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EMBODIED CONSCIOUSNESS IN NON-FICTION ILLNESS NARRATIVES:
A PHENOMENOLOGICAL-SOCIOLOGICAL APPROACH

By

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B.S., Indiana University, 1991
M.A., University of Louisville, 2000

A Dissertation
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University of Louisville
Louisville, Kentucky

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A Dissertation Approved on

November 17, 2011

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DEDICATION

This dissertation is dedicated to my mother,

Nancy Aboud Henderson.

who has inspired me all of my life
with her faith, perseverance and love.

I share this dedication with my father,

the late L. H. Henderson,

who taught me the value of hard work.

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Finally, I thank my husband, Jerry, for his constant love, faith and patience. I could not have earned this degree without him.

ABSTRACT

EMBODIED CONSCIOUSNESS IN NON-FICTION ILLNESS NARRATIVES: A PHENOMENOLOGICAL – SOCIOLOGICAL PERSPECTIVE

Kathryn A. Jacobi

November 17, 2011

This dissertation uses a phenomenological and sociological lens to explore how non-fiction illness narratives help us understand how perception of the self is disrupted because of serious illness or injury. Specifically, I use the French philosopher, M. Merleau-Ponty's phenomenological thought concerning the body and the sociological perspective of medical sociologist, Arthur Frank and his types of narratives and how culture helps construct illness. I analyze the works of four different writers: Sarah Manguso, Oliver Sacks, Jean Dominique-Bauby, and Anatole Broyard.

Chapter one serves as an introduction to the subject of illness writing and an overview of some of the material published during the past several decades. I discuss some of the functions of illness writing and summarize Frank's narrative types as well as explain some of the theories of Merleau-Ponty which are relevant to this study.

In chapter two I analyze Sarah Manguso's *The Two Kinds of Decay*

approaching her narrative as a poetic type of prose in which she addresses her illness from the perspective of someone who came through a particularly harrowing illness experience and emerged to cautiously recount the experience several years later.

The third chapter's focus is Jean Dominique-Bauby's *The Diving Bell and the Butterfly*. I discuss Bauby's sense of disassociation caused by locked-in syndrome as a result of his need to escape what he metaphorically names the diving bell. Bauby, like Anatole Broyard who is discussed in the last chapter, does not survive the illness.

Chapter four's focus is Oliver Sacks and his book, *A Leg To Stand On*. Like Manguso, Sacks tells the story looking back from the present into the past. He moves beyond his injury, but the self-objectification that occurs in his narrative is a testament to the nature of disembodiment as an almost necessary phenomenon for living through severe physical trauma.

Chapter five is a discussion of Anatole Broyard and his book, *Intoxicated By My Illness*. Broyard's book is a compilation of his writings – mainly journals – created during the time from his diagnosis and his subsequent journey through prostate cancer, which eventually took his life.

In the conclusion I speculate about the effect of these narratives on the reader and briefly explore several other texts written by professional writers who were ill.

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CHAPTER ONE

Embodied Consciousness in Non-Fiction Illness Narratives: A Phenomenological - Sociological Approach

1.1 Overview

This dissertation explores what written illness narratives reveal about how perception is mediated by the body, and how that perception is disrupted, changed or limited by illness or injury. To this end, I explore four illness narratives – creative non-fictional works – written by professional writers. These four works were chosen from a cross section of social location: Sarah Manguso is a poet and a woman; Oliver Sacks is an American neurologist; Jean Dominique-Bauby was a French editor and writer, and Anatole Broyard was an African American writer and critic. Their works respectively are: *The Two Kinds of Decay* (2008); *A Leg to Stand on* (1993); *The Diving Bell and the Butterfly* (1997) and *Intoxicated By My Illness* (1992). These works are examples of contemporary illness writing in its varied forms. Only two of the four of these writers survived their illnesses.

The heart of my thesis is that the act of writing and publishing the illness narrative offers the ill writer a chance to gain back some integrity of the self that has been lost to the disruption and fragmentation caused by the illness. To

approach these issues I use as a general frame the phenomenological thought of the twentieth-century French philosopher, M. Merleau-Ponty, specifically his work, *Phenomenology of Perception*. I also use the medical sociologist, Arthur Frank's three types of illness narrative (chaos, restitution and quest), discussed in his book, *The Wounded Storyteller* as another lens through which these narrative works can be illuminated from a sociological perspective. More specifically, I analyze the literary techniques and structures these four writers use to produce narratives that evoke empathy and move audiences to a better understanding of what it means to be ill. But more importantly, for my thesis, I look at these literary types and structures to understand how the writing helps the writers themselves, as mentioned above, to gain back some lost sense of self caused by the illness they suffered or are suffering through. In the next three sections of this chapter I will explain the phenomenological and sociological frames used to view these illness narratives.

1.2 The Phenomenological Frame

In the preface of *The Phenomenology of Perception*, Merleau-Ponty defines phenomenology as “the study of essences” and that it “is also a philosophy which puts essences back into existence” (vii). Phenomenology is concerned with the nature of our perception of phenomena or essences of the world. Merleau-Ponty, following other phenomenologists and existentialists including Husserl, Heidegger, Sartre, is particularly useful for this discussion of illness because his focus is on the physical body. Used as a phenomenological tool, his theories help provide an understanding of our perception of our bodies in the world, important for thinking about physical illness and how its disruption is perceived by the self. For Merleau-Ponty, the human body itself is the way we understand our existence and relate to the physical world. In *Phenomenology of Perception* he writes:

Our own body is in the world as the heart is in the organism: it keeps the visible spectacle constantly alive; it breathes life into it and sustains it inwardly, and with it forms a system. When I walk around my flat, the various aspects in which it presents itself to me could not possibly appear as views of one and the same thing if I did not know that each of them represents the flat seen from one spot or another and if I were unaware of my own movements, and of my body as retaining its identity through the stages of those movements. I can of course take a mental bird’s eye view of the flat, visualize it or draw a plan of it on paper, but in that case too I could

not grasp the unity of the object without the mediation of bodily experience... (203).

His ideas indicate an appreciation of and the integrity of bodily experience because we are more than just objects in the world because we actively inhabit the world. We know the world through our movements within it: "The thing and the world, are given to me along with the parts of my body, not by any 'natural geometry,' but in a living connection comparable, or rather identical, with that existing between the parts of my body itself" (205).

My connection with narratives written by those who are ill, or in the case of Oliver Sacks, severely injured, with the theories of Merleau-Ponty is this: The narrative becomes an essence in the world which enables the ill person to take that part of the self – the illness – and place it beyond the whole self where it can be objectively perceived by the writer. Also, if the illness itself disrupts the relationship described by Merleau-Ponty in the above passage, then writing about the illness and placing it out in the world gives the writer the ability to perceive the illness as a thing in the world. Through this process the ill person gains more integrity of the self because the fragmentation is being mediated by the order of the narrative. The illness becomes synthesized into something new (a narrative). This is not to say that the illness goes away or is changed somehow. It is the perception of the illness itself that changes. I believe that this process is important for the writer to attempt to retrieve a wholeness that has been lost to the illness.

In her book, *Narrative Medicine: Honoring the Stories of Illness*, Rita Charon, Professor of Clinical Medicine and Director of the program in Narrative Medicine at Columbia University, confronts this issue of the body and its relationship with the world when she writes:

The body defines the self from the inside, but the body does not define the self to the outside. There are two bodies; the one lived in and the one lived through. One body absorbs the world, and one body emits the self. Poised between the world and self, the body simultaneously undergoes the world while emanating to that world its self. Or again, the body is simultaneously a receiver with which the self collects all sensate and cognate information about what lies exterior to it and a projector with which the body declares the self who lives in it. The body is in the copulative position between the world and the self. (88-89)

The phenomenological significance of what Charon says in this passage is that if there is a give and take between the world and the self that uses the body as mediator, then an ill or injured body would break down this system. The self and its relationship to the world become disrupted. The illness narrative is a way for the self to put order back into this relationship of self, body and world. Narratives order life because they have a specific beginning, middle, and end.

1.3 Arthur Frank's *The Wounded Storyteller*: The Sociological Frame

In the quest to understand illness narratives and the meaning they invoke, and though I use Merleau-Ponty's theory of the body as a frame for explication of the narratives chosen for this dissertation, it is helpful to understand the medical sociologist, Arthur Frank's categorization of illness stories that he discusses in one of the seminal works in the study of illness narratives, *The Wounded Storyteller*. Frank notes that in published illness stories "injuries become the source of potency" (xii) and that they create "the social rhetoric of illness" (21). Published works are specifically important to Frank because published works can be quoted and have the ability to influence those who read them. However, he cautions that in one respect published works are also edited, though he acknowledges, speaking of his own writing experience, that he cannot remember what some of those compromises he made with his editors were. Thus, for Frank: "The truth of stories is not only what *was* experienced, but equally what *becomes* experience in the telling and its reception" (22). He points out that the illness narrative becomes the experience of that illness even though it is not the illness itself (22).

Society has expectations for how those who are ill should respond to illness. The psychiatrist and anthropologist, Arthur Kleinman, in his book, *The*

Illness Narratives: Suffering, Healing and the Human Condition, points out that illness is “culturally shaped” (5). He acknowledges the paradox in using the phrase “normal ways of being ill” but makes the point that society has expectations as to what is “appropriate” (5) with regard to certain social situations. I believe that illness narratives are a conduit for the ill person to culturally represent herself in what are deemed appropriate ways by the community. Illness narratives may be a way to reintegrate the self, to come back to some sense of wholeness that the individual had before she became ill. I will specifically discuss this idea later in the paper using the works chosen mentioned earlier. Illness, disability, disfigurement and impotency are all examples of how the ill person loses confidence based on what society expects of him or her. All contribute to the fragmentation and disruption to self caused by illness.

