choices...unpredictable circumstances”, growth and learned social patterns. Macdonald argues that what has been ignored or better yet, what must be considered is the “personal responsiveness” to the binding connection between individual and life. It is through these perceptions of the lived experience and self that the human potential can expand, escalating, at times, beyond comprehension.



### *Education and Identity*

Macdonald's transcendental development theory embodies the key to clarify how a sense of spirituality is fused with one's perceived identity. As transactions occur between an individual and the environment, meaning any *other* outside of that individual, and the effects and results of this interaction are digested, whether consciously or into the unconscious knowing, perceptions of self generate in relation to the *other* and others. These perceptions merge formulating a notion that either life is worth living, that is existence outweighs the struggle, or life has little or no significance, no personal meaning for existence. Spirituality is the premise for meaning and purpose, and as Macdonald's theory evolves, and the time arises when the individual has a need and a desire to press forward, to persevere through adversity, the soul searches for reinstated equilibrium, and when the conscious is unable to provide the solace and endurance, the soul beckons for a source from which to draw inner strength, a source of faith.

The crippling effect of education is compounded by ignoring the spiritual dimension of the individual. Education today is not about nurturing, nourishing and nursing the soul. Education is about the business of educating, a goal oriented, "fund drive" (Grumet, 1988, p. 91), just as the medical field is about the business of healing. A cancer patient enduring much pain notes, "During the day the clusters of residents and doctors and nurses tend to our bodies, but at night ...[we] tend to our souls" (Post, 1999, p. 12). If education is the business of educating, learning about life, learning to live, then that which initiates a desire to live, a purpose for living must be addressed. How can we claim to educate if we fail to give meaning to life? We have much to learn from the chronically ill.

Illness exemplifies what all experienced educators already know, in that what lies below the surface of our skin is different within each individual. This outer covering, this shield is but a shell concealing intricacies that perform uniquely for each individual. Generalizing health, assuming that every individual's body make-up and chemistry is the same would be ludicrous. Blood, varying in types, substantiates the claim. Education is a surface discourse, working solely to enhance the mind, the academic, the collective beings, allowing what lies below the surface, the depth of the *other*, to be ignored. "Thus, work for teachers and students is seen as segregated from their private lives" (Macdonald, 1975, p.113). The private, the inner self, the self that swells with emotion and feeling is left outside of the school grounds.

Illness is one component of private life which cannot be detached. Entering as an appendage, illness demands recognition, possibly exposing students to the hardships, the adversities others face in confronting illness. First hand experience of life's challenges, to sustain life, to sustain relationships, to trust in these relationships, is a lesson to learn packed with a wealth of knowledge; unfortunately, few state mandated objectives address this. The chronically ill are experienced learners in what is involved in reaching the optimum human potential in every facet, to reach deep for inner strength, to look for sources to provide this strength, and to believe and trust that the effort put forth will be rewarded with another day.

#### *Afterthoughts*

"Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience" (Frank, 1995, p.115).

Each human life is a journey, an exploration of how a being interacting with others and things can ultimately change and alter the present, all the while, being vulnerable to the happenstance that life can change and alter the individual. What obstacles, twists, and turns each will confront is obscure, concealed; however, when ill-fate settles, claiming yet another, the individual possesses the means to boldly confront the adversity by turning inward, becoming reacquainted with what lies within, ultimately a '*centering*.'

*'Centering'* requires one to interact with the outer world bringing knowledge from this interaction into the inner being, then through reflection on the experience, grappling with the conscious and unconscious being. I believe that many individuals suffering from chronic illnesses illustrate an innate progression through the process of centering, and in doing so, consciously choose a source, or various sources of faith from where personal motivation and drive can be attained, a uniting with spirituality. This search for completeness and wholeness provides individuals an opportunity to share the struggle, lift the burden, relieve the sole ownership of life's impediments.

The chronically ill are well versed in confronting the unforeseen future, living day to day, living in limbo on the margins between coping pain and unbearable pain, approaching each new circumstance with determination in search of tomorrow. It is this indeterminate state that leads Kleinman to recognize those with chronic illnesses as possessing "a kind of quiet heroism" in confronting the challenges "of getting through each day," of persisting through "the long course with grace and humor and even spirit." Both the ill and their kin "understand the courage" necessary to face each day, even when others are unaware (p.45).

Life is given with no promises, no assurances. Each individual must refocus, turn within to conjure the strength, the will, the determination to press forward in a world that dwells in adversities. A return to spirituality, a consciousness of the soul, will allow for perseverance, the necessitous pursuit for another day.

## CHAPTER 4

## The Ill –Bodied Education: Living in Pursuit of Spiritual Wellness

I tend to believe there is a God. Maybe not a guy with a white beard, but I think I feel the presence of some divine form...though like the Tao, God could be formless. I have come to believe that God put me on earth to get Stage IV alveolar rhabdomyosarcoma. Why? So that I could show the world how to have Stage IV alveolar rhabdomyosarcoma – or rather how to handle what is close to the worst thing that could possibly happen to me with as much strength and grace as I could manage. I promise to continue to be the best model I can. (Levin, 2007)

Belief in God, entailing diverse beliefs about God, varies from individual to individual. Although collectively, many may believe in the existence of a higher power, the intricate components of that existence may be as differing as the perceived image of the being. Religious beliefs, stemming from lived experiences, assist in one's understanding and purpose for life, in the peaks, valleys, and the *in-between* of the journey. Religion, then, is uniquely individualized, involving a permeation of lived experiences, and individual perceptions of religious connotations. Dewey (1950/1922) stated, as a whole, "Religion...is the most individualized of all things," whereas the individual uniquely identifies "connections to the whole," most of which are "spontaneous, undefinable and varied" (p. 331). With this in mind, I assert that religious, and most importantly spiritual conversations are testimonies, a sharing of views with substantial personal reasoning to justify one's beliefs in God, faith and spirituality. Matthew Fox (2006) asserts religion and spirituality are sharply dividing, creating a gap which is "growing ever wider and deeper" whereas religion has little to do with the

“Spirit, courage, joy, youthfulness, love or compassion” (p. 136). Fox calls forth for a spiritual awakening in an effort to restore, or renew religion. Puchalski (2006) claims there is no implication for “belief in a supreme being” for the spiritual, but rather, religion which presents “beliefs, practices, and rituals” which refer to a “specific system of beliefs” (p. 10). In this chapter, I will focus on spirituality, most specifically, Creation Spirituality, not religion.

Scholars have questioned and argued a continuum of eternal discussions concerning religious boundaries, such as existence of God, the significance of faith, and the most accurate definition of spirituality. I contend these argumentative conversations to be of little importance in the face of mortality. The *conversations* of such are of value, and immensely significant in the lives of those searching for validation, purpose and solace; however, to argue my religion over another’s is ludicrous. The lived experience of one’s existence, that which forms the innermost, should not be argued. I call for a sharing, a bearing of the soul. Arguing my points will strip away the essence, the aura of the spiritual mindset. As an intellect, I will not present “in your face” arguments to convince one of my beliefs. Quite contrary, my argument for this chapter spirals and builds from the previous chapters in that I contend that beliefs about God, faith and spirituality all spawn from lived experiences. These concepts build as individuals approach varying situations in the journey of life. It is my intention to explore these three topics through a spiritual interpretation of Mysticism by Matthew Fox. I do not contend to be a mystic, rather, I am a Christian; however, I find that the Four Paths of Creation Spirituality allow for overlapping, interweaving, and intersections with not only spiritual beliefs, but life lessons, as well.

Why, then, you ask, would I as a Christian, explore, even encourage mysticism? My answer is simple, yet complex. It is for the sake of the children, and the spiritual dimension which is overlooked in the educational arena of the day. Noddings (1992) states “the greatest lack in modern public schooling is spirituality” (p. 81). Fox (2006), in reference to the adult working world, states that it is of dire importance to include “inner work” as a necessary component of “work worlds” since “work is the adult arena for spiritual decision making” (pp. 114-115). I agree with Fox and Noddings, and extend this notion to “inner teaching” essential in our schools, since the spiritual dimension is vital in understanding and coping with the lived experience. The diversity in this great nation is not isolated to race, gender, and socioeconomic backgrounds. Religious preferences and beliefs are dividing lines between our citizens as predominately as any racial issue or custom. I believe this form of mysticism, not labeled as such, preferably spiritual consciousness, would allow for an inner alertness across religious borders. I believe religious specifics are the responsibilities of the family and church; however, bringing about a spiritual awareness would open the floodgate for children to tap into the innermost self.

A spiritual engagement is what I call for, whereas individuals grow to become cognizant of the inner world, spirituality. Hawkins (1999) states “illness can be an occasion for spiritual growth,” as evidenced by numerous pathographies, most notably those cases where one has recovered from a serious illness (p. 60). I encourage a manner in which children may turn inward, searching the soul for a better understanding of life, of illness. Fox (1991) defines spirituality as “a life-filled path, a spirit-filled way of living” (p. 11). Children need to be cognizant of the spirit, so that adversities do not

conquer. I speak with those who are ill, but most profoundly with our children, a fragile part of humanity increasingly falling victim to chronic and terminal illnesses. Huebner (1996) once asked “Who in this culture speaks for our children and youth? For the most part, they remain essentially voiceless” (p. 443). Children deserve a voice, and a choice as to which path to consider while living and learning.

In this chapter, the Four Paths of Creation Spirituality will be explored, sharing the lived experiences of the ill as sacred testimonies, and offering my own assertions of pragmatic thought to the Four Paths to Creation Spirituality. Through this spiritual baring, I will attempt to unmask possibilities of why the conversation of illness is emerging in the curriculum field; however, upon discussing spirituality, I must argue two points which are peril in continuing the conversation in favor of Matthew Fox’s interpretation of the Four Paths of Creation Spirituality. One argument stems from what Fox terms postdenominationalism, and the other suggests a fifth path, a path I will call *Via Subsistiva*.

I will begin by explaining the latter, postdenominationalism, which according to Fox (2006), is about “stretching our piecemeal religious boundaries and *setting aside our boxes*” such that religious parameters are no longer “challenging us nor nourishing us deeply anymore” nor are religious beliefs “interfering with the pressing earth issues of our time” (p. 104). A giving up, a letting go of religious margins is what I interpret Fox as meaning. I understand Fox to advocate chiseling out any part or portion of a religion which differs or makes it unique, and/or which causes friction, animosity, disagreement or disaccord with any other religion. But is this not the very core of what molds and shapes the individual? I, too, am for harmony, peace, and a spiritual coming together, but



I stand firm in my religious customs and beliefs, and I contend that this suggests a certain giving of the self, a surrender of what one has believed, as well as who one is. I inadvertently disagree with Fox in that compromising one's religion is the answer to spiritual discovery and bliss. Religion should be personal and private, and taught and practiced within a given sector. Individuals should be allowed to practice their religious beliefs within the realm of spirituality without fear of discrimination, oppression, or prejudice. Spirituality, for me, is a knowing of the self, a reassurance of the inner, a clear vision of what makes one stronger, wiser, and more content. Again, and for clarity, I must restate that I believe Creation Spirituality is a starting point for our educational arena, but the religion of an individual is carved into one's soul, one's existence. How one applies Creation Spirituality to the soul inspiration is unique, distinctive to that individual's lived experience. Spirituality does not call forth a rendering of self, nor does it engage in argumentative dialogue. Spirituality is a knowing, a confidence in being, and a consciousness of existence, which brings about my second argument.