Gay Becker discusses the cultural and societal repercussions of illness in *Disrupted Lives: How People Create Meaning in a Chaotic World*. She writes:

When I began to examine the notion of order in the different studies of disruption I conducted, I found that the nature of the disruption dictates the cultural images of order that are invoked. Infertility, for example, brings women and men face to face with a cultural assumption: that biological reproduction is an automatically occurring event, one that is part of the natural order of life. . . Failure to fulfill this cultural expectation is disruptive to women’s and men’s lives and to their sense of their place in U.S. society. (62)

Though Becker is not talking about the types of illness I discuss with the four works later, an analogy can be made between cultural expectations of those who are infertile and those who cannot lead a productive life (as defined by society) because of illness or injury. The failure to meet cultural expectations can certainly lead to a disrupted sense of self.

In his introduction to his book, *Recovering Bodies: Illness, Disability, and Life Writing*, G. Thomas Couser observes that illness writing is a way of “treating the body’s form and function (apart from race and gender) as fundamental constituents of identity” (12). He notes that illness writing of any form puts the human body at the “intersection of culture” because today we see this writing as a “concretely situated personal appropriation of a public instrument” (12). He believes we can learn much from illness narratives because they “[acknowledge and explore] embodiment of the self” (13).

The professional writers who produced the works discussed in this dissertation are struggling to find their place – their role – that they had before illness robbed them of parts of themselves. They are all professionally recognized individuals, not used to being in marginalized situations. Analyzing professionally written illness narratives has some resemblance to the analysis of anonymous individuals telling their illness anecdotes to doctors and researchers, such as the examples in Frank’s *Wounded Storyteller*, and in works that use illness narratives such as Gay Becker’s *Disrupted Lives*. However, as I will discuss later in the chapters set aside for each book, the very structures of the written narrative, as

well as the creative abilities of a professional writer help write these illness stories in a way that may move the reader more effectively.

Frank's categories of narratives – chaotic, restitution, and quest narratives – can be very helpful in analyzing these published works. Like “regular” patients who tell their personal stories, these writers are fulfilling a need within themselves to recapture parts of the self that have been robbed by illness and transmit to the reading public narratives that serve to pull together the pieces of self that have been scattered during the chaos of being ill.

Believing that stories help “repair” the body's sense of self that illness disrupts, Frank builds a framework of specific types of illness narratives. First, he considers plot, and second, how the narrative type relates to the issues of embodiment, such as how the body relates to the self, to others, and the kind of control and desires the body has. Third, he considers how narrative works in terms of the self-story. Lastly, he considers what power and limitations each narrative type has. These types include the restitution narrative, the chaos narrative and the quest narrative.

It should be noted that the narratives discussed in this dissertation do not all fit neatly into any one of Frank's categories; rather, they exhibit many characteristics of his types of narratives. However, these categories can be used to help illuminate how these stories help the writers come to terms with the fragmentation of the self that illness has caused. A sense of selfhood comes from feeling whole with regard to how one sees oneself and how one perceives others

see her. Nancy Mairs, who has M.S. and who has written several books on what it is like to be a person with a disability, writes in *Waist High in the World* about losing confidence in herself and feeling inauthentic:

I often perceive myself to be living less authentically than other people.

Whether I'd feel this way if I were congenitally disabled, or if my condition were not degenerative, I'm not sure; my perceptions may be shaped by a sense of contrast with the twenty-nine years I lived before diagnosis and by the bleak knowledge that, no matter how bad my symptoms are today, they will be worse tomorrow. How can I believe that my life is real when it feels so desperately provisional? I don't consider the lives of other people with disabilities to be similarly inauthentic. Only my own seems flimsy and counterfeit. (9)

As Nancy Mairs' comments show, illness takes away that wholeness and confidence, and often replaces it with a sense of helplessness that ensues when navigating the endless journey of medical issues, family relationships, loss of income, and other myriad problems that occur when one is seriously ill. The way others respond to the ill person is also what helps whittle away the ill person's confidence because she feels marginalized.

The Restitution Narrative

Arthur Frank writes that at any given time in an ill person's life all three types are told:

At one moment in an illness, one type may guide the story; as the illness progresses, the story becomes told through other narratives. The particularity of any experiential moment can thus be described by the narrative type that predominates at that moment. The three narratives are like patterns in a kaleidoscope: for a moment the different colors are given one specific form, then the tube shifts and another form emerges. (76)

However, it is the restitution narrative that people prefer to tell (77). There are particular expectations as to what people want to hear and the restitution narrative is the most common (77-80). I believe that the notion of an individual feeling acceptable to society is rendered, in particular, through his restitution narrative because the restitution narrative is characterized by an optimistic perspective with regard to illness and people, especially Americans, who prefer stories that have happy endings. Another reason the optimistic restitution narrative is the type of story that society likes to hear is that the restitution narrative is mainly about health and not about illness, per se. The basic plot of the restitution

The Necessary Angel: Essays on Reality and the Imagination. London: Faber and Faber, 1951. Cited in the text as *NANarrative* is that yesterday there was a healthy body; today there is a sick body, but tomorrow there will be a healthy body again. The body has an “unlucky breakdown” (Frank 88) and requires “fixing” much like a mechanical device: “The mechanistic view normalizes the illness: televisions break and require fixing and so do bodies” (Frank 88).

Restitution means that there is an actual future – a future to which the healthy body will return. This anticipation of a healthy future is a response to an interruption of health. Frank contends, then, that the restitution narrative is a response to the interruption caused by illness but that the “narrative itself is beyond interruption” (89).¹ We see restitution narratives daily in the print media as well as broadcast media. They come in the form of advertising of cancer centers and pharmaceuticals for every form of physical ailment. Cancer centers picture smiling patients and staff who give glowing accounts of survivor stories. Brochures and other media picture former patients going about life as if there were never disruptions caused by illness. As Frank points out, what is portrayed in the restitutive media is that there is a remedy for sickness and all one has to do is take the medicine and she’ll be better. But as Robert Couser observes, this action is a paradox in that even though modern medicine has proved very effective in treating illness and promised a “quick-fix,” the public’s confidence in the medical

¹ The psychotherapist, Kathlyn Conway, calls these types of stories “triumph narratives” (18-19) She concurs with Frank in that she says the triumph narrative is the narrative most Americans prefer.

establishment has dwindled. This lack of confidence stems from two things, according to Couser: the quick-fix doesn't always work and when it does work it "alienates us from our bodies" (10). The ravaging effects of chemotherapy and the loss of control a patient has over what happens to his or her body while being treated for cancer certainly brings to mind an example of a restitutive procedure alienating ourselves from our bodies. The restitution narrative seems to be what the medical establishment prefers, however, as it continues to offer treatment of certain illnesses for which there is no hope. These treatments are an issue in the forefront of patient care discussions today with end of life care discussions and how far medicine should go in continuing to treat someone when there is little or no hope for survival. This is especially an issue when the treatment itself ravages the body as much as the illness.

The Chaos Narrative

Frank refers to the chaos narrative as an “anti-narrative” (98) and as having a “non-plot” (97). Because the chaos narrative does not have the restitution narrative’s order – having a beginning, middle, and end – it is the opposite of the restitution narrative. There is no sequence of time in a chaos narrative because the person telling it is actually living the chaos. There is also no ending. A good example of the lived chaos narrative is living with someone who is chronically ill and hearing the same “story” every day. A dominant characteristic of the chaos narrative is the lack of control. Frank uses Gilda Radner as an example of giving readers a glimpse of what it means to live in chaos because of illness.

Although acknowledging that Radner’s narrative isn’t chaos because it actually is a narrative, he seems to broaden his definition of chaos by saying it is a loss of control, even when someone, such as Radner, has the space for reflecting on her illness – something he says that doesn’t usually happen in his chaos category (100). Living in the midst of the chaos of illness does not allow for a final story, especially a triumphant story, to be told. At least sections of the illness narratives that will be discussed in subsequent chapters of this dissertation contain elements of the chaos narrative. Frank’s chaos “narrative” seems to be more about

the condition the ill person finds herself in than in her story itself since he argues paradoxically that those who tell their chaos stories are “wounded storytellers” but that “those who are truly *living* the chaos cannot tell in words” (98).

When one is immersed in the chaos, there is a sense that there is no way out. The body is not in control and is just pushed along. The bottom line is that listeners are often annoyed by the chaotic storyteller because the story never seems to end. Therefore, relationships – just when the chaotic narrator needs them – are not there. So the ill person telling her chaotic story every day often wears down the listener. Frank argues that it is important to actually listen to chaotic storytellers, something that is difficult to do because those listening have trouble facing illness and the possibility it could happen to them. It is a reality no one wants to face: “Hearing is also difficult because the chaos narrative is probably the most embodied form of story. If chaos stories are told on the edges of a wound, they are also told on the edges of speech. Ultimately, chaos is told in the silences that speech cannot penetrate or illuminate” (Frank 101).