Fox identifies Four Paths of Creation Spirituality, which "guarantee an organic understanding of our spiritual journey and of our theological heritage" (Fox, 1983, p. 23). I contend that each path, which Fox asserts is based on scripture, mystics, prophets and tradition, suggests spiritual activity or action on the part of the individual. The Via Positiva proposes the individual is alert and attentive to the "wonder, and mystery of nature and of all beings" whereas "all creation breaks out anew" (Fox, 1983, p. 34; Fox, 1991, p. 18). The Via Negativa implies the individual takes part in an emptying, a letting go, a time of allowing pain to be pain. The Via Creativa involves a "birthing...where previously there was nothing," basically a coming together of both the Via Positiva and

the Via Negativa, where “we co-create with God” (Fox, 1983, p. 176; Fox, 1991, p. 18). The fourth path, the Via Transformativa, involves judgment of one’s creativity, where “compassion is the goal” to “save and liberate” (Fox, 1983, p. 247). Each of the four spiritual paths involves an active awareness, responsiveness, a conscious wakefulness.

I propose an additional path, one which situates in passiveness. This path which I have termed Via Subsistiva, entails an awareness, but an awareness coupled with no action, no deed; a spiritual realization with no provisions. Fox (1983) outlines the spiritual paths as “spiral, not ladderlike” being fluid, and flowing “in and out of the others” as the spiritual journey expands and develops (p. 23). I must emphasize that when an individual enters into a spiritual journey, one cannot assert that the journey will only expand, and remain spiritually focused. There is always an alternative passageway, which may, many times, be taken without a conscious notion. The Via Subsistiva is a path where the spiritual is not top priority, it is only present, a path which is taken as life itself slowly begins to dominate and control the individual. Fox is clear to explain that the Four Paths of Creation Spirituality are specific to living which implies the “love of life, and ...love of others’ lives” (Fox, 1983, p. 9). In Via Subsistiva, there is a “love of life,” but the point is the “love of life” is not realized in its deepest form. The individual has a “love of other’s lives” and respects the lives of others, but does nothing to emulate this love, enhance this love, or solidify this love (Fox, 1983, p. 9). The Four Paths of Creation Spirituality imply that once one embarks on the spiritual journey, the spirit is in constant growth, even in the darkest, loneliest moment within the Via Negativa. I argue this assumption, in that I contend there are times of spiritual plateau that do not take place within the other specified paths. This stage in one’s life must be recognized within the

spiritual journey as a learning experience. This path, which is always present as an additional fork in the road, can be taken from any other path, a detour which distracts, diverts, and sidetracks the spiritual progression.

It is difficult to pinpoint the path for which each individual currently resides; however, I contend that education as a whole, places society within the *Via Subsistiva*, a spiritual plateau, where leaders are aware of personal spirituality, love life, and love the students who consume the schools. To subsist, to be, the *Via Subsistiva* identifies a path of complacency, a state where many persevere in a life of order, love, and spiritual ease, until a lived experience thrusts one into another spiritual path, or perhaps in the occurrence of illness, revives the spiritual journey. Life itself opens doors to experiences that challenge the human existence, and force one to confront complex circumstances and situations. Dewey (1938/1963) stated,

As an individual passes from one situation to another...He does not find himself living in another world but in a different part or aspect of one and the same world. What he has learned in...one situation becomes an instrument of understanding and dealing effectively with the situations which follow. (p. 108).

The confrontation with illness forces one to journey into different spaces of the existing world. Past experiences embossed in the mind inherit integral roles for how the individual will approach illness, as well as how the individual will respond to experiences that follow the onset. Schools, homes, churches and all other spaces harbor the ill, whereas the individual and ill-body are inseparable, fused, one-and-the-same. Illness acts as the shadow, an entity that at times escapes notice, yet, at other times, appears larger and more overbearing than the individual. I will consider each of the four paths of

creation spirituality, the Via Positiva, the Via Negativa, the Via Creativa, and the Via Transformativa, placing the most emphasis on Via Negativa as well as an additional path, Via Subsistiva, in order to discuss the different spaces of the existing world. I contend that most spiritual growth, spiritual turmoil, and spiritual awakenings take place in Via Negativa, however, I assert that a large portion of society travels along the path of Via Subsistiva. The life journey through these paths is cyclical, transpiring through repetitions as life progresses. Through these spiritual paths, I will examine not only the life-lessons through the teachings of the ill, but also the complexities into the depths of the spiritual journey which may lead to silence, oppression and fear. I will visit spiritual healing from social injustices as well as physical ailments, and the spiritual transformations sought to proceed in one's exploration of spiritual paths in the journeys through life.

#### *Paths of Life Journeys with Illness*

Life journeys, depending on the lived experiences, take one on various paths. It is my intention to begin by approaching five pathways, Via Subsistiva, Via Positiva, Via Negative, Via Creativa, and Via Transformativa. These five paths capture moments in time during one's confrontation with illness. Briefly, I will demonstrate how illness may initiate a spiritual journey.

The spiritual dimension is the aspect of life which can be overlooked, ignored, consciously or unconsciously, with little discernment on the part of the other. This is evidenced by education today, where the inner, rather, the spiritual is disregarded. I contend that spiritual avoidance is widespread, much of which is unintentional and not limited to the educational arena. American society, for the most part is good, behaving as

productive citizens, but most members remain oblivious to tapping into the soul, the inner realm of the spirit. It is for these reasons, I allege that the spiritual journey actually begins in a state of subsistence. To ignore this season of one's existence is to ignore the lessons one learns. Illness allows one to reflect upon times of subsisting when everyday occurrences, loved ones, and time were easily, yet unknowingly taken for granted. The *Via Subsistiva* is a profound part of the spiritual journey, maybe not in the present, but in the past as one reflects. In the present, the physical and mental dimensions have recognizable implications of neglect; however, the spiritual, the mysterious connection within, is imperceptible, hidden and concealed.

The spirit beckons when lived experiences reveal trials and hardships. It is out of a spiritual complacency that one is awakened to search the soul for answers, for strength of mind, for character. It is the *Via Subsistiva*, the path of spiritual plateau, where I contend many dwell prior to and during spiritual quests. Even those engaging in spiritual journeys tend to have periods of inattentiveness, becoming distracted from and unmindful of the inner. All four paths in Creation Spirituality can merge, hardly without notice into the *Via Subsistiva*, and likewise, any path may lead out of *Via Subsistiva*, renewing the spiritual quest.

Spirituality may flourish during a time of rejoicing, sending one on a spiritual path of thankfulness and wonderment. Remission, a diagnosis of living cancer free spawns a new beginning, a second chance. The spirit is elated. The journey on the path of *The Via Positiva* begins. According to Fox (1983) the *Via Positiva* is a conscious appreciation for life's journeys which are "deeply entered into, deeply felt, and deeply shareable" (p. 34). This is an awakening, a realization of the full implications of God's

presence *in* everything, where life is a blessing, where each individual may “launch” the “spiritual journey” (p.83). The Via Positiva is a path of love, where wonder and awe consume one’s being, a sense of joy. I maintain that the Via Positiva is a subtle state of spiritual happiness.

Dewey (1957/1920) describes happiness as “found only in success” which suggests a “succeeding, getting forward, moving in advance” (p. 179). Via Positiva suggests this motion, this movement in positive progression. The succeeding in the case of illness is the overcoming, the rising above. I emphasize that this wonderment and spiritual bliss is not minimized to defeating an illness, where triumph over some thing is what brings about appreciation. It is the mental acceptance, the peace which comes with the isolated moment in the life journey, the acceptance of where one finds himself along the path, and the realization that the whole is worth appreciating. This overcoming may entail the mental and spiritual acknowledgement of the obstacle of illness. The “getting forward, moving in advance” means appreciating what time is left, in the face of terminal illness, and making the most of the each moment. This venture with illness in the Via Positiva does not suggest a claiming of happiness as a tangible accomplishment, or as stated by Dewey, as a “bare possession...a fixed attainment” (p. 179). The Via Positiva is a state of conscious becoming, and must be present to lead to the path of creative works, The Via Creativa; however, the awe and wonderment must mesh with the depths of suffering and pain, The Via Negativa, in order to fully meet one’s creative potential.

#### *Via Negativa*

We become, as adults... automatized to the beauty and form and shapes and colors and smells that are around us all the time; we lose our sense of pleasure, of

the preciousness of life. Unwished-for pain...can often bring that love of life back to us. (Fox 1983, p. 144)

Relapse. *I'm sorry, the cancer is back.* The spirit plummets to the depths. The Via Negativa. All too often, appreciation for what one has is not fully understood or comprehended until it is taken away, eliminated, or compromised. The relinquishing of that which is taken for granted, many times brings about a realization that life, is finite. Fox (1983) stated, "The Via Negativa opens us to our divine *depths*" (p. 130). Fox continues that "when one has suffered deep pain" and has "allowed the pain to be pain," then one may realize the magnitude of the individual in comparison to the Grand Canyon whereas the individual "is even deeper and more powerfully carved over millions of years by the flowing tides of pain" (p. 130). I interpret Fox as meaning when an individual endures grief and sorrow, and embraces it as such, there is no limit to the enormity of the deepest, darkest pain and suffering one may endure. The Via Negativa takes one to "nothingness," where a "letting go" may occur in the "silence and emptying" (1991, p. 18). Fox explains that whether this is initiated through a death, possibly of a loved one, or of the self through life changes, this "always...takes place with darkness and mystery" (1983, p. 136). "The depth of nothingness" according to Fox, "is directly related to the experience of everythingness." (1983, p. 130).

From "everythingness" stems illness. Illness may lead to "the depth of nothingness" not only for the ill, but others caring for, or associated with the ill. An abrupt change in everyday life may plunge one into the Via Negativa without fair warning. Within the darkness, the loneliness, the depths of the emptiness, the individual may confront the oppression, the fear and the silence which so often accompanies illness.

In order to fully situate the ill and the other(s) in Via Negativa, I feel it is necessary to spend some time clarifying the concepts of oppression, fear, and silence as each pertains to the ill. The next section of this chapter will approach these areas to illustrate how illness has crept in and silently embedded itself within the lives of many, exposing its presence to all members of humankind not to compromise, negotiate, or rationalize its presence. The role of spirituality in rising above these predicaments will be approached.