Because of the disease and the social mistreatment caused by the disease, the body must be disassociated from the self in order for the self to survive: “The chaos narrative is lived when ‘it’ has hammered ‘me’ out of self-recognition (Frank 103). Elaine Scarry points out that another person’s pain is invisible to another because of the impossibility of sharing another’s pain. It is very real to the person feeling the pain, but, as she notes “it may seem as distant as the interstellar events referred to by scientists who speak to us mysteriously of not yet detectable

intergalactic screams” (3). Pain cannot be shared, Scarry says, because it resists language (4). She further states that “[p]hysical pain does not simply resist language but actively destroys it, bringing about an immediate reversion to a state anterior to language, to the sounds and cries a human being makes before language is learned” (4).

I believe that the written narrative can be the voice of pain or the author’s way of *writing* the pain. It is also a way of communicating that pain to someone else, which seems to be a necessity for those who are actually in pain. This gives them a voice. Being able to write the pain is a way of placing it out into the world where the writer can perceive it outside of herself. Being able to write the pain is a way of giving voice to that which is difficult or impossible to communicate.

Scarry reasons that our inner consciousness must have a referential point in the world outside the body, meaning that we do not just have feelings, but have, for example, feelings *for* something or somebody. However, she notes, “physical pain – unlike any other state of consciousness – has no referential content. It is not *of* or *for* anything. It is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language” (5). Scarry is talking about spoken language, about trying to tell a physician what kind of pain one is feeling or what intensity of pain one is feeling. I want to emphasize that illness writing may be a way for the person in pain, whatever the type, to accomplish this objectification of pain as an avenue for a kind of psychic healing – making whole what has been disrupted and fragmented.

With regard to an audience, a person reading an illness narrative cannot absolutely know what the pain is like or was like for the writer. We can never know exactly how another feels whether the pain is physical or emotional. We can know only up to a point because we are all human and have a shared human-ness. However, if a person has never had, say, the pain of cancer and the ensuing symptoms caused by chemotherapy, she will never truly be able to completely feel what the cancer patient feels, despite her empathy. But she can come close if the cancer patient writes an eloquent or powerful narrative that brings her closer to understanding the experience and bringing her into the realm of his illness.

Frank offers an empathic view arguing that modernity seeks to silence the chaos story because it wants to steer those who are ill toward the restitution model. He strongly advocates *honoring* the chaos story because as he says, life is actually sometimes horrible and chaotic and liberation from this chaos is not always possible (112). As he says: “The attendant denial of chaos only makes its horror worse” (112).

Without specifically placing particular illness narratives in any of these categories, one could draw a conclusion that some illness narratives are written, specifically, (one example being Jean-Dominique Bauby’s, *The Diving Bell and the Butterfly*), as a chaos narrative, to a certain extent. However, a work like Bauby’s does indeed reveal a reflection on his illness, something that Frank says the chaos narrative cannot do. Pain “denies reflection” according to Frank (114), a paradox even for him, unless we can take into account that some illness narratives

are part chaos and part restitution narrative, which, of course, they are. Bauby's work, like Sacks', Manguso's and Broyard's do not comfortably fit into Frank's notion that the chaos story cannot be told. Though part chaos, these works do, indeed, reflect and tell the story, naming and marking the chaos as the writers lived it in the present as well as in the past.

The Quest Narrative

Frank defines the quest narrative as journey narrative and says that most illness narratives are quest stories. While acknowledging that the journey pattern may be faddish, he nonetheless acknowledges that Joseph Campbell's well-known archetypal pattern of the hero's journey can be used to understand these types of illness narratives. There are three stages in the hero's journey: the call to action, the initiation and the return. Frank believes that Campbell's motif deserves to be recognized because the hero cannot get through all three phases of the journey without perseverance and the hero's journey motif, above all, represents perseverance. No one can doubt that perseverance is necessary for fighting an illness, and the meaning of the hero's journey lies in the initiation: the trials, the suffering, and the agony the hero must endure. In the return phase the hero brings back knowledge to share with those he left behind. In illness journeys, the ill person comes back from illness, and for Frank, she then becomes a witness. He calls this witnessing both a "responsibility" and a "problem" for the ill person (119). The problem is contained in the agony of the initiation phase. The initiation is the pain, suffering, and challenges the hero goes through. The initiation is never seen by anyone else – or is "lost to view" as Campbell says.

Frank uses the hero's journey motif to argue that the significance of the quest narrative with regard to illness lies in the witnessing of the experience in initiation. With illness, the "initiation" is the illness, the suffering, and the treatment. The quest narrative assumes the protagonist will return and will then offer testimony to what otherwise would be left unspoken. The telling of the story – the witnessing – of the ill experience helps bring order to the ill person's experience as well as providing a kind of guidance for others who are not ill, and helping those who are caregivers come to an understanding of what the experience of illness is like (140). In addition, the body itself becomes the witness. Finding this voice, then, is one way of authenticating the ill person because the ill person is heard – is relevant.

What Frank is arguing for with witnessing is a social ethic that takes into account the presence of the "embodied teller" (144) in the text. His ethic requires a "communion" with the sufferer through her story and he names what the ill can teach the rest of society through the "pedagogy of suffering" (144). Perhaps, then, part of the significance of the illness narratives discussed in this dissertation lies in their testimonies, in the voice of the ill person that speaks for all those who are ill, who might be marginalized, and who allow the rest of us to enter into that other world where the ill reside.

Frank's narrative categories help in explicating how these writers use their narratives to gain back some sense of self lost to illness. The integrity of the self

must be maintained in order for an individual to feel whole in the world. The sense of self, however, is not constructed in a vacuum. Cultural and social patterns and expectations help a person construct a sense of whom she is, and when a person becomes ill, cultural expectations become even more glaring because the person may be seen not to be a full participant in the culture or society.

Individualistic tendencies which characterize American culture play themselves out in illness by stressing individual responsibility for illness. We tend to believe that a person should take full responsibility for her illness, that somehow the ill person has done something “wrong” that has caused the sickness. One doesn’t have to look far to see how this blame sometimes shapes attitudes about being ill: AIDS, cancer, heart disease, stroke are illnesses that are often blamed on poor lifestyle choices. That responsibility also is reflected in how the patient is treated by the medical establishment. The “cure” also depends on how much individual responsibility a person is willing to take.

CHAPTER TWO

Introduction

We tell ourselves stories in order to make sense of life. Narrative is reassuring. There are days when life is so absurd, it's crippling – nothing makes sense, but stories bring order to the absurdity. Relief is provided by the narrative's beginning, middle and end.

*--Norman Mailer
from The Spooky Art*

Like the adventure narrative, the illness narrative can take the reader on a grueling journey of physical, mental and emotional anguish, and sometimes even exhilaration. The narrative can be told from the confines of a bed or from a single room; often the narrative depicts a very long period of struggle, and sometimes it runs a course of only a few years, or months and even days. The motivation for this interest in what it means to suffer physically seems simple enough to rationalize: our tentative existence in the physical world is only as meaningful as our bodies will allow. Being chronically or terminally ill, disfigured or disabled brings a particular clarity to the meaning of existence because, as much as we would like to escape it, we are bound, both inwardly and outwardly, by our bodies. As Arthur Frank notes in *The Wounded Storyteller*: “The head is tied to the body through pathways that science is only beginning to comprehend, but the general

principle is clear: the mind does not rest above the body but is diffused through it” (2).

Since the 1980s many illness narratives and studies about illness narratives have been published. This material continues to be an area that garners much interest from those in the medical, literary, and general humanities fields. Susan Sontag’s, *Illness as Metaphor* (1978), Arthur Kleinman’s, *The Illness Narratives: Suffering, Healing & The Human Condition* (1988), Arthur W. Frank’s *The Wounded Storyteller* (1995), and Howard Brody’s *Stories of Sickness* (2003) are four seminal works that identify and explicate the role of illness narratives in understanding this human condition by delving into a subject that many find unpalatable. Referring to narrative as a “magnet and a bridge” (11), Rita Charon, Professor of Clinical Medicine and Director of the program in Narrative Medicine at Columbia University, is a pioneer in using narrative in the field of medicine. The psychotherapist, Kathryn Conway, writes about the limits of language in expressing catastrophic illness and pain in her 2007 book, *Illness and the Limits of Expression*. Richard Zaner, the medical ethicist, in *Conversations on the Edge: Narratives of Ethics and Illness*, takes the reader to the bedsides of the ill and dying.

During the past thirty years many creative non-fiction narratives have been written by professional writers and poets that bring the reader into the world of the terminally or chronically ill or injured. These include works by Oliver Sacks, Andre Dubus, Reynolds Price, and Anatole Broyard. Others are works by G.

Thomas Couser, Robert Murphy, Jean Dominique-Bauby and the poet, Sarah Manguso. This is certainly not an exhaustive list of authors and does not include the related genre of disability writing.

There is a very specific role that illness narratives play for the writer. People who are terminally or chronically ill or who are severely injured must somehow come to terms with the catastrophic situations in which they find themselves. Specifically, there is a need to pull together the fragmented sense of self that illness causes. Other issues, such as the effect of cultural constructions of illness, are part of the disruption and fragmentation with which the ill person must cope. By producing an illness narrative, the writer may be able to transcend the confines of the ill and fractured body into a cohesive construction of the self.

The disruption caused by illness includes how cultural expectations and the use of language structures cause the ill person to see himself. It is worth noting, then, some of these cultural constructs. There is a place where the sociological and the philosophical meet and though the social perspective is not the only focus of this dissertation, it can help explain some of the disruption that the ill person must endure.