### *Oppression Embodies Silence*

Spirituality encompasses all inner turmoil and chaos which is initiated both within and outside of the body. Oppression, initiated outside of the body, deeply affects the inner, the spiritual self. Although working through and rising above oppression occurs in the Via Creativa, the inner repercussions must be discussed in Via Negativa, as one penetrates into the darkness under the influence of oppression. I must step back and bring oppression into view, into the conversation of illness.

Delese Wear, a leading scholar in curriculum theory and medical education, has authored, coauthored, and edited many books which intricately examine medical education, exploring various perspectives from patients, doctors, medical professors, and others. A feminist, Wear writes about oppressions throughout society at large, and explores how individuals within society should come to know themselves as both the oppressed and the oppressors, realizing that as a society, we are all “victims and perpetrators of oppression” (1997, p. 66). This twofold citizenry of the oppressor and oppressed, perpetrates in cycles, as one’s role within society flows in and out of the comfort zone, confronting new and mind-altering experiences, which potentially contribute to the oppression of self or others.



During a class discussion of assigned literature, Wear (1997) gives account to how medical students share this dual role as oppressor and oppressed. Drawing on the novel, *The Bluest Eye*, Wear and class members discuss an excerpt about “a relentlessly poor, sad woman trapped in a lonely life and an unhappy marriage” (p. 62). This unhappy woman, Pauline, has decided to have her second born child at a hospital where she encounters a “racist male doctor” who proceeds to make racist comments as he and other doctors stand by her bedside. As Wear’s students discuss and scrutinize the passage in relation to oppressions of the patient, Pauline, the conversation quickly shifts as the medical students reflect on their own experiences, unmistakably identifying themselves as the oppressed. By mirroring the description of the patient, Pauline, to the likenesses of their own clinic patients, the students diverted from the oppression of the patient, to the oppression of the caretaker. Many of the medical students were unable to “make the link between Pauline and their own patients, or between Pauline’s doctor(s) and their own doctoring” (p. 64). The personal struggles, adversities and hardships experienced when serving clinic patients engrossed many of the students’ thoughts and comments, thereby obstructing the picture of the oppressed patient, clearly being shunned by her doctor. The obvious scenario, doctor initiating the oppression, was for the most part avoided, and through the course of the conversation was reconstructed as the doctor enduring as the oppressed. Clearly, this conversational experience illustrates how one can both function as the oppressor, while at the same time, feel the effects of being oppressed; however, the admission to taking part in the oppression of others is a much more difficult pill to swallow. I allege individuals within our society, by nature, are better able to identify

instances where personal oppression has been experienced, rather than how personal actions have contributed to the unjust treatment of others.

Educational situations share the same challenges. Who is the oppressed, the teacher or the student? And who is the oppressor? Does the political system claim ownership to some of this oppression? A myriad of questions arise when attempting to pinpoint the source from which oppression initiates; however, the looming cloud hangs heavy over society at large, a domino effect which continues to mount. My questions then arise, “How does the ill child blend into a classroom of well children?” and “What different oppressions might this child encounter?” The child, possibly months, maybe years behind academically due to excessive absences, may be viewed as needing extra assignments to make up for lost time, long days without ample rest may give rise to sleeping during lessons, and lack of energy may appear as a lack of willingness to do, or lack of motivation. Will the teacher view these responses as oppressive? An unwilling child deficient in studies, as well as deficient in health makes a teacher’s job more strenuous. What about the ill teacher confronted with a classroom full of disgruntled students? I will answer my own questions in part by stating that from the onset, the ill are oppressed, first and foremost by their bodies, and from there, a complex assemblage of oppressions have the potential to emerge.

Creation spirituality, according to Fox (1983), addresses oppression stating, “Creation-centered spirituality is a spirituality of the oppressed and of those who have learned...to identify with the oppressed in order that the oppressed might liberate themselves and eventually even the oppressor might become liberated” (p. 267). Based on commonalities of prior arguments, Fox describes beliefs about oppressed groups in

general, as people who “are or doing something against nature,” who are “‘naturally below’ those who pronounce their fate” (p. 268). Chronically and/or terminally ill children, which I will include among the “the so-called weaker peoples of the earth” are not natural, not in the sequence of the circle of life, and there is, according to Fox (1983) a “colossal lack of respect for the diversity of nature itself” (p. 267, 269). Hawkins (1999) claims that terminal and chronic illness in the twentieth century became detached from the life of the individual, whereas society for the most part “consider[ed] health as the norm and illness as a condition to be corrected” (p. 11). Illness, according to Hawkins, is “never simply accepted,” thereby, I contend, compounding the oppression (p. 11). Creation spirituality is the spirituality of oppressed in that it “will empower them [the oppressed] by way of imagination, which is divine power” to start anew (p. 269). The oppressed groups must let go, let be, and reach inward to create ways to begin again. In an effort to confront oppression, the individual must also cope with the fear which accompanies. The Via Negativa is a path where the spirit contends with oppression and fear.

Audre Lorde (1980) shared her inner most thoughts of being an African American, fighting an ongoing battle with breast cancer. Lorde opened her journals stating that what mattered most in her life had to be “spoken, made verbal and shared” regardless of whether there would be negative repercussions or misinterpretations (p. 19). By transforming “silence into language and action” Lorde moved the reader from a vision of an oppressed marginalized woman to an empowered individual with a voice and a story to tell, confronting the fear of her own mortality (p. 20). This fear, merging with the fear of being judged, being misunderstood, and being ignored, had the potential to

allude to silence. These feelings of oppression, partly inflicted by others and partly brought on by the individual fears, can be identified and shared by both the oppressor and the oppressed; thereby spawning an immediate need for individuals to confront fear, take ownership of the fear, and take strides in overcoming the fear.

Children suffering from illnesses share this fear Lorde vividly describes. At times, their fears are blatantly shared, other times these fears are expressed through pictures, candid comments, or actions. Abby, a 12 year old patient suffering from a malignant brain tumor, expressed her thanks to a staff member for helping her “to not be scared of doctors or nurses etc. or of... [her] greatest fear: dying” (2004, St. Jude Children’s Research Hospital, ALSAC). Eric comments about his art work which portrays a body lying in a coffin with dirt on top,

This is what I first thought was going to happen to me when I got cancer. I would die automatically. But now I’m half way through my treatments for this dreadful disease and I feel like I’m going to live. The thought of dying still scares me though. The name of this painting is... “Till Death Do Us Part.” (2002, American Cancer Society, p. 24)

Dewey (1958b) states that “fear, whether an instinct or an acquisition, is a function of the environment....because [the individual] exists in a fearful, an awful world” which is “precarious and perilous” (p. 42). The mystery of illness, and the uncertainty of the journey through illness are obscure, with no guarantee for time, no guarantee for a future. To be in and of the world becomes questionable and unfamiliar, compounding this trepidation. This fear filters into the schools, haunting each and every facet of life, in social, emotional, physical and spiritual aspects. Schools, according to

Dewey (1938), being driven by preparation for a “suppositious future,” fail to authentically prepare since “the very conditions by which a person can be prepared for this future” are omitted (p. 110). Dewey continues, “We live at the time we live and not at some other time” and the only manner in which we can genuinely prepare for the future is by “extracting at each present time the full meaning of each present experience” (p.110). Preparation for illness, preparation for life with illness, and preparation for life in general is only attainable through authentic experiences which allow one to interact, respond, reflect and learn. The interactions, the responses, the reflections and the lessons learned all encompass the confrontations with oppressions, the rising above the silence, and the sharing of illness stories to allow others to attempt to conceive of the encounter with dis-ease.

Oppression and fear drive one into the Via Negativa, where emptiness and darkness surround the individual. Ironically, fear, according to Fox (1991) originates from love so to determine to the root of fear is “to get at the issue of what we truly love” (p. 99). Fox questions fear as being the most prevalent problem we approach in the world today possibly setting the stage for fundamentalism. Fox asserts, fear places “one religious sect against another, one race against another” with issues such as the “fear of the universe...science...loss of self...nothingness” (p. 99). In keeping with Fox’s notion, fear for the ill stems from the love of life, the love of ‘normal’ living, pain-free living, and the love of a sense of immortality. Pain and suffering magnify this love of the past, escalating fear to new heights. Pain, suffering and silence dwell in the Via Negativa.

Silence is multi-faceted. It may imply a stillness, a calming, a peace, or a quietness instigated by rest, harmony and contentment. This silence is one aspiration of

the Via Negativa, in that with the still of silence, one may reach deep into the inner to gain insight into the spirit. However, deeper probing into silence may uncover a silencing, a series of occurrences or situations that impinge on one's freedom of voice, desire for voice, or strength to voice. Frank (1995) asserts that being ill in this postmodern era calls for not only a voice, but rather "people feeling a need for a voice they can recognize as their own" (p. 7). The silence, then, I am approaching here is the silence that thrusts one into the Via Negativa, a silence which causes pain and suffering, not the silence which is desired upon while dwelling in the Via Negativa. Holding steadfast onto the self, and the recognizable voice, as it transitions through this journey, can prove to be overwhelming, as one slowly relinquishes the self to the dependencies on the *other(s)*.

#### *Emerging Dependency on the Other*

Is the silence of the ill in part due to the newly formed dependency on doctors, medicines, and family members? Is it a giving up, a relinquishing of a part of oneself to another viewed as the path to restored health? Is the silence due to a turning to an *other(s)* in an act of faith for strength, solitude, and guidance? Marla Morris, a curriculum scholar diagnosed with gastro paresis writes of her experiences of teaching and living with illness. Morris (2005) states that at the onset of illness, "one regresses psychologically to a childlike state, as one becomes more and more dependent on the medical community. One gives oneself over to doctors" (p.1). Arthur Frank (1991) draws on this submission by stating "In becoming a patient...you lose yourself....you may lose your capacity to make choices, to decide how you want your body to be used....It is difficult to accept the realities of what physicians can do for you without subordinating yourself to their power.

The power is real, but it need not be total” (p. 57). One relies heavily upon the medical advices and procedures offered through the doctoring process. Broyard (1991), in discussing his relationship with his physician states “my illness is a routine incident in their [the physicians’] rounds, while for me it’s the crisis of my life” (p. 169). The ill person, and/or the significant others, eagerly in search of answers within the medical arena, an avenue, a protocol for restoration, a medication in which he may depend upon, vigilantly strives to return to the life before the onset of the illness. A humbling dependence, an entrusting of one’s very existence to the medical community and significant *other(s)* to provide assurance, rehabilitation and relief calls forth a submission of self in the hands of others.

A “narrative surrender” is how Arthur Frank (1995) describes the rendering of a part of one’s voice to the physician. He explains that the language of the ill alters to fit or match much of what the medical experts have repeated, thereby allowing these experts to become “the spokesperson for the disease” (p. 6). I believe that this relinquishing of self can be directly related to what Sumara (1996) referred to as “unskinning,” a vague, ambiguous term used in a novel to describe how a character removed the skin from a fruit. Under closer scrutiny and class discussions, Sumara defined ‘unskinning’ as a “significant transformation for...[an] entity” (p. 89). Illness, in my opinion, brings about an ‘unskinning,’ a chiseling away at what is and was, a transforming of the body, the mind, the lifestyle, and the spirit into a foreign space, such that the self becomes unfamiliar. As individuals endeavor to re-identify and reclaim the self, feeling “out of touch, inarticulate, beyond the bounds of the remembered self,” relationships become crucial in rediscovering the perceived self (Sumara & Davis, 1998). Through the meshing

of experiences from the past, present and future, the identity of self can once again become familiar; although the “past selves can never be fixed – as these become interrogated in relation to new experiences, they change” (1998, p. 78). Sumara and Davis describe the ‘unskinning’ as an awakening to a new self which evolved through experiences which cement certain aspects, others that allow for change, and yet others that alter without knowing.

There is a need to delve deeper into ‘unskinning’ with the onset of illness, for not only is the ‘unskinning’ felt within, it is a perceived humbling, a surrender of the outer to the demands of the inner. The outer is summoned to respond to that which lies beneath, the hidden, which can only be exposed and perceived when an ‘unskinning’ occurs. When one speaks of pain, displays anguish, and ceases to feel in control of the body, as one focuses attention on the internal, the external becomes blurred, and indistinct. The inner cries out claiming the voice of the outer.

The inner pain and anguish felt by one, whether physical, emotional, or spiritual, is a part of the lived experience which carves lessons into the soul. Fox (1983) asserts that experiencing pain assists one in understanding “other people in pain” (p. 143). Fox continues by identifying pain as being “profoundly social...eminently shareable...and always a schooling for compassion” (p. 143). Once an individual experiences pain and suffering, and “has owned that suffering,” that individual “can never forget and never fail to recognize” other’s pain and suffering.

The ‘unskinning’ of the self, the withdrawal within, the confusion with self identity, tends to silence even the strong at heart, while living and creating life stories.



*The Ill-Conceived Identity*

“But what is life except many stories, happening to many people, and what are these stories but individuals’ perceptions of what has happened to them? (Frank, 1992, p. 3). The lived experience that is personal in discernment, but intermittently collective in conception, molds, shapes and sculpts self-identity through the progression of interaction and reflection. This personal view of self, according to Sumara and Davis (1998), is both collective identity and personal identity, and cannot be disconnected, in fact, these two identities are “not two separate things” (p. 78). One develops identity through how the individual perceives and interacts with the world, meshing what is known with how it is known. This sense of self-identity evolves through the integration of communal and individual experiences, weaving together “perceptions, understanding, and interpretations...[through] lived, remembered, and projected experiences” (p.78). Arthur Frank (1991), in discussing an article about patients and the need to talk about their illness, indirectly illustrates how the collective self identity blends with the personal identity. In the account, one patient when approached by a stranger, openly discusses the illness, even removing a wig to reveal the results of chemotherapy treatments. The other patient, quite dissimilar in nature, declines further treatment, and withdraws from family and personal acquaintances. Both patients’ behaviors reflect a “history of relationships with other people,” and these learned responses typify the relationships “with family, friends, schools, and medical staff” (p. 125). Though both are different, Frank offers the explanations behind the responses.

The openly expressive patient, he asserts, has experienced support, and thereby feels valued. Minimal stigmatism, and supportive new acquaintances have led the patient

to believe that future contact with others will be positive and supportive, as well. The withdrawn patient, on the other hand, senses dissatisfaction in the people around him. He views his illness as a failure, not only to himself, but to his family, the medical staff, and other children. His response of withdrawal is a way that he can remove himself so that others are not burdened with his presence. Frank states that the reaction of each patient is not due to individual personalities, rather, a result of the assistance or denial of the surrounding 'social groups.'

I believe that the two patients respond to these lived experiences based on the blending of the collective and personal identity. The image of self is perceived through the actions, reactions and responses of 'social groups,' associations sought for strength, motivation, help, and the broadening and confirmation of self. The patients, in a strong sense, have placed faith, trust, dependency and belief in these social groups, to in turn either become encouraged or discouraged by the responses. This evolution of self identity is cumulative, a progressive compilation of all that is known, and consciously unknown. Sumara and Davis (1998) allege, "our sense of identity always emerges from the fusing of previous, current, and anticipated experience. The memories we have of past selves can never really be fixed – as these become interrogated in relation to new experiences, they change" (p. 78). Pinar (1991) states, "who we are invariably is related to who others are" in addition to who we aspire to become and "who we have been." (p. 244). Pinar recognizes that identity is not solely self imposed; more accurately, it is dependent upon the associations in our lives, as well.

Marla Morris (2001), drawing on Greene's notion and inquisition of "why," asserts that "why" may also be linked to the identity of self. Morris states,

The why of self concerns not only a self who thinks but a self who feels. The self who feels may not feel very well...[this self] well may feel exiled, alienated, and marginalized...the feeling bad about oneself affects the ways in which one interacts with others. But engagement with our world cannot be healthy if the self feels bad. Negative feelings about oneself may be co-complicated with how others define who we are and how we then internalize those negativities. (p. 58)

Morris, not necessarily referring to illness in this passage, but rather to the relation of anti-Semitism, makes claims that how one feels about oneself, coupled with the perceptions of how others feel about that person, can not only determine who the person is, but also, how the person reacts to the world around him. In terms of illness, just as Frank illustrated, the meshing of the 'social groups' and the perception of self may determine how one responds to, approaches, and ultimately progresses through illness.

An understanding of relations is what Morris (2001) calls forth, an in depth examination of the relations of the self to others as we write life stories, as we experience the world and learn from it. Education initiates with relations, the relations of individuals to the lives each leads, and as Dewey (1915/1962) states, "the public school is to teach the child to live in the world in which he finds himself, to understand his share in it, and to get a good start in adjusting himself to it" (p. 123). Although we abide in the same world, we do not engage, function or partake of the world by the same means. Chronic and terminal illnesses alter the capabilities of the individual, thereby reclaiming the point at which the individual must begin to decipher his place in the world. The duty of education is to meet the individual at this embarkation, and facilitate the movement through the pilgrimage, to rediscover, reclaim and understand the self with illness.

In reference to an evolving society, Dewey (1959b) states,

...the ethical responsibility of the school on the social side must be interpreted in the broadest and freest spirit; it is equivalent to that training of the child which will give him such possession of himself that he may take charge of himself; may not only adapt himself to the changes that are going on, but have power to shape and direct them. (p. 11)

Likewise, an individual should be encouraged so that in the face of an evolving illness, one may take ownership of the voice, the body, the self, and the fate. The path to the re-acclimation of self may become ill-defined and overpowering, whereas the individual is compelled to turn to the *other(s)* for comfort, encouragement and reassurance, an act of enduring, accepting, and embracing pain and suffering. Kleinman(1988) verbalizes the pains that may force one into the Via Negativa by stating,

The moral lesson illness teaches is that there are undesired and undeserved pains that must be lived through, that beneath the façade of bland optimism regarding the natural order of things, there is a deeper apprehension of a dark, hurtful stream of negative events and troubles. (p. 55)

The spiritual exploration in the Via Negativa helps one cope, approach and accept the darkness which accompanies illness. This time of suffering, coming to terms with a life changing experience prepares one to continue life differently, whereas creative works in the Via Creativa offer avenues for rising above the pain and suffering.

#### *Via Creativa*

Creativity is nonexistent without the Via Positiva as well as the Via Negativa.

That is to say that to be creative stems from nothingness, as well as “pleasure and

delight” (Fox, 1983, p. 175). To live, to “be courageous enough to create”, mediates the Via Creativa (Fox, 1983, p. 244). For it is “art as meditation,” according to Fox, which will “lead to fuller living and deeper spiritual celebration of both pain and joy” (1983, p. 190). In the shadow of terminal or chronic illness, physical pain, as well as the mental anguish of confronting mortality, can rob one of joy, stealing the desire to create, to birth. However, Fox asserts that “all creativity involves destruction and deep suffering,” for it is out of the appreciation and awe within the depths of nothingness that creativity thrives. Fox parallels creativity with a “birthing,” a creation of something, where “ previously there was nothing” (p. 175). I contend that creativity can also entail a re-birth, a rekindling of something that revives the soul, and sets the spiritual journey anew. The rebirth, which reminds the soul and spirit of lost desires, brings forth a re-teaching of a previous lived experience.

Morris (2005) states that we have much to learn from the un-well body, most significantly, the lessons of the soul. The assent of the soul, the view that “life is holy,” and the attentiveness to “soul-work” brings about a renewing, a replenishing of the soul (p. 99). Morris contends that confronting illness for her brought about a return to this soul-work whereby the mind, body and soul “find flow with objects,” engaging in that which enables one to become better able to feel the unification between object and soul (p.101). I have witnessed children engaging in this “flow with objects” as I sit in the oncology playroom, watching young cancer patients create magnificent pieces of art as they diligently manipulate the paint, the glue, the beads, the pom-poms. The crafts allow time to pass, mind over matter, creative juices to flow, and the children for a short while express themselves through their artwork, absorbed in their own creations. Drawing,

writing, building, and most profoundly, interacting with companions who have experienced the fight, the struggle, the experience of cancer, and joined the multitude of the ill. The solace and encouragement that is shared through the glances, the touches, and the smiles, are quiet acknowledgements that comfort comes when the spirit can experience this “flow with objects.” A letting go, a release, or as coined by Morris, “soul work, the work of the soul” (p. 102). This flow with an object, according to Morris, “takes a lifetime to find;” however, I see these children, completely enthralled, consumed and engaged in the creations of their souls. A lifetime, the span of a human life. I raise the question, can experience, facing one’s mortality, mature an individual far beyond biological years? Creativity dwells in the youngest at heart.

Fox (1991) asserts,

Creativity is not about painting a picture or producing an object; it is about wrestling with the demons and angels in the depths of our psyches and daring to name them, to put them where they can breathe and have space and we can look at them. This process of listening to our images and birthing them allows us to embrace our “enemies” – that is, the shadow side of ourselves – as well as embrace our biggest visions and dreams. (Fox, p. 21)

In keeping with Fox’s assertions, the union of illness and creativity involves acknowledging the illness, and the fears and anxieties, which Fox calls “the demons,” and identifying them as such, thus “daring to name them.” One must allow these to run the course of life, alongside, between, within, all the while conscious of their presence. This knowing thereby allows the individual to confront the adversities in living out hopes and aspirations. Aligning the inner world with the hardships of the lived experience provides

the opportunity for one to embark on transforming not only the self, but reaching beyond the personal borders, and touching society as well.