In her introduction to *The Body in Medical Culture*, Elizabeth Klaver, while discussing the way medical culture “constructs” the body, explores the material/cultural binary and questions whether the material (what she calls “fleshy stuff”) is deleted in favor of the cultural construction of the body (6-7). Klaver is concerned with how the ill person see herself as an artifact of culture – constructed

by culture – and to what extent this construction renders the narrative. People who are chronically ill or injured may lose confidence in the way society sees them. They may feel as if they are viewed as something less because of the weakness and dependency that may follow an ill person.

The fragmentation and disruption of illness causes the self to be lost and telling the story is a way of getting back this lost sense of self. Though this act of telling stories may be a necessary act for people who are ill and who may be dying as they recount their personal stories to physicians, ethicists, family members or to anyone who will listen, it is the skilled writer, who has undergone the ravages of illness and its treatments, who brings the story to an audience in a way that ordinary people cannot. The skilled writer manipulates language sometimes lyrically, sometimes with vivid imagery, and often writes in a way that puts the reader in the skin of the writer. Through this kind of illness writing, we as audience may experience empathy and pathos. The writer herself may experience a type of catharsis and possibly transcendence, though she may not outwardly note her experience as cathartic. This extraordinary experience of being both the writer and the individual experiencing catastrophic illness first hand gives the writer of illness narratives a means of communicating through his or her creativity that which is difficult and sometimes impossible to communicate by any other means. I will discuss in later chapters how, specifically, these writers accomplish this task.

People love to tell stories in general and people love and most likely need to tell their sickness and treatment stories to their friends and loved ones. I do not

want to discount the need we have as human beings to talk about our ill selves because sometimes that's all we have and certainly being ill is a lonely existence. Though anecdotes from those who are ill as told to physicians and other health care professionals have a very important role in the area of illness writing, professional writers whose works in creative non-fiction illuminate and inspire all kinds of readers. They bring to light experiences of illness that continue to raise questions about the notion of perception and how we navigate the world with our bodies, and the meaning and function of illness narratives for people with illness. As Tobias Wolff notes about the personal essay, specifically those of Andre Dubus, illness writing has the potential to catch the writer "in the act of being human" (xiii). Certainly, illness brings everyone (writer and reader) back to the essence of being human because of our reliance on our bodies in how we navigate and make sense of the world. We cannot separate ourselves from our bodies, so when the body goes awry with illness or injury, the self becomes disjointed.

For those who are not affected by illness, the need to know goes beyond the mere prurient. Indeed, it might be said that most of us – those who do not work day to day with the ill among us -- shun the thought of illness, much less put ourselves in places where the ill reside. G. Robert Couser notes:

Bodily dysfunction is perhaps the most common threat to the appealing belief that one controls one's destiny. Perhaps, then, narratives of illness and

disability serve to expose and dramatize what we would prefer to ignore most of the time, to arouse and (ideally) assuage our anxiety about our somatic selves. (9)

But finding some empathy with the ill can bring those of us in the realm of the healthy a better understanding the “kingdom of the ill” as Sontag called it. Knowing how illness impacts our bodies can bring us a better understanding of ourselves. It is possible that this empathy may also make us better able to treat with respect, dignity, and understanding those whom we often shun or for whom we feel indifference.

The phenomenological perspective lends itself to this ethos: seeing the body – the self – as in the world and not just an entity on the outside looking in allows a reciprocal appreciation for all that is other. The creative writer can accomplish this task of inducing empathy in an audience in memorable ways. The way these writers use language and its constructions is discussed in subsequent chapters, each devoted to one writer.

Mark Johnson, linguistics scholar from the University of Oregon, has argued that it is within the narrative form that we make sense of our lives. The unity of the self, he contends, is a “narrative unity”:

When it comes to explaining how it is that humans experience their world in ways that they can make sense of, there must be a central place for the notion of “narrative unity.” Not only are we born into complex communal narratives, we also experience, understand, and order our lives as stories we are living out. Whatever human

rationality consists in, it is certainly tied up with narrative structure and the quest for narrative unity. (172)

To find meaning in the seemingly random events of life, especially an event such as an illness or disability is the work of storytellers, according to other observers and writers, as well, such as Howard Brody, author of one of the seminal works in the study of illness narratives, *Stories of Sickness*. The narrative self is more distilled when one is ill because illness and pain cause the person to focus on the body, to be almost constantly aware of the body because the body in its pain is drawing so much attention to itself. Since the body is at the forefront of one's experience when illness and pain take over, it seems natural that one might question the world in a way she did not before.

When one is ill or injured there is a disruption in how the self is perceived because the body is the center of experience. One uses the senses to perceive the world. When that experience is ruptured by illness or injury, the perception of the world, as well as the sense of self, morphs into another type of experience of the world. The act of writing one's illness is an attempt to somehow find meaning in the damaged body. One *has* a body and one *is* a body, and one truly *cannot escape* one's body. Narrating the disruption of illness is a means of trying to not only come to an understanding of the illness for the writer, but for those around him or her who are not incapacitated. No one can truly understand what it is like to be another person, and the seriously or terminally ill as well as the injured pose an even greater challenge to all others who may have good empathetic intentions but

who cannot possibly have a true understanding of what a limited and disruptive life is like because of illness or injury.

The celebrated historian, Tony Judt, who died in 2010 of complications from ALS, discusses this sense of confinement and lack of understanding of others in his essay, "Night." He compares himself to Kafka's Gregor Samsa, the character in "The Metamorphosis" who awakens one morning only to find himself turned into an insect. Judt writes:

The point of the story is as much the responses and incomprehension of his [Gregor's] family as it is the account of his own sensations, and it is hard to resist the thought that even the best-meaning and most generously thoughtful friend or relative cannot hope to understand the sense of isolation and imprisonment that this disease imposes upon its victims.

He notes that "[h]elplessness is humiliating even in a passing crisis" and then asks his readers to remember a time when they were temporarily at the mercy of a friend or helpless bystander after a fall or some form of temporary incapacity. Judt is struggling with an issue of acceptance from the other. The lack of empathy from those around the ill person contributes to his sense of being invisible, much like Ellison's invisible man. To be authentic is to be a full productive person from the perspective of others in a particular culture or society. In the eyes of society, illness renders an individual with an incomplete self-hood, incapable of contributing to the good of society. It is a type of marginalization that is often

overlooked but can be just as isolating. This is particularly true in the west, especially in American culture.

Speaking generally, American culture glorifies the rise of the individual above adversity. It reveres the notion of not giving up, of always finding a rational explanation and therefore a cause and cure for whatever is holding back the individual, group, or society in general. Americans believe that an answer can be found if one is looking hard enough. So to be authentic in society is defined by those gazed upon as well as those doing the gazing. This feeling of losing authenticity is echoed in the narratives that will be discussed. It can also be seen in the writing of many others who write about illness as well as disability, specifically Nancy Mairs and Robert Murphy and many others.

Pain as Language

Elaine Scarry's analysis of how pain "makes" and "unmakes" the world can also shed light on why a person writes illness narratives and how the narrative helps alleviate the breaking apart of the ill person's world that comes from chronic illness or injury. She argues that outside the boundaries of the body pain is not "of" or "for" anything (161). It is alone:

This objectlessness, the complete absence of referential content, almost prevents it from being rendered in language: objectless, it cannot easily be objectified in any form, material or verbal. But it is also its objectlessness that may give rise to imagining by first occasioning the process that eventually brings forth the dense sea of artifacts and symbols that we make and move about in. (16)

To understand what Scarry is saying about pain one has to think about the pain just existing in the body. One doesn't say my pain is for something or that it is of something. Writing about illness and pain puts the pain in the world as a separate entity from the self so that it can be objectively viewed by the self. Scarry notes that this is not easy. In order to live with acute pain, especially chronic pain, a person must see the pain as outside the body in order to maintain the integrity of the self. Otherwise, one would experience chaos, as reflected in the chaos narratives described by Frank. Certainly not everyone in pain can do this. This is

the reason that illness narratives can be so effective for the writer and possibly for the reader.²

This notion plays itself out in the illness narratives that will be discussed in this dissertation as well in my own personal experience of taking care of someone these past ten years who is in chronic pain. In their article, “The Experience of Agonizing Pain and Signals of Disembodiment,” published in *The Journal of Psychosomatic Research*, Janice Morse and Carl Mitcham note that the language an ill person uses reflects the sense of disassociation that they feel as a way of protecting themselves from excruciating pain (667). An ill person’s language used to refer to an injury or to a body part can change from using, for example, an article (the) to a possessive personal pronoun (my), as in “my pain” or “the pain” (669-671). Using the article (the) puts the pain in the world as an object that can perhaps be dealt with – an object over which the person has some control. Robert Murphy discusses this kind of language use in *The Body Silent*. Murphy, a quadriplegic, writes:

I have also become rather emotionally detached from my body, often referring to one of my limbs as *the* leg or *the* arm. People who help me on a regular basis have also fallen into this pattern (I’ll hold the arms and you grab the legs”), as if this depersonalization would compensate for what otherwise would be an intolerable violation of my personal space. The paralytic becomes accustomed

² I briefly discuss the reader/audience of illness narratives in the conclusion of this paper.

to being lifted, rolled, pushed, and twisted, and he survives this treatment by putting emotional distance between himself and his body. (100-101)

Perhaps for some audiences it is difficult to understand why a person has a need to objectify horrendous pain, unless the audience has been in pain or who has spent a significant amount of time living with the pain of someone else. Those who are suffering are trying to make sense of pain and illness as well as, in most instances, imminent death – or at least the possibility of death. Maybe for some who write illness narratives, there is a need to impart to an audience that they, (the ill), are in a world that some, though not all, may encounter someday. This idea is echoed in Susan Sontag's famous work, *Illness as Metaphor*:

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

It is part of the human condition to suffer physically and sometimes emotionally or mentally. Suffering is something we may not be able to escape, although some are luckier than others. But at some point in our lives, chances are we will suffer at some level. In order to come to understand how some navigate through the world of illness and suffering looking at illness narratives from a social as well as a phenomenological perspective can be enlightening.

For the writer, the creation of an illness narrative is a way of synthesizing the illness experience. Though not all of the four writers I have chosen to discuss in later chapters could be considered literary "artists," they are professional writers. By creating narrative these writers are attempting to keep the self's integrity, to find a way to bear the pain, whether they live through the illness or not.

The ill person's world seems to become distilled into acute observations of those things that may not have been noticed before. An example of this distillation point is the writing of Sarah Manguso, who will be discussed in a later chapter. She wrote that her illness caused her to pay attention, meaning that if death could happen at any moment, it is important not to let any detail pass by. When people become ill they question and respond to the world in a way that they did not before. The process of writing puts the self on paper in specific ways for each specific writer. The eminent scholar, Martha Nussbaum has written that literature can pursue important questions about what it means to be a human being and live a human life:

A view of life is *told*. The telling itself – the selection of genre, formal structures, sentences, vocabulary, of the whole manner of addressing the reader's sense of self – all of this expresses a sense of life and of value, a sense of what matters and what does not, of what learning and communicating are, of life's relations and connections. Life is never simply *presented* by a text; it is always *represented* as something. This 'as' can, and must be seen not only in the

paraphrasable content, but also in the style, which itself expresses choices and selections, and sets up, in the reader, certain activities and transactions rather than others. (5-6)

Certainly, those writers who write about their illnesses use their texts to represent what they have gone through. But in a more personal way, their writing of their texts puts the illness in the world where it can be viewed with some perspective. The effect on the reader can be enlightenment about what the ill must face, but it seems almost a necessity for the writer as he uses the narrative to bring back order to life.

Wallace Stevens wrote that “poetry is the violence from within that protects us from the violence without” (77). Certainly, even creative writers of non-fiction write with a poetic sensibility. The writers discussed in this project have enough “violence without” and seem to have come to terms or are attempting to come to terms (by reason of the fact that they write an illness story) with their illnesses or injury. Creating a piece of writing that is lasting, valuable and compelling is the hallmark of a true professional. Their created works are there for audiences in the present and in the future and contribute to the building of understanding what illness can do.

Language as a Bridge

Manguso, Sacks, Bauby and Broyard all use a particular style, voice, and literary construction to achieve the purpose of reconstructing the self during and after the ravaging effects of illness. Specifically, metaphor is the most powerful literary element used to convey these experiences that are so difficult to name. Metaphor can be used as a bridge to connect the previously well life with the now disrupted ill life (Becker 60). Metaphor also is a way to create particular cultural meanings. Becker notes that metaphor “can be seen as a ‘split reference,’ that is, it opens up new possibilities for referring to the literal and the conventional, as well as to a fundamentally new view of reality” (60). Metaphors are concrete language constructions that enable the ill person to fully undertake the job of telling the illness in order to make some sense of the enormous disruption to the person’s sense of self which includes the perception of life as a linear construction – with a beginning, middle and end – the Western metaphor for the life process.

In his preface of “The Nigger of the Narcissus,” Joseph Conrad writing about the role of the artist/writer offers the following:

The artist appeals to that part of our being which is not dependent on wisdom; to that in us which is a gift and not an acquisition – and, therefore, more permanently enduring. He speaks to our capacity for delight and wonder, to the sense of mystery surrounding our lives; to our sense of pity,

and beauty, and pain; to the latent feeling of fellowship with all creation – and to the subtle but invincible, conviction of solidarity that knits together the loneliness of innumerable hearts; to the solidarity in dreams, in joy, in sorrow, in aspirations, in illusions, in hope, in fear, which binds men to each other, which binds together all humanity – the dead to the living and the living to the unborn.

These illness narratives bring the reader into the realm of the ill so that the reader can participate in the synthesis that must occur if the ill person is to reshape his or her life's journey – Conrad's "solidarity that knits together the loneliness of innumerable hearts." The reader becomes very important in the imagination of the storyteller, a very necessary part of the healing process – the healing of the disruption (if only temporarily, since not all illness writers heal) while the writer imagines her audience while writing the story. By writing a work that is published later, the illness writer achieves a limitless voice – a voice that echoes through space and time as long as there is a reading audience. This seems to be a way of cheating the limits that illness and death impose on the individual self, helping the self achieve a level of wholeness again by giving order to the disruption and piecing together the fragmentation.

Howard Brody, in his *Stories of Sickness*, offers this about the role of storytelling and illness: "Suffering is produced and alleviated by the meaning that one attaches to one's experience. The primary human mechanism for attaching

meaning to particular experiences is to tell stories about them” (13). Certainly, the stories told by the writers discussed in this dissertation helped each of them find some meaning in their experiences as recounted in their illness stories. These witnesses reinforce the impact of and the very basic human need to tell stories.

CHAPTER THREE

Sarah Manguso

The Two Kinds of Decay

“Those who claim to write about something larger and more significant than the self sometimes fail to comprehend the dimensions of a self.”

--Sarah Manguso

Sarah Manguso was a young MFA student when she was diagnosed with a rare form of Guillain-Barré syndrome called CIDP, an autoimmune disease in which antibodies attack the peripheral nerves' myelin, their protective protein sheath. Manguso was told the disease could go into remission or progress and result in death. Treatment included replacing her blood plasma which worked temporarily but sometimes the relief lasted only a few days. Later she used steroid treatments and wore a Medic Alert bracelet with the message: “Takes prednisone for chronic idiopathic demyelinating polyradiculoneuropathy” (Manguso 19). Manguso spent most of her twenties being treated for the disease as well as battling alcoholism. By the time she was thirty, she felt she was just beginning her adult life.

In 2008 Manguso published her illness memoir, *The Two Kinds of Decay* in which she gives a non-linear chronicle of her illness. Written in a sometimes stark, poetic form, the narrative uses language to name Manguso's horrifying

experiences into a manageable form. The language and structure of the memoir, with its one or two page chapters, short paragraphs, clipped sentences and sentence fragments mimic the confusion and disruption of the illness itself. Although it is not a simple matter of putting a narrative like Manguso's in a particular category, her narrative fits some of the criteria of Frank's chaos narrative. Frank makes the point that the chaos of illness is actually "told in the silences" since language is so limited in communicating pain. This being said, Manguso's memoir mirrors this definition of chaos, especially with the fragmented form she uses. However, another aspect that lends power to Manguso's narrative is her use of metaphor to name the unnamable – the unnamable being what she had become during her illness and how she navigated through the pain, humiliation and despair. I will discuss this more specifically later in the chapter.

In addition to her illness memoir, Manguso has published two books of poetry, a short story collection, and is working on a novel about memory and time entitled *The Guardians* due for publication in 2012. She was educated at Harvard and the Iowa Writers' Workshop and has been a faculty member of the BFA writing program at the Pratt Institute and of the MFA writing programs at Columbia, Fairfield Universities and the New School.

Manguso asserts she had a very simple purpose for writing about her illness based on the new knowledge her illness journey brought her: she says she simply

wrote down what she remembered and that her message to readers is to “pay attention” to daily life. However, Manguso’s work is much more than that. She is an artist who synthesized her harrowing experience of coping with a debilitating disease with the prospect of death into a piece of literary art that provided her a way of keeping the complete disruption and fragmentation brought on by the experience from obliterating her whole self. In an interview with Jessica Ferri for the website, *Bookslut*, Manguso says that she doesn’t believe that suffering or pain produces better art, again stressing that everyone suffers and the only difference with her is that she wrote it down. She captures the fragmented memories of the pain and suffering she endured during those years and renames them in order to face the illness itself and to make some sense of her suffering and the loss of self that resulted from her excruciating experience. She does this very effectively because she is a poet.

She communicates this suffering lyrically and urgently to the reader. The reviewer Emily Mitchell notes that because Manguso was already a writer when she became ill she was obsessed “with words, their capacities and limitations.” Manguso notes in the book’s liner: “Ultimately, though [her story] is not so much a chronicle of triumph or tragedy as it is simply a story about learning to pay attention.” With her self-awareness, her technique of focusing on seemingly random experiences, she not only engages the casual reader, but does something very important for herself: she moves her memory of pain away from the internal chaos by giving it a voice through language. She objectifies the pain with her own

particular style of language – a fragmented, poetical and honest style. For example, in her chapter entitled, “Paralysis,” she talks about a wheelchair:

I was afraid of the chair. It would indicate I wasn't going to get better. And my doctors didn't want to believe that any more than I did.

Chair or no chair; a binary relation. Bad or good, sick or well, hopeless or hopeful.

This is how I described paralysis to my friends: *Sit down right next to me on a bench or sofa, me on the left, our four thighs in a row. Lift your right thigh and put it back down. Then the next thigh over, lift it and put it down. Then the next thigh after that.*

That feeling of trying to lift someone else's thigh with your own Mind is how it feels to be paralyzed. (50)

It is not easy to maintain language when one is in pain, but also when one is remembering pain. So it is a testament to her abilities as a writer and poet that she is able to do that (put her pain into language) and offer it to an audience.