### *Via Transformativa*

The last path in Creation Spirituality, the *Via Transformativa*, has compassion as the ultimate goal. “We cannot enter compassion (Path Four) if we have not entered the darkness of suffering and pain (Path Two). Compassion is often born of a broken heart, and all persons who live fully have their hearts broken.” (Fox 1991, p. 25) The needs of the individual, according to Fox (1991), become the needs of community, and likewise, the needs of the community become the needs of the individual. This is evidenced through the numerous foundations and non-profit organizations working earnestly to raise money for cancer research, AIDS, diabetes, and the list continues. The community, the world at large convenes to raise money for a common cause. Compassion is the driving force for this assemblage. Engaged compassion implies a faith in one’s feelings that an act or acts will better the quality of life for others.

Faith, defined by Fox (1983), is the primary definition of trust. Trust, then, accompanies one through the journey of the four paths of creation spirituality where one embarks on a “journey into trust and a journey of deepening trust” (p. 82). In the *Via Transformativa*, faith implies a trust in our visions, whereas our aspirations emerge with a concern for others who undergo pain and suffering; however, I contend that it is the faith and trust of the *Via Negativa* which helps one move on to a place, a path, rather, where visions and aspirations may be sought and trusted as worthy creations. Faith and trust in the *other*, or some other as discussed in Chapter 3, is an important undertaking for the ill

in order to move on to the Via Transformativa, an act of collaboration, an act of oneness in the present with purpose for the future.

Dewey (1958a) stated

...the future is not ominous but a promise; it surrounds the present as a halo. It consists of possibilities that are felt as a possession of what is now and here. In life that is truly life, everything overlaps and merges. But all too often we exist in apprehensions of what the future may bring, and are divided within ourselves.

(p. 18)

The “apprehensions of what the future may bring” tend to hover in the minds of the ill and those close to the ill. Once the spiritual journey gives one the freedom and peace to reach out, the future has possibility for a better tomorrow, even if tomorrow promises nothing more than death. Creation spirituality allows one to live while staring into the face of death. The spiritual attentiveness offers avenues for rising above the adversities, the obstacles which ultimately claim the life which brings about existence. Nancy Levin (2007) in reflecting upon her son’s relapse stated,

Cancer changes a person.....in mostly good ways. A person is forced to develop humility, compassion, patience, and gratitude....I’ve learned to take it as it comes. I’ve learned that nothing is for sure until it’s for sure. I’ve learned to expect nothing and be grateful for everything.

Levin articulates life in the presence of death. “Be grateful for everything” through living, awakened through the illness of the other to the bounty of blessings before her. By focusing on the inner, one can not only learn, but also teach invaluable lessons while traveling, sometimes at a rapid pace, down death’s path. Puchalski (2006) claims that



“love and service to others as the foundation of our lives” is possibly the most important lesson one may learn in confronting death (p. 365). The act of service and love stretches beyond the self for “the possibility and hope for change, for making a difference, and for healing” (p. 365). The act of service and love stretches into our schools, into the educational path where individuals are obliged to learn, obliged to live. Reynolds (2003) states “education and spirituality must be life-centered...A life-centered curriculum or education would dwell in life as we live it, not in creating elaborate models of the way things are and trying to force-fit all of us into those models.” (p. 59) One cannot “force-fit” another into life, illness has taught that lesson. In addition, illness teaches that education is centered around life with its peaks and valleys. The darkest valley, the acting of dying, must be approached as the final journey, the path to spiritual oneness.

## CHAPTER 5

## Beginnings and Endings: Writing the Book of Death

I never realized how fast everything would happen....I guess I should have, I had prayed the day before that God please take Joanna and PLEASE not let her suffer anymore....He answered my prayer. (M. McAfee, personal communication, December 21, 2006)

The sky was darkened by immense clouds of purple and gray. Thunder roared, and lightening crashed as the motorcade progressed toward the cemetery where Joanna would remain in her final resting place. Hail the size of golf balls fell furiously from above, and rain descended in heavy thrusts. Heaven and earth mourned with us.

The final journey of life ends in death, *or does it?* Death brings human life, lungs expanding, heart beating, blood flowing, to a halt. Even though termination to one's human existence is predestined and inescapable, the *other's* response to death is typically that of disbelief, anguish and sorrow. The lived experience between individuals bonds spirit and soul, whereas death not only claims the deceased, but also deep rooted emotions, heartfelt voids and wishful longings in the spirits and souls of those left behind. The path of living is inevitably the path of dying in that each individual who draws a first breath, must also draw a last; however, each passageway to death is a unique corridor. Kleinman (1988), in describing death states, "There is no single, timeless pathway toward death....An individual's course of death, like that of life, may take dozens of different turns, circle back to the start, or enter a state previously unknown" (p. 154). The confrontations with death are meticulous battles with consequences and scars. The triumphs bring forth new challenges, obstacles and attitudes towards life, with a

realization that the next battle may end in defeat. In reference to facing one's mortality, Puchalski (2006) states it is not a journey one "need[s] to walk alone" (p. 365). Puchalski proposes that the ill "look for the spiritual companions" who share life in social spaces, as well as in the family and family associations (2006, p. 365). These relations with others will be the basis for my final chapter, where I will approach life in death, life with death, and life after death.

The final journey of life ends in death, *or does it?* Dewey (1908/1929) stated that the deceased "lives on in some mode," somewhat ambiguous, but still "potent, still a member of the group" (p. 64). In this chapter, I will argue death as life, reaching far beyond the literal confines of the word. I contend that the lived experience, the most critical means of education, is the channel for which we can learn that life continues within the *other*, alongside the *other*, and outside of the *other*. The act of dying, writing the final chapter in the book of life, is a prologue in the book of life for the *other* who must begin anew, forced into a life with an absence. I will begin by exploring life in death sharing pathographies of the ill as each is aware that death is near. Through the eyes of individuals facing mortality, I will share fears, revelations, and testimonies of how living while dying may affect the precedence of life, family and social relations, as well as the *other*. To illustrate life with death, I will delve into testimonials of loved ones, who share the journey of death outside of the ill body, connected through the soul, the spirit, the bloodline. The loss of a loved one will be carried through the mourning and healing process as one enters an alternate life path. And finally, life after death will be uncovered through a careful weaving of how the lived experience carves lasting

impressions on and within the *other*, such that lives are changed, and memories are storehouses for rebirth in absence.

Rebirth, waking to a new space, an unfamiliar place, occurs at a crossroad where one has the option to progress or regress. Death, dying, and rebirth will be expanded beyond the individual, escalating to an educational body where progression allows a society to continue to thrive, to adapt to new situations. The educational system will be examined which must move forward with the advancement and evolution of a society. This chapter will carefully describe a masked deteriorating educational era where the outward appearance is thriving, but beneath the surface, the systemic rhetoric is crippling. The *educational malignancy* quietly metastasizes, silently breaking down the foundation of the American educational system. Emphasis on uniformity and efficiency, guarantees and promises, and fact regurgitation may be the symptoms of an impending ill body of education. I argue that the figurative death, the ceasing of the methodology and philosophy of the current system may allow for the resurgence of meaningful education which is applicable to life, to the lived experience, and to the knowing of the self. And most importantly, I will argue that death must join the conversation of life, as a partnership at the onset. Although death signifies the end, it compels the *other* to a beginning, a new way of approaching life, a new way of approaching education.

### *Living with Death in Sight*

What you'll one day realize...is that death is not something to fear, it is only something which one must come to understand....something that happens just as anything else happens....On a personal level, it doesn't look to be an unpleasant experience. (Levin, 2007)

Facing death appears complicated, complex and detrimental; however, for many approaching the conclusion of life, there is peace, acceptance and hope. Miles Levin (2007) shared his outlook on death when he relapsed with rhabdomyosarcoma, the same aggressive pediatric cancer that inhabited Joanna. Levin (2007) states that death is “something one must come to understand” which will occur or take place “just as anything else,” thereby implying a natural event in the circle of life. This conclusion is fairly easily stated for one assuming health is in place, but to articulate death as a natural event and acknowledge death as an occurrence one must simply “come to understand” while staring at death, and anticipating its arrival is heroic. The accepted comradery between death and one’s life is courageous beyond words, brave beyond comprehension, and an example beyond imagination. If only the ill could help all learn the lesson of acceptance, and lesson of appreciation for life while health is not a conscious concern. If only life were lived consciously aware that death at any moment would justify a natural occurrence, an anticipated phenomenon.

Dying is a natural event, for a part of birth is consenting to the imminence of death. Dewey (1908/1929) stated “the entrance of a new life...and the disappearance of the animating breath...might well impress man with the mysteries of the world” (p. 64). Although aspects of birth and death are mysterious, one undeniable reality is birth and death come adjoined. According to Kübler-Ross (1981), “birth and death involve great changes and adjustment” very often involving “inconveniences and pain” along with “joy, reunion, and a new beginning” (p. ix). Joy and sorrow, the union of opposites, merge to signify one’s existence in birth and death. Illness, according to Kleinman (1988) may teach each individual a valuable lesson about life, and that is “how to

confront and respond to the fact that we will all die” (p. 157). Harris (2004) asserts each individual will without a doubt “die at some moment in the future,” and if “being prepared” means one will know “when and where it will happen,” then chances are no one will be prepared (p.37).

Rather than preparation for death, the anticipated method of how death will occur keeps one guessing when health issues arise. Arthur Frank (1991), when anticipating a diagnosis of cancer, believing that he would die soon, stated that the greatest pain in the thought of death was “losing my future with others [family members]” (p. 37). In this mindset, Frank confessed that his “reasons for living” had never been more evident (p. 37). Sedgwick (1999) reiterates Frank’s feeling by stating “my own real dread had never been about dying young” rather, it was “about losing the people who make me want to live” (p. 72). Even children voice apprehensions based on family bonds and relations. Joanna once told her mother, Misty, that she really did not want to be the first to go to Heaven because it would be “so hard to leave family” (M. McAfee, personal communication, December 13, 2005). And again, Ling (1999) acknowledges a consciousness of life’s treasures stating having to “face...death” allowed her to “appreciate how full and satisfying...life actually is” (p. 132). The *ill* facing death also teach *others*, as is the case with Groopman (1997) who stated that Dan, infected with AIDS, was his teacher, teaching him how to “draw strength and courage” from the “ordinary pleasures of life in the shadow of death” (p. 62). The threat of death often awakens the senses to experience the present beauty through eyes of appreciation and wonder.

Joanna, up to the day she left this life, displayed a deep concern for others, a giving of self, and a love that was unwavering. From the time Joanna was very young, I would kiss her tiny toes, and ask for “Pinkie Kisses.” The week prior to her death, Joanna had spoken only occasionally in a weakened whisper, and for the most part, she asked for pain medicine, or replied to yes or no questions. When it came time for goodbyes, the family entered the room with Joanna. Everyone spoke to her one at a time, and she gave little response. As I was leaving the room, I heard a questionable whisper. I quickly realized that Joanna had whispered, “Aunt Leigh.” I turned to the bed and saw her still lying there with her eyes closed. I asked, “Joanna, did you call my name?” She nodded her head yes, and slowly opened her eyes. “Don’t you want some Pinkie Kisses?” My heart melted, and my first thought was, as always, Joanna is thinking of what others want or need. “I surely do” I whispered, and in her weakened state, she slipped her tiny foot out from under the cover and remained very still. I bent down and kissed her precious tiny toes. I wanted to reach down and hold her. It was the last words I would ever hear her say. It was another example of how these precious individuals are in tune to the needs of others, and that joy comes in the little things in life, the things which appear mediocre to many.

Three months prior to his death, Miles Levin (2007), a cancer patient, demonstrated his attentiveness to the wonder and appreciation of life by stating,

As I was sitting outside on a bench...something special happened. Suddenly, the world (picturesque Beaumont Hospital) became more beautiful than I could ever recall seeing it. There’s a certain time at dusk when the sun sometimes sets everything aglow in a most angelic, hyper-real way....The splendor of [the] world

was overwhelming. As we drove up Woodward...its beauty nearly moved me to tears. I can't remember when being alive ever felt so good, and everything around me—the trees, the people in their cars—they were so vibrant with life as well.

It is as if the dying are able to view surroundings through eyes that see only beauty, only magnificent splendor. Ordinary objects such as “trees” and “people in cars” illuminate. The ill teach *the other* to experience the “splendor of [the] world” as being “overwhelming,” and to appreciate being alive, and basking in the joy of life. Thought of the future, or lack thereof, encourages one to enjoy life and relationships. Dewey (1922/1950) stated that thoughts concerning the future are the only way one may evaluate the “significance” of the present (p. 267). Without an outlook for the future, “there can be...no plans for...overcoming present obstacles” (p. 267). For those confronting death, future projections may shuffle priorities of the present as life is threatened, many times placing family members and personal relationships at the top of the priority list.

Mehren (1997) states that positive adaptation, which suggests “making the best of a bad situation,” is a common characteristic of many cancer patients in that they realize “how important their personal relationships are,” dismissing the “petty distractions of life” (p. 178). Mehren asserts that her friend, a psychologist, found that many women cancer survivors “stopped caring about housework” for the reason that it “took precious time away from their families or their friends” (p. 178). What once took precedence over relationships becomes trivial in comparison when time is consciously finite.

Henderson-Holmes (1999) testifies to readjusting priorities in confessing how her feelings towards her brothers evolved with the onset of illness. Prior to the diagnosis of breast cancer, Henderson-Holmes (1999) confessed to wanting her own space, separated



from her brothers. Henderson-Holmes states, “I wanted my own room...I wanted to kick my younger brother out, smother his snores, tear his baseball heroes from my walls, fumigate his scent from my closet” and remain in a room with flowers and lava lamps (p. 41). However, sitting in the hospital room, she reconsidered her thoughts from many years before stating, “I pray for my brothers to come here, stand in the way of this hospital bed,” fill the room with their snores and smells, “junk up this narrow closet with their big shoes and pants,” while “shout[ing] sports scores,” cart-wheeling and stomping (p. 41). Henderson-Holmes longed for the conversations, the visits, the warmth of togetherness. Illness potentially changes one’s perceptions of relations, allowing what was once viewed as an annoyance in the past to become a treasured act in the present. Nature’s gifts which were once taken for granted, even ignored, seem refreshed and anew when death looms.

According to Jackson and Vessey (1996), children enduring illness for a long period of time “often have an understanding of ...death well beyond their chronological age” (p. 52). This understanding is based on adult reactions to other deaths, as well as the child’s intuitive notion of “who is comfortable dealing with their impending death and who is not” (p. 52). Children with cancer experience life and death, in that visits to clinics allow for great amounts of time socializing with other cancer patients. With the declining health of friends, and ultimately the death of those friends, the child is “likely to use the response of staff and other families” to determine the anticipated response of his or her own death, as well as determine the quality of assistance others will offer in the “process of preparing for death” (p. 52).

According to Mehren (1997), Michael, an eight-year old child with cerebral palsy, appeared to have “an uncanny understanding of life’s larger issues” (p. 141). His mother, overhearing a conversation between Michael and his brother, stated that the two were discussing “differences between Christians and Jews, the war in El Salvador” and other issues (p. 141). During this conversation, Michael’s brother, Teddy, told Michael that he loved him, and asked him not to die. Michael then replied that he had to die. Six weeks following this conversation, Michael was taken to the doctor for a severe headache. He died of a brain hernia. Michael had a broader sense of life as it appeared, and he was certain that death was approaching.

My sister, Misty, often spoke with Joanna about Heaven. It was a great anticipated venture in their conversations, where a brilliant golden beach was awaiting the two of them to bask in the sun. Joanna’s greatest love was the beach, the waves, the sunsets, and most importantly, the seashells. The two of them agreed that whoever went first to this place called Heaven, would play on that magnificent beach until the other arrived. Joanna viewed the act of dying as a journey or a trip to a charming place, so the conversation which occurred just days prior to her death, illustrates the child mentality of traveling to a mystical land of no pain and suffering. Joanna was very weak, uncomfortable, and in pain. Misty told her that when she became too tired, not to be afraid, to go ahead and go to Heaven, thereby releasing the struggle for her to endure more pain. Joanna began to cry, and innocently asked, “But how will I know how to get there?” Joanna was not concerned or worried about the permanence of death, the pain she would endure while dying, nor was she worried about the process of dying alone; rather, her most pressing apprehension was about knowing the way to Heaven.

Another example of apprehensions of Heaven is expressed by a thirteen-year-old girl referred to as L., who suffered from an abdominal tumor. Kübler-Ross (1981) witnessed days of L. lingering in pain, stating she “simply could not die” (p. 6). With the mother at her side, and the mother’s consent, Kübler-Ross asked the child what kept her here, what kept her from letting go. L. responded that she would not be able to go to Heaven. Puzzled by her response, Kübler-Ross inquired about why she believed that she could not go to Heaven. L. proceeded to explain that the priest had told her that in order to go to Heaven, one must love God more than anyone else on earth. L. then admitted that she loved her mother and father more than anyone else, thereby believing that going to Heaven was not a possibility. After a careful and meticulous conversation concerning an analogy between teachers and God, Kübler-Ross stated that L. seemed at peace about Heaven and dying.

Not only do these children emanate a peace, they also have an innate sense of death. Taylor, thirteen years old, once told her mother that sometimes you have to “let go of the grass.” When her mother asked her what she meant, Taylor replied that by letting go of the grass, one could fly to heaven. (M. Arrington, personal communication, Tuesday, June 20, 2006). Dying for these children did not signify a sad ending. Peace and assurance came with knowing that death would arrive, and take away their pain. Leo Buscaglia (1982) asserts if individuals lived life to the fullest, facing death would not be a detrimental act. Those who die happy are individuals who “attempted to know life” (p. 181).

Children teach us to love life, to see rainbows, to watch sunsets. Facing death is heroic, and many approach the door with no complaints, most being thankful for each

blessing received. Each day is viewed as a gift. Poetry was a means of expressing thankfulness for Mattie J. T. Stepanek, who suffered from a neuromuscular disease. He died at the age of 14, but his poetry expressed his inner thoughts. In an excerpt from *Prayer for a Journey*, Stepanek (2001) wrote,

*Thank you, God,  
Not just for life,  
But for our journey through life.* (p. 1)

Children suffering from terminal or chronic illnesses have a remarkable appreciation for life, and the journeys for which their lives travel through the lived experiences. Just two months prior to Joanna's death, she remarked, "I never knew I could be sick, and have so much fun!" (M. McAfee, personal communication, October 25, 2005). Even when awaiting death, children invariably return to the lived experience for how to approach their passing, as well as how to journey into and through death. The past experiences drive the process whereas children find the peace and courage to *live* up until the dying moment. Likewise, the lived experience of the *other*, gives one the strength to witness, not only through a visual connotation, but through storytelling, through a verbal sharing of the heroic act of one leaving this world as it is perceived in the form of human existence.

### *Life with Death*

Life for the *other* and death for the loved one may come so close that the lines between the two touch, momentarily merge or meet. "*Death always brings one suddenly face to face with life. Nothing*, not even the birth of one's child, brings one so close to life as his death (Gunther, 1949, p. 187). Frances Gunther eloquently captured her reality

when her son succumbed to a fifteen-month battle with cancer. She stated that the anticipation of the death of a child “raises many questions in one’s mind and heart and soul” concerning “the meaning of life...the relations between things” (Gunther, 1949, p. 187). Gunther verbalized the questions raised about life itself, how it is lived, the relationships between each entity and the purpose. For Gunther, death initiated a closer look at the lived experience pertaining to the family, society, politics and religion. Life with death pressed for a deeper understanding of mortal existence. Mehren (1997) shares Gunther’s views of the death of a child stating that when a child dies, “we are plunged into a...well where questions bounce from every wall. We are forced to examine some of our most basic beliefs and assumptions” (p. 22). These basic beliefs entail “what we understand to be the natural order of life” (p. 22).

Life occurs at the side of death, nearby, next to, as close to death as possible without fusing into and following death. Frank (2004), in discussing a case in palliative care, refers to this closeness as being “on the boundary” (p. 111). Life with death allows one to witness pain, suffering, and preparation for a relinquishing of self to death’s summon. The helplessness, the yearning to make things better, the certainty of watching one cease, and the mystery of an afterlife all encompass profound emotional outpours in life with death. Often times, previous misunderstandings and disagreements suddenly appear trivial and insignificant. As death becomes imminent, many family members, as well as dying patients, seek reconciliation. Puchalski (2006) contends that by resolving differences and “make[ing] peace with significant people in our life,” the remaining quality of life improves, and the perceived spirit is more tangible. In describing how his sister shared her terminal diagnosis with family, Shapiro (1997) articulates how his father

“broke down” and asked his dying daughter “if she could ever find it in her heart to forgive him for his stupidity,” and she “went over and embraced him, with her forgiveness” (p. 115). Often times, a bleak diagnosis tends to break barriers with unconditional love and forgiveness.