However, putting pain into some kind of language is a difficult and sometimes impossible task. Manguso is successful in doing this which is why her illness story is so compelling. Elaine Scarry's analysis about how pain can sometimes eradicate language shows just how difficult it is to do what Manguso and other writers have done. Scarry offers a compelling argument about how pain eradicates language comparing that state with how human beings voice pain before language is actually learned. The cries, groans, and screams of pain come when structured language cannot name it (4). She notes that pain has a particular character that is different than other human feelings. We do not just "have feelings" but have "feelings *for* something." The "something" is out in the external world and shows the human capacity to "move out beyond the boundaries of his or her own body into the external, sharable world" (4-5). However, Scarry argues, this process comes to a halt when we come to the point of pain:

[P]hysical pain – unlike any other state of consciousness – has no referential content. It is not *of* or *for* anything. It is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language. [W]hen physical pain is transformed into an objectified state, it (or at least some of its aversiveness) is eliminated (5-6).

Scarry contends that putting pain into language is our way of "forcing *pain itself* into avenues of objectification. A key word from Scarry's work is "shareable." When the pain is no longer just internalized but is externalized, it is

shared by whoever is there to listen. Manguso's illness and her pain, social deprivation and frustration become an object she wraps herself around in order to understand it. Her writing is a means of allowing her readers to hear her physical pain. Why does she find it necessary to share her pain? It is part of human nature to need understanding and empathy from others. But more importantly, by her writing the pain, making it the object outside herself, making pain Other, allows her the ability to be less afraid of it, especially as she wonders if the illness will someday return. By writing her pain, she paradoxically detaches that part of the self, yet then is able to maintain some integrity of the self.

Pain makes the body seem surreal, detached from the self and therefore defies language. It is the palpable thing that never leaves. Pain is the body screaming for attention, for some kind of release. Pain is an ever-present entity that colors everything in the life of the body that is experiencing it. Pain cannot be set aside and ignored. We stand in front of a mirror as Sartre wrote, and we see the body in the mirror but it is not the body perceived by the embodied consciousness permeated by physical pain. Embodied consciousness is taken over by physical pain. Consciousness of the world outside of the body is altered because pain alters everything. Writers write of the pain as a way of placing themselves concretely in the world. Pain disembodies the consciousness from the body. Manguso remembers the pain and writes down what she remembers. She forces herself to face the Other, objectifying the pain that dominated her life for nine years.

Having severe pain, as Manguso had, in addition to the treatments and the fear of death certainly placed her in a peculiar place with regard to how she sees her body in the world. There is more of a consciousness of the physical aspect of the body. For example, we don't really ever think about breathing. It comes automatically, unless we are congested, or have some shortness of breath. But when we start thinking about breathing, the act of breathing becomes a manual activity and we pay attention to this automatic activity. In this way pain makes us more conscious of the body even as the self feels somewhat disembodied.

In their study of the language used by burn patients suffering severe pain, Janice Morse and Carl Mitcham, in their article, "The Experience of Agonizing Pain and Signals of Disembodiment," published in the *Journal of Psychosomatic Research*, conclude that patients in severe pain use the language of disembodiment as a way of maintaining the integrity of the self. Though body image doesn't change, they argue, patients exhibit a "distinct physical distancing" from their own bodies, using impersonal pronouns and articles when referring to their body parts. This depersonalized language includes using *it, the, and this* as in "the leg" instead of "my leg" or "this foot" instead of "my foot" (668):

When analyzing transcribed interviews with burn patients, [the authors] noted that, in describing their experiences, the patients regularly refer to parts of themselves as objects . . . Yet when these individuals describe the rehabilitation period, they resume using possessive pronouns to refer to the same parts of their bodies. This depersonalized language includes the use of

the definite article to refer to self (i.e. *the*) and also it, this and that. To further examine the uniqueness and function of such linguistic signals, indicating an experience of disembodiment of the self, and the subsequent linguistic reversion, indicating the self's re-embodiment, these interviews can be compared with descriptions of pain experienced by persons whose illnesses or injuries differ from burn injuries in important dimensions (668).

Patients using language that distances themselves from their own bodies must feel that the trauma of the injury to be so overwhelming as not to be a part of themselves. Maintaining a whole self, rather than a broken one may be a means of surviving extremely traumatic pain.

Manguso does just this with her use of language as if her body is separate from the self. She is very conscious of the body, its physical functions as well as its pain. She often writes as if her body is separate from the self:

I didn't start writing this until my body made another decision. The day before the decision I wrote. I resisted as long as I could. A narrator must keep a safe distance from the story, but a lyric speaker must occupy the lyric moment as it's happening. Or so it seemed at the moment . . . I think my body's decision shone a light on the memory that once my body steered me. Or that it steers me (166).

This is not to say that Manguso is aware she is doing this. I do not believe that illness writers are consciously aware of why they write illness narratives. As creative people they are writing because they have a compelling need to create. However, the notion of thinking about pain as an object is not a new one. Writing about the body and consciousness, Sartre discusses the act of being aware of pain as an object:

But now suppose that I suddenly cease to read and am at present absorbed in *apprehending* my pain. This means that I direct a reflective consciousness on my present consciousness-as-vision. Thus the actual *texture* of my consciousness reflected-on – in particular my pain – is apprehended and *posited* by my reflective consciousness. We must recall here what we said concerning reflection: it is a total grasp without a point of view; it is a knowledge which overflows itself and which tends to be objectivized, to project the known at a distance so as to be able to contemplate it and to think it (440).

Sartre notes that during reflection of the body and of pain, it moves from being conscious of pain to actually objectivizing pain. Manguso must objectify the pain because the pain causes a schism between her perception of her body and her sense of a whole self. She cannot function through the illness without this disembodiment because pain is the enemy— the entity that causes such abnormality in the way a person must live. There is no other way to cope with it

unless it becomes something outside herself. Sarte refers to the “animism of illness” and a “living thing which has its form, its own duration, its habit” (442).

However, though Sartre and others have personified illness, pain itself still resists language, and certainly Manguso struggles but succeeds in putting her pain into language. But as a poet, Manguso can present her illness to the reader in such a way that we feel the disruption, the chaos and even the anger she must have felt as a young person just starting out her adult life and being knocked down by an illness no one knew how to control.

Like any truly good narrative, readers get close to what the writer feels. Her narrative elicits more empathy because of the literary skills she uses to describe her experience. Manguso sometimes uses a wry sense of humor which is sometimes ironic given that she was almost completely paralyzed and feared she would die soon. For example in a chapter entitled, “Cavities,” in which she talks about her shocking weight loss as well as her fear of getting cavities, the irony and subtle humor are evident:

People brought me rich foods to eat, but there was no point. Extra food would turn to fat in me . . . And the fatter I got, the harder it was for my muscles to move my body.

Not all the nurses understood this. Particularly not the tubbier ones.

I did care about my teeth, though. Having my teeth drilled seemed an avoidable inconvenience.

And so at night, after my teeth had been brushed, when I was offered a cup of soda for my bedside table, I asked for diet instead of regular.

And sometimes I got the look. The look that says *Oh you goddamned malingering brat, starving yourself to get attention while in the next room there are people dying.*

Corticosteroids, which I took for a long time, eat away at the skeleton, and it's not uncommon for the teeth to rot a little. And that's not even taking into consideration that my teeth weren't being brushed very regularly or very well.

But it's been twelve years since my diagnosis, and I still don't have a single cavity. (54-55)

Manguso is able to stand aside and paint a picture of her experiences as effectively as someone screaming in pain gets the attention of others. She garners our attention by bringing us into her world through her poetic sensibilities:

The events that began in 1995 might keep happening to me as long as things can happen to me. Think of spacetime, through which heavenly bodies fly forever. They fly until they change into new forms, simpler forms, with ever fewer qualities and increasingly beautiful names.

There are names for things in spacetime that are nothing, for things that are less than nothing. White dwarfs, red giants, black holes, singularities.

But even then, in their less-than-nothing state, they keep happening. (4)

In this section from the beginning of her book, Manguso is lamenting the time she lost during her illness, particularly since she was so young at the onset of the disease. Because she was so weak, she shares that she took just a few notes here and there because she wasn't strong enough to write much down. She muses that maybe what had begun in 1995 – the beginning of her illness – continues to happen even though it is not visible; thus the metaphor of those things in space that are “less than nothing” yet “they keep happening.”

Manguso's book is not written in a typical autobiographical linear form. Sometimes chapters are not connected in time or place with previous chapters. She goes back and forth in time and her prose is sometimes fragmented and poetic in how it appears on the page and in the structure of her sentences and paragraphs. It mimics a person's memory and how during illness (and even sometimes when one

is not ill) one remembers scenes, bits of conversation, images of faces as well as a sense of time being skewed. Her chapters bounce back and forth in time much like her illness ebbs and flows. Some chapters are a page long, some a couple of pages. Her style reflects the fragmentation caused by the illness itself: short, clipped sentences, fragments and beginning sentences with conjunctions.