Mary Aswell-Doll (1995) speaks of unspoken forgiveness and reconciliation when her mother was diagnosed with Sezary Syndrome. The sharing of the news initiated a conversation of life experiences. Doll writes, “Here we were...talking about her dying when we had so seldom talked about her living” (p. 56). She continues that her mother was “sharing her death....We wept....We were delighting in the company we gave each other” (pp. 58-59). The reconciliation spawned a desire to please, to let the other know she was loved. During a hospital visit, Doll carefully describes how each, mother and daughter, portrayed acts of love in subtle ways. Doll wore her mother’s clothes in an effort to allow her mother “to see herself in me” (p. 85). And to her astonishment upon entering the hospital room, her mother had brought an afghan, one Doll had made her for her seventieth birthday and placed it across the bed. Doll states, “I had never seen her use it [the afghan],” for it appeared that she was “thanking me, as I was her” (p. 85). Her mother’s death sentence had created a beginning, a new start for a mother-daughter relationship, a silent assurance that love was present.

In present-day society, love gets entangled in the everyday, the busy regiment of work, children, and of course, entertainment. Harris (2004) asserts that although individuals love family and friends, and are “terrified of losing them,” we are not “in the least free *merely* to love them while our short lives collide” due to having to take care of the self (p.37). Awareness of death is universal where “parents lose their children and

children their parents,” where relations are “separated in an instant,” and goodbyes are stated hastily, not knowing that it may be the last (p. 36). The flippancy of everyday life catches many off guard when the realization of the finality of death touches home, and guilt and regrets emerge. Groopman (1997) contends “there is no more awful death than to die with regret,” when one believes, as approaching death, that “you had lived a wasted life” (p. 37). He refers to dying with an “empty soul” when regrets are present. The *other*, at times, acknowledges regret for various reasons, things left unsaid, lack of time spent together, or other unspoken sorrows. Morris (2005) recounts memories of her father’s death stating “There was no funeral. There were no services. There was no gathering. Only a gathering storm of my emotions. Only a lot of regret” (p. 39).

Dewey (1958a) once stated,

The past hangs upon...[most mortals] as a burden; it invades the present with a sense of regret, of opportunities not used, and of consequences we wish undone. It rests upon the present as an oppression, instead of being a storehouse of resources by which to move confidently forward. (p.18)

Dewey, not speaking of death, per se, made reference to how the past can “burden” the present with “a sense of regret” and “consequences we wish undone,” thereby making everyday life oppressive (p. 18). Dewey does not write of the death of two of his children, nor the death of his grandson, but the undercurrent of this quote speaks to me from experience. The mourning process assists in helping one “move...forward” and in using past experiences as a “storehouse” in order to continue with the life as living, life as the lived experience, to continue to live, after struggling to make sense of death.

Fully understanding the impact of dying may only be possible when consciously approaching its door, and/or when there is a consciousness of spirituality. Buscaglia (1982) contends that one must “make peace with death in order to choose life, because death is an incredibly good friend” (p. 180). Death forewarns, according to Buscaglia, that “we don’t have forever,” and death beckons “not to waste time....to grow....to become” (pp. 180-181). Death as a “good friend” urges all to live, to live *fully*, acquiring happiness. A “great gift” is how Campo (2003) views death, which “reminds us our little lives must give us pleasure as we live them” (p. 140). Finding happiness and contentment in life is the contribution death brings forth. Among some cultures, death is viewed as a celebration. I find it difficult to consider Joanna’s death as a celebration. I find peace in her death, but not joy. Death is an awaited visitor who relieves one of pain and suffering, and accompanies one to a serene tranquility. Thinking of death as a friend allows me to bare the absence in the circle of lives that surrounded her, the circle that still yearns for her presence, and sheds heartfelt tears in her absence. An adversary at times, death takes without asking. “Death is no enemy of life” according to Frank (1991), “it restores our sense of the value of living” (p. 120). As the *other*, one must evolve into a state that death is not perceived in a negative manner. Reassuring and supporting the dying will allow for guilt free release of mind and body.

Many times, out of fear and grief, loved ones will encourage, even urge the dying to keep fighting to live. Too often, the ill honor this request enduring additional pain and suffering. Kübler-Ross (1983) shares about a mother, whom after her son’s death, Derek, realized in regret that “it may have been *us* [Mother and Father] who made Derek hang



on and linger through all that suffering. We certainly may have been holding him here” (p. 194).

Response to the death of the *other* is somewhat arbitrary, even when death is expected at any moment and apprehensively anticipated. Although death awaits, the finality is still difficult to conceive, still overwhelming to conceptualize. The day of her son’s death, Nancy Levin (2007) stated, “We knew it was coming, yet we’re shocked. We knew it was coming, yet we’re unprepared. We knew it was coming, yet it feels unreal. We knew it was coming, but we hate it.” Levin testifies that no matter how prepared the family was for the death of Miles, her son, they still found themselves unprepared, stunned, and totally helpless. Shapiro (1997) recalled his sister’s death by stating,

Much as I knew her death was coming, much as I had waited for this moment, and imagined it, now that it was here it was the last thing I expected in the world, the last thing I was ready for. (p. 112)

Shapiro (1997) had awaited Beth’s death for weeks, but in the final moments, he realized he was ill-equipped for the absolute. Along with the feeling of disbelief, loved ones often verbalize feelings of guilt. Groopman (1997) in sharing about the death of a young boy who suffered from leukemia, stated “Although I knew that Matt was going to die...I still felt a sense of failure, of guilt” (p. 110). Frances Gunther (1949) spoke of guilt after her son, Johnny died by stating, “I am haunted by my own shortcomings, how often I failed him,” (p. 193). She continued with examples of being a failure for living after he died, for sending him off to school, for not maintaining “the marriage that created the home he loved” and for not being able to satisfy his last desires (p. 194). Although Gunther (1949) verbalized that she and her husband loved Johnny very much, she confessed, “I wish we

had loved Johnny more when he was alive (p. 194). Kübler-Ross (1991) asserts that love is life and death; “it is all the same thing” (p. 23). Love is what allows one to depart in peace.

Rafael Campo (1997), in describing the death of a patient, states “I imagined his soul had already begun its departure, leaving his body only partly filled with the physical ingredients of life....I imagined his soul, dancing away upon the rise and fall of his mother’s quiet voice” (p. 169). Witnesses to death often speak of the departure of the soul, a leaping, a flying, a separation. Shapiro (1997) in describing his sister’s death stated that Beth exhausted “an eerie moan....it was the sound of the spirit moving on” (pp. 111- 112). In an effort to share with you the unspeakable pain, coupled with the subtle transition into the death of a child, I will share an excerpt from a journal log from Janet Sims (personal communication, March 19, 2003), the mother of a five-year old little girl, Janie, who died from ALL – Acute Lymphocytic Leukemia. Sims shares,

On the last night of Janie’s life, I asked her 4 questions. She was having trouble breathing so I asked her yes and no questions.

“Janie,” I whispered, “Are you hurting?”

She shook her head “no.”

“Janie, Are you in pain?”

She shook her head “no.”

“Janie, Are you happy?”

She shook her head “yes.”

Then the last question carried with it the weight of knowing that time was small...

“Janie, Are you scared?”

She shook her head “no.”

...She was so innocent, not knowing I was soaking in every sentence she uttered as I knew soon no more words would be spoken....At one moment when I sat up to rearrange the blanket, I heard her say “I love you.” It was unlabored and soft.

A peaceful departure may signify abundant love for and from the *other* (s) and/or may represent an inner restitution and tranquility. Many speak of asking God to take the loved one to avoid further pain and suffering. Rafael Campo (1997) speaks of his description of the physician’s “God Complex” by stating “the patients who are dying, or ...getting well, all have a place to go; each holds hands inside and is held by the beating heart and the feverish closeness of his loved ones” (p.61). He continues that even patients who have no one, may turn to “one who truly does have the power to heal” (p. 61). Life through death and dying is an act which can be shared, an act which is not solitary, a brave submission into another dimension. For after death, there is life.

### *Life After Death*

I would like to begin by clarifying the purpose of this section of this chapter. I do not wish to argue nor prove that an individual will awaken to an afterlife following death. Although my religious beliefs assure me this is so, and many studies on near-death experiences have been documented, that is not where I would like to take this conversation. I want to direct this towards the lives which endure the loss. I will illustrate how one’s life continues beyond the body confines through the *other*, and those in relations to the deceased. Gunther (1949) stated that although his son died in mortal life, he still lived on through the “influence, the impact, of a heroic personality” which continued to resonate “long after mortal bonds are snapped” (p. 138). I intend to argue

that death is not an end, but a beginning of a new segment of life, a familiar/unfamiliar life which progresses in a new way akin to the previous walk with the deceased. T. S. Eliot (1943) wrote

*What we call the beginning is often the end*

*And to make an end is to make a beginning.*

*The end is where we start from.* (p. 46)

Infinity is obsolete in terms of the human existence in living form. I interpret Eliot as meaning beginnings and endings are adjoined, synonymous, where one prompts the other. Human lives do cease, but may continue to resonate not only through the *other*, but through each life he/she touched.

Dewey (1958b) claimed it to be common sense that a *thing* would not last indefinitely. In this case the *thing* I will refer to is life in human form. Regardless of how some *thing* ceases, whether it be “a matter of fact consummation, or a deplorable tragedy” the fact remains that there is an end (p. 97). However, Dewey suggests that the “genuine implications of natural ends” may possibly be better understood if one considers “beginnings instead of endings,” in that “what is true of beginnings is true of endings” (pp.97-98). I interpret Dewey as meaning when one thing ends, a reaction occurs whereas an immediate new beginning is initiated. The ending of life for an individual’s loved one marks a new beginning for that individual in a known world which becomes estranged with the absence.

Because death of a loved one entangles passionate emotions, one may find difficulty in thinking of the end as a new beginning. It seems to imply a negligence, a dismissal, possibly a disregard for a precious life. But when examining life as a story, *a*

*life story*, one may come to realize that the end must mark a starting point for another life story without the loved one, or those remaining become static, stagnant, in essence, subsistent. A new beginning allows life to continue, picking up the pieces of life before the loss, weaving precious memories with a rebirth. Accordingly, this beginning is surrounded by grief, mourning and pain; however, the grieving process allows one to accept and come to terms with a new beginning, and attempt to adjust to a life in absence. Arthur Frank (1991) contends that when an individual loses a loved one, “the loss must be mourned fully and in its own time” for it is only through this process that one can find “a life on the other side” (p. 40). He continues “to grieve well is to value what you have lost,” in that within this loss, life itself is valued, and one may “begin to live again” (p. 41).

The start of a new day, a new beginning, requires good mourning. Grief affects each individual in a myriad of ways. Frances Gunther (1949) stated that grief was “much simpler and sadder” than a “desolation or rebellion at universal laws or deity” (p.190). It was the occurrences which were reminiscent of Johnny that brought her to tears, such as “a sunny fast wind...good sailing weather...a new light boat” because she knew how much he would have loved those things (p. 190). Elizabeth Stratton’s mom states, “Grief is such a strange thing. You go along, fairly strong, and out of nowhere it knocks you off your feet, leaving you with a staggering pain and completely breathless” (S. Stratton, personal communication, November 27, 2006). Alan Shapiro shared about his grief when his sister died quietly by stating, “I wanted everyone to grieve. I wanted life to stand still and acknowledge sorrowfully the loss of my sister, someone without whom my own life was unthinkable” (Shapiro, 1997, p.33).