Since Manguso is a poet it is not surprising that her memoir resembles poetry. Memory comes in fragments that lend some credence to her assertion that she was simply writing down what she remembered. Paragraphs are sometimes only one sentence long and are not indented. Instead there is extra space between paragraphs, much like stanzas in some types of poetry. She uses at least one attribute of Frank's chaos narrative in that in addition to her fragmented style, she does not follow a specific sequence of time. The difference between a piece of literary art and a patient verbally telling her story to someone, though, can be compared in order to illuminate how the art is more effective in having an impact on the listener/reader. Frank notes that often listening to the patient recounting the details of her illness wears down the listener because of the unstructured nature of the communication. The narrative is characterized as chaotic. Chaos is there because of the pain, and pain is difficult to verbalize because illness causes a person to live a disarrayed life.

Chaos is the most embodied kind of narrative, according to Frank (101). The disruption caused by illness forces the person to question the abruptness, randomness, and unfairness of being singled out by disease or injury. Therefore, it

is very difficult to find the most effective way of communicating that which is so embodied to another. How does one make something so subjective and internal into something objective and external? Sometimes caregivers become weary of hearing the chaotic story. They no longer “hear” the pain of the other because they hear it so much. The chaotic storyteller talks about her pain as often as she can and a caregiver sometimes has no choice but to listen, but the more the chaos rages on the less the listener wants to hear. Manguso is telling her pain in her work, but she has found a way to express the pain using a language only a literary artist can. Because it is art and because it is engaging, the listener/reader gets very close to experiencing Manguso’s frustration, pain and terror – as close as anyone can get into the mind and heart of an artist through his or her work. As already noted, putting the pain into language puts it in an objective form.

Manguso's Metaphors

Specifically, how language is used determines how effective it is in communicating bodily pain in order to engage and therefore, share the pain externally. Manguso's use of metaphor is a result of the difficulty of putting this kind of experience into language. There is also the need to use metaphor to compress a large, sometimes inexplicable experience into something more concise that all or at least most who speak the same language can understand. She writes:

All autoimmune diseases invoke the metaphor of suicide. The body destroys itself from the inside.

I secreted poison into my blood. The poison was removed and replaced with other people's blood and with chemicals.

The new blood became mine as soon as it entered me. Or maybe it took a moment to mix with what was there. Or maybe it took an hour, or a day.

My blood came out dirty and went out clean. It came out hot and went in cold. It came out old and went in new.

And the new, cold, clean blood was better than the blood I made myself (14-15).

A central experience in Manguso's illness journey was blood replacement. Although it was a temporary "fix" it nonetheless evokes a powerful metaphor of having "cold" and "clean" blood put inside her body and dispelling her own "hot" and "dirty" blood. Her rejection of her diseased body is another way of objectifying illness. Though the physical part of ourselves is, indeed, part of the *Self*, the binary of clean/dirty and hot/cold indicates a sense of disembodiment that is not so abstract: part of her body is actually removed and replaced with someone else's body "part," in this case, blood. But blood is a powerful and concrete part of ourselves, as well as a figurative part of self. Manguso's blood transfusions were a traumatic experience, probably more traumatic than she lets on in her wry style. Trauma can and does lead, at least in some cases, to a sense of disassociation, a sense of distancing from the self.

At the very least, some boundary has been crossed especially when a person has to receive some physical body part or bodily substance from another person. The integrity of the self becomes muddled. For Manguso, the blood transfusions were traumatic becomes the boundaries of self became blurred. This

recognizes that bodily experience is very much a part of the individual sense of self.

To create her memoir, Manguso says she only wrote down what she remembered. However, as noted earlier, she admits she revisited her medical records and talked with her parents about the experience in order to use actual facts and situations she was unable to remember and had to reconstruct. However, there is no doubt that she uses her literary skills, in particular her skills as a poet to distill this experience as a way to bring back a sense of a whole self to herself as well as to exhort the reader to “pay attention.”

What Manguso may not recognize is that she had to, paradoxically, objectify her illness (which physically cannot be separated from the physical person) in order to maintain a wholeness of her self. Manguso does not philosophically consider these issues. She is intent on communicating her illness experience with a “lesson” of being aware. This lesson, one speculates, is learning of the arbitrariness of nature with regard to the roll of the dice for those who become ill and who remains healthy. At the end of the book, Manguso writes:

Most people consider their own suffering a widely applicable model,
and I am no exception.

This is suffering’s lesson: *pay attention*. The important part might
come in a form you do not recognize.

You might not know to love it.

But to pay attention is to love everything.

To see the future as *brightness*.

You can't learn from remembering. You can't learn from guessing.

You can learn only from moving forward at the rate you are moved,
as brightness, into brightness. (183-184)

She writes as if she is reporting the facts, but facts colored by the haze of memory, pain, and paralysis. But this matter of fact tone does not take away the impact of the literary skills she uses to bring language to her suffering.

With regard to form, Manguso's memoir cannot be classified using Frank's restitution model because she notes that her illness could come back at anytime and wonders when that will actually happen. Her tone suggests that she is expecting it to come back because that has always been a possibility. She is more aware of time passing and the limits of time. In one of the last short chapters entitled, "Measuring," she ruminates:

I tend to forget that I rose out of this explosion and – despite my feeling I am unique from it – will someday fall back into it.

Why nine years?

Why do I need to read sixty minutes in the morning, and swim twenty laps in the afternoon, and write a thousand words at night, in order to feel that a twenty-four period has been well-used?

What are all these numbers for? What do they measure?

At the beginning there's conception, gestation, the growth of the brain in the womb. There's the crowning, the first breath, the naming.

At the end, unless you are vaporized in an explosion, the heart stops and the blood still moves in the veins, then the blood stops and the tissues still live, then the tissues die slowly, and at some point the last neuron in the brain dies. How long this takes depends on too many variables to measure.

What times aren't open to debate? What times are clear? (180-181)

Manguso's narrative reflects some aspects of the chaos narrative only because of its fragmented style. It is mostly a quest narrative in that, although Manguso does not use a classical linear form to tell the story (hero's journey), she has been through the classic "call to action" and descent into an alternative reality from which she emerges. In the last phase of the hero's journey, the hero returns back home and is reintegrated back into society. But the hero has to share some kind of knowledge with the society to which he or she returns. Manguso's gift that she receives after her journey is self-awareness and a new ability to notice those things we take for granted in everyday life. Though she may be typical with regard for a new appreciation of life, much like other survivors of serious illness, she imparts this gift to her readers in a way that only someone with her talents can. She creates a poetic journey that is powerful and prophetic.

Perhaps part of the power of her memoir is that she was so young when the illness occurred and is still relatively young even today. She published the book when she was in her mid-thirties. To be struck with such a mysterious illness at a point in her life when she is trying to come into her own – during her college years – is a mind-numbing experience. She was able, however, to channel her suffering and, I suspect, her sense of the unbelievable into a powerful piece that, despite her young age, speaks volumes about how these illness experiences transforms people and force them to come to terms with, when really deconstructed, an absurd situation. How Sarah Manguso dealt with her harrowing experiences is different than those of the other writers discussed in this dissertation. However, they all face

an absurd situation. Writing about the experience is the only way to somehow find relief. Their narrative brings some order to the otherwise chaotic sense of self caused by the trauma and disruption of illness.

CHAPTER FOUR

Jean-Dominique Bauby *The Diving Bell and the Butterfly*

Writers write stories because they have to . . . They cannot rest because they are human and all of us need to speak into the silence of mortality, to interrupt and ever so briefly stop that quiet flow, and with stories try to understand at least some of it.” – Andres Dubus

The writers and works discussed in this dissertation have starkly different circumstances and experiences of illness, even though their common denominator is their creation of illness narratives; however, Jean Dominique Bauby’s experience of locked-in syndrome puts his experience and the narrative he created in a slightly different category because of the nature of his bodily situation and the way he created the memoir. This is not to sound like a judgment of which piece is more powerful or effective because this type of evaluation is not the purpose of this dissertation.

At the very least, a profoundly severed sense of self and body is what happened to Jean-Dominique Bauby after suffering a massive stroke that left him completely paralyzed and “locked-in.” In 1995 Bauby was forty-three years old when he was stricken. Once the vibrant editor of the French edition of *Elle* magazine, as well as a writer, he was left completely paralyzed with the exception

of the ability to blink one eye. With the help of a therapist he learned to communicate with his one eye describing it as “my only link to the outside world, the only window to my cell, the one tiny opening of my diving bell” (53). He used this one-eye communication system to dictate his book, *The Diving Bell and the Butterfly*.

One of the common characteristics of the seriously ill that is prevalent in the autobiographical works discussed in this dissertation is the disassociation of the self from the physical body. This disassociation could be a psychological necessity for coping with the absurdity of pain and suffering. The fragmentation of the self that occurs with the ill or injured, the breaking apart of the physical body and not having the power to change these frightening conditions, changes the way the individual sees and feels herself or himself in the world. Bauby’s situation is profoundly disturbing because he is literally trapped in his own body. His apt metaphor of the diving bell evokes suffocation and a frustration that is next to impossible to create in the mind of the healthy person, yet may name physical fears that human beings harbor: the fear of not having any control over one’s body, but having the clarity of mind to understand and experience it.

For Bauby, this perception was captured as he experienced it – in the present. The audience experiences his detachment by his ability to write about how his conscious self leaves the body, so to speak, and doubles back to see himself as object. Manguso wrote her illness narrative after she had recovered,

though throughout the work there looms the worry that the illness could reoccur. Through the course of our reading Bauby's experience, the knowledge that he will not survive lurks just beyond the words on the page. We experience him within the illness and not beyond it.

The bodily system –that with which we manipulate our physical selves in the world, which includes our perception and how we are perceived, how we relate to the physical world with which we are a part –becomes detached for someone like Bauby in a way that is much different – on some levels – than that of Sarah Manguso. Manguso did not write her memoir while she was ill; rather, she wrote down her memories of the trauma and pain from a perspective of being once again a part of the world – as if she had traveled and had now returned. Her experience somewhat mirrors Frank's quest narrative because she has a beginning, middle and return back in her illness journey. Bauby wrote while in the midst of the trauma, even to the point of having to find a way to manipulate his world in order to have the ability of basic communication. He does not return; his experiences are in the current moment. Knowing that he will not return makes the writing of the narrative even more urgent and necessary because the construction of the narrative becomes the reconstruction of his sense of self.

The disassociation and brokenness caused by his stroke leaves Bauby unable to recognize himself in a reflection. Of course the literal, physical result of his illness is just one aspect of Bauby's trauma. The need to objectify his illness, to put this part of himself beyond himself is necessary to help bring back a

wholeness that has been lost. His mind is perfectly intact. In fact, when he first awoke from the coma he thought he was answering the doctor's questions, but they could not "hear" him. His whole sense of being, his sense of himself in the world was completely taken away by the stroke. Inside, he was the same, but those looking at him from the other side saw something completely different. Bauby is able to gain this sense of wholeness, or some semblance of it, through his dictation of his book. His transcriber voiced the letters of the alphabet and Bauby blinked when she reached the letter he needed. Bauby claimed that he composed paragraph upon paragraph in his mind in preparation for the dictation. Then when his transcriber arrived he was ready to dictate. The process could be tedious depending to whom he was communicating. Bauby writes:

It is a simple enough system. You read off the alphabet until, with a blink of my eye, I stop you at the letter to be noted. The maneuver is repeated for the letters that follow, so that fairly soon you have a whole word, and then fragments of more or less intelligible sentences. That, at least, is the theory. In reality, all does not go well for some visitors (21).

Bauby's sense of being in the world, though he is physically there, was changed in a way that is rare for most people with illness. The rarity is that he cannot manipulate any part of his body and therefore, comes to live mostly in his thoughts. In addition, Bauby was in a coma for two months before awakening into his new reality and speculates that while in the coma, "[s]ince you never really

return to reality, your dreams don't have the luxury of evaporating" (49). Once awake from the coma, he describes how the dreams "pile up on one another, to form a long ongoing pageant whose episodes recur with the insistence of a soap opera" (49).

A phenomenological reading of Bauby is an effective way to understand what he actually does with the narrative and why he had to write it. Bauby's act of writing – in his case dictating through his blinking eye, and the completed narrative become an essence in the world. The illness becomes embodied in the narrative so that now Bauby can see his illness more objectively. It is still part of him, yet it now dwells beyond him. Merleau-Ponty theorizes that the body knows itself by being a part of the world. We are both in the world and a part of it:

Our own body is in the world as the heart is in the organism: it keeps the visible spectacle constantly alive; it breathes life into it and sustains it inwardly, and with it forms a system (203).

The system referred to above is like an automatic one that we are not aware of as it is happening, yet it is how we have a sense of the self in the world. For example, we don't really think about breathing but we do it constantly. Once I start to actually think about breathing it is no longer automatic. I'm aware of air going through my pulmonary system; I see my chest moving in and out. It is almost difficult to breathe when one is so conscious of it. Once I forget about it, it is once again automatic. Pain, the inability to walk, or the inability to manipulate

things, or to communicate by speaking – these are all examples of how the self can be disrupted by injury or illness.

What happens to this “system,” this embodied sense of self with reference to the world, when the body undergoes extreme trauma, such as that endured by Jean-Dominique Bauby? In her work, *Disrupted Lives*, Gay Becker notes: “The narrative process enables the narrator to develop creative ways of interpreting disruption and to draw together disparate aspects of the disruption into a cohesive whole. Narrative is a way of expressing development over time” (26).

Illness disrupts this figurative system. Therefore something else must be put out there into the world, beyond the self in order to make the system whole again. That thing is the creation of a narrative that orders the illness experience so that the writer’s sense of self can reclaim some of the integrity lost by the trauma of illness. Bauby does not lack all physical sensation as he is able to feel his eye itch and some pain in his extremities. However, his sense of being “trapped” in the diving bell, the inability to move his body except a few centimeters at a time, must contribute to a knowledge of the world in a much different and binding way than one who is not bound by complete paralysis. Merleau-Ponty’s theory of perception of the world –that we are in the world and of the world – like a glove turned inside out – would be radically changed when a person such as Bauby goes from being mobile, free from physical restraint, “normal” so to speak, to being completely locked in. Because of the lack of mobility and restriction of his senses, his

knowledge of himself in the world must change and this change, this knowledge, is put to language in his memoir.

Again, like all the writers discussed in this dissertation, Bauby must write the memoir because it helps to order the disorder caused by his trauma. We cannot know ourselves as others see us; but, at the very least, to say that he suffered disruption and fragmentation may be an understatement. This is not just knowing the world the way one would know the world with all of one's faculties and abilities, but knowing the world as a completely different experience with the disruption, pain, and sometimes humiliation that accompanies the person who is not physically whole.

Self-knowledge is not easy to define relative to the way we consciously see our bodies in the world. Though it would seem that even though a person cannot ambulate himself through the physical world, it is still out there and so is he. More specifically, our knowing of our bodies relative to the world has to rely on physical movement and sensation as well as our perception of what is on the outside of us that we know through our senses. The world would seem quite different to me if I couldn't walk on the ground, if I had to be forever wheeled around in a wheelchair or if I couldn't move my body or speak in order to communicate with those around me, and was forced to stay supine, in bed. This is Bauby. It also must be a perplexing perception of knowing the body through the body's place in the world if one was born in Bauby's situation and never knew what it was like to move about in the physical world and communicate with

speech and body language. Self-knowledge is relative to a person's physical state at certain points in his or her life.

One day Bauby catches a glimpse of himself reflected in the glass that held the bust of Empress Eugenie. He writes that it was an "unknown face" that interrupted his day dream with the Empress:

"[I] saw the head of a man who seemed to have emerged from a vat of formaldehyde. His mouth was twisted, his nose damaged, his hair tousled, his gaze full of fear. One eye was sewn shut, the other goggled like the doomed eye of Cain. For a moment I stared at that dilated pupil, before I realized it was mine" (25).

After seeing himself in the reflection he says that a "strange euphoria" came over him. He did not realize before how he looked and there is an epiphany-like quality to his response: "Not only was I exiled, paralyzed, mute, half deaf, deprived of all pleasures, and reduced to the existence of a jellyfish, but I was horrible to behold" (25).

If the body is disordered, as noted by Becker, then one's understanding of the world and the self must be completely changed and possibly even skewed in such a way that it would be difficult for someone not in that same situation to come close to understanding. But it is the understanding of one's self, of one's body, that changes. There must be a difference then, between someone born in particular physical state – someone, say, with cerebral palsy who cannot control

his limbs or someone born with spin bifida who cannot use the lower half of the body – and someone who because of injury or illness, such as Bauby, finds himself completely paralyzed after he has experienced over forty years of his life. The knowledge of what he was before and his new knowledge of himself causes a discord in his perception of himself. He feels damaged.

This description or acknowledgement of Bauby's sense of the before or after is just part of the trauma that has caused such a disruption in his sense of who he is and how he perceives himself. The violence his body has experienced cannot be fathomed by those on the outside looking in. This extreme trauma is something Bauby cannot fathom either. But he has to live with the knowledge that it truly is himself he sees in the reflection; that the limbs he cannot feel or move are his; that the eye that is sewn shut is his. His action of actual dictation of his narrative with his one eye to Claude and her transcription are part of how he puts the self out there in the narrative. His narrative voice is not fragmented once it has been transcribed. But it is fragmented as he is dictating. The act of dictating, Claude's transcription and the actual production of the final text was necessary for Bauby to come to terms with his illness.

Arthur Kleinman, even though his focus on the social and personal meanings that illness brings to the person, is relevant to the phenomenological explication of a text like Bauby's. Kleinman, like others, including Arthur Frank, by using a sociological perspective with regard to illness, explicates the patient's life world to help construct meaning. The life world of a patient consists of

situations such as work issues, relationships, traumatic experiences that become magnified or otherwise experienced some other way because of an illness. This type of relationship uses a cause-and-effect paradigm to make meaning of a life wracked with chronic or terminal illness (30-32):

For in the context of chronic disorder, the illness becomes embodied in a particular life trajectory, envired in a concrete life world. Acting like a sponge, illness soaks up personal and social significance from the world of the sick person. Unlike cultural meanings of illness that carry significance *to* the sick person, this third, intimate type of meaning transfers vital significance from the person's life to the illness experience. (30).

This kind of transfer is significant to Bauby's experience and how he objectifies his illness. More than the other three writers I use in this dissertation, Bauby positions himself out into his life world through his memory and imagination. Writing in the present tense he describes a typical morning after awakening:

My diving bell becomes less oppressive, and my mind takes flight like a butterfly. There is so much to do. You can wander off in space or in time. . . You can visit the woman you love, slide down beside her and stroke her still-sleeping face. You can build castles in Spain, steal the Golden Fleece, discover Atlantis, realize your childhood dreams and adult ambitions. (5).

The above example from Bauby indicates