Tschudi (2006) states that losing a loved one, and grieving for a loved one are “very personal experiences” that affect “the way that we view life and live our lives” (p.332). But grief is a learning experience, whereas we may “live with our pain, and transform it...into a lesson” (p. 332). The grieving experience allows for growth, for restitution; however the lessons learned usually originate within, and according to Kübler-Ross (1983) “no one can take our grief away” (p. 22).

Although the transformations are initiated through inner resolution, many times, relationships and conversations help one move through the grieving process. Two years following Joanna’s death, my sister, Misty McAfee (2007) shared her inner thoughts of how our family was working through the grieving process. McAfee (2007) stated,

We are “Okay” as we will tell you, when asked. Meaning... always on the verge of tears, but usually able to control it. Always thinking of Joanna, but usually able to do something else at the same time. Always absolutely heartbroken beyond words, but usually able to smile and continue through the days as we promised her we would. (personal communication, April 30, 2007)

McAfee verbalizes that although the other can continue to live and function, and even be happy, there remains a void, feeling of absence. Burton (2000) expressed feelings of frustration following the death of his son, Kelly. He explained that those individuals he felt would discuss, ask about, or verbalize their sentiments were silent. Burton stated it was his belief that this silence was due in part to sparing him additional grief, for which he identifies as “another one of life’s great paradoxes” (p. 124). Burton expressed a desire to “talk about him [Kelly]...to be reminded of him...to talk about the tragic events that happened,” and to have the opportunity to share his grief (p. 124). Death is overlooked,

disregarded. Burton coins death as the “untouchable subject,” which may silence individuals because it prompts thoughts of one’s own mortality (p.124).

Why is it that those things that frighten one the most initiate silence?

Unfamiliarity typically spawns fear, but the absoluteness of death is literally breathtaking. I contend that conversations bring about comfort, certainly not a pleasurable comfort, but a comfort level which is agreeable. In other words, by talking about death, one can at least consent to its consequences. One can at least live alongside death’s anguish to prepare for new beginnings.

### *Educational Malignancy*

The history of the world is full of anguish and despair. But in spite of the turmoil experienced in this life, the lived experience has taught valuable lessons for how to proceed. The malignancy infiltrating our educational system is growing in strength, still unbeknownst to the body of society for which it serves. An ending, a closure, a metaphorical ‘death’ is silently approaching in a thriving time of surveillance, testing and conformity. I fear what will spawn a new era in education. To what extent will our country allow education to continue before a new beginning is unavoidable?

Present day schools, according to Clifford and Friesen (2003), are “ ‘from the neck up’ places” which disconnect “children and teachers from their bodies...their feelings....their experiences and from each other” (p. 103). Continuing, Clifford and Friesen contend that the range of “experiences that feeds all their [students’] senses, touches their hearts, and moves their souls” is reduced to segments of “activities, drills, and worksheets” (p. 95). Isolated minds are targeted, with emphasis solely on the intellect, ignoring the lived experience which entails the illnesses, the emotional

responses, as well as the spiritual realm. Life itself is condensed to book knowledge. In conclusion, Clifford and Friesen (2003) ask, “What kind of courage...will it take to live life differently-to change our schools, to change ourselves so that children have a chance to emerge from public education as passionate, robust, committed learners?” (p. 110). Courage requires risks, significant risks which could be beneficial or detrimental to the systemic body of education. I do contend this to be the reason the educational methodology has survived decades, even after being declared a dying entity over 30 years ago. Security and complacency are found in the current rhetoric which has been used for numerous generations. Although technology, society and the lived experiences of our youth have radically changed over the past century, our educational practices have remained basically the same, with the most substantial changes occurring in terms of accountability efforts.

“Maintaining friendships and routine interactions with peers,” according to the Children’s Cancer Group, “is essential to normal psychological development and is at least as important as academic issues” (Ablin, 1993/1997, p.271). In health, many live with eyes closed, content with the mediocrity of schooling, whereas the social aspect is at a bare minimum; however, the chronically and terminally ill patients know that the social realm of life is every bit as important as the academic realm. It is from the relations that one draws meaning, allowing one to learn about life as well as facts and figures from the educational space. Ablin states that the “social component of the school experience” is very significant, and should be utilized as long as the patient’s health permits (p. 271). And as health deteriorates and death approaches, the child is left with priceless memories of friends and relationships which warm the heart. The involvement of the ill among the



perceived healthy is beneficial and life-changing for both parties. Testimonials have been given such as friends shaving heads to make cancer patients feel welcome and more at ease, friends donating blood and being tested for bone marrow to assist a friend, and friends simply remembering the deceased years after death. Burton (2000) shares that years following the death of his son, Kelly, he and his wife still receive a card on the anniversary of his death, which is signed by all of his classmates. Conversely, death, according to Noddings (1992), “is largely ignored in schools unless tragedy strikes close to home,” and the conversation of “death is necessary for self-understanding” (p.81). The conversation of death is basically omitted.

Death may be perceived as taboo, but death is a certainty, a reality. Death is inevitable. It is imperative that we live life cognizant of death, willing to allow death to seep into conversations, willing to acknowledge death as a presence, willing to accept death as a truth. Avoiding the absolute does not make it disappear. As evidenced by conversations with dying children, Muir (1992) stated,

Let children...see the beautiful blendings and communions of death and life, their joyous inseparable unity, as taught in woods and meadows, plains and mountains and streams of our blessed star, and they will learn that death is stingless indeed, and as beautiful as life. (p. 140)

Terminally and chronically ill children have stories to tell, and no, they are not all grim and somber. Many of them are intriguing, fascinating, motivating and innocent. The life which is lived, the air which they breathe is precious and appreciated. I think that my brother-in-law summed it up best by stating, “These [ill] kids seem to have a gift to sort

through and latch on to what is truly meaningful in life. Perhaps it is a clearer definition of life itself” (J.K. McAfee, personal communication, August 1, 2005). Maxine Greene (1995) states “we can learn from those who have already learned to listen to children, paying heed to what they say and write.” By placing them in situations where they can write and speak, “they can find out what they think and why and what they see and how as they talk about it, write about it, and bring meaning into their words” (p. 54). If we listen, children will open up and allow us into the world in which they exist, a world full of nurses, doctors, medicines, hospitals, and hope.

Education and learning are initiated from the world in which one lives. The lived experience originates lessons which cannot be taught through textbooks and lectures. In reference to progressive schools, Dewey stated (1969) that each meaningful education “is a direct enrichment of the life of the young” and not simply a “repellent preparation for the duties of adult life” (p. 281). He continued that these schools consider life to be growth, and although this entails “meeting and overcoming obstacles” that it is, in essence, “to be enjoyed now” (p. 281). Life-long learning should be insightful, where one fully lives and learns, infusing intellect with the lived experience. When one examines the life, the inner self woven into the lives of others, he/she may find that many of life’s lessons are learned as one walks or journeys down the path of life, becoming lost in confrontations with adversities, lost in the apprehensions of the present, then finding solace in the outcome. *Curreré* allows one to “slow down, to remember...the past,” and then contemplate the future, assisting in the understanding of the present (Pinar, 2004, p. 4). It is the self-understanding which leads one to educational heights, where life-long lessons can be found.

I will draw on the work of William Reynolds in an effort to conclude in a coherent manner. Reynolds (2003) states

How ironic it is that just as we think we have found something, we are lost. But being lost is not a bad place to be. We can't simply bifurcate lost and found and say that one is good and one is bad. Sometimes there is a foundness in being lost and a lostness in being found....And we experience that lostness as a need for order and reason. (p.54)

As I attempt to pinpoint the aim, make sense of illness, grasping for 'order and reason,' I find myself lost. How can I perceive, or draw meaning from this horrific phenomenon? I find solace in the literature, reassurance that is calming, confessions of fear that validate our humanity, and a sentimental connectivity to others touched by the life of one who has encountered illness, and ultimately death. I have found one aspect of my refuge. Yet I remain unsure, uncertain as to where all of this leads. Why the children? What is the cause of the pain and suffering our children must bear? I am at a loss for words.

Reynolds (2003) continues, "It is when you are lost in the forest that you personally determine what you find there and what matters to you" (p. 55). Most certainly, throughout my journey of choosing which direction to proceed, I have been fortunate enough to flesh out "what matters" most to me. Dwelling, disoriented and fearful for another's survival, I realize that the richness and priceless memories are rooted in my loved ones. My life branches off, but remains connected and nourished by those roots. Miraculously, when a magnificent bloom flourishes for a short time, then withers in due season, I still have the precious memories to remind me of the beauty and the vitality of its aura. Leo Buscaglia (1982) states that looking for answers outside of the self is

worthless, and will take one “into the forest” where one will become lost. “If you want answers,” he advises, one must look “inside, not outside” of the self (p. 70).

Perhaps being lost in the forest encourages one to turn inward, to explore the depths of the soul, to find peace in life. “The forest is a hopeful place to be. It is dark and uncertain, yet hopeful” (Reynolds, 2003, p. 60). Wherever the educational journey may lead, whether it be face-to-face with death, along side a loved one facing death, or even dwelling alone feeling lost in the forest, may we find peace in the present, hope for the future, and admiration for the past. May we hold on to the memories of those who have taught valuable life lessons in order that others may live life more fully, more vibrantly, with a respect and appreciation of the lived experience. May we continue to search within, to cultivate the spirit, to project outside nurturing relationships, and to listen as we learn from each other, for it is through the lived experience that one truly teaches, one truly learns, and one truly lives.

## AFTERWORD

I approach the end of this dissertation with a myriad of emotions. The finished product is an accomplishment for which I am pleased; however, approaching the final chapter was a visual reminder that Joanna's story in this context must come to a close. My writing began at the onset of her illness and continued throughout the treatments, a year of healing, and regrettably, the relapse. Her death took my writing to a place in which I did not intend to visit. In the early stages of my writing, I was convinced that this would be a success story, a miracle for which I would testify, being a witness that one could beat the statistics. Joanna's life journey took her down a different path, a treacherous path, a painful path. But although Joanna's life was but a brief encounter, I want to leave you, the reader, knowing it was lived to the fullest extent, full of joy, full of love, and full of lessons for all to learn. Joanna was an extraordinary teacher, teaching lessons through her lived experiences, her life journey. She modeled unconditional love, she marveled at nature and all of God's creations, and most importantly, she bonded with the souls and spirits of those she encountered. Her child-like faith was witness to all that even terminal illness could not deplete one of the pleasures of life. Joanna lived an abundant life. She was courageous and brave, teaching not only how to live life, but also how to depart with grace and unmistakable heroism.

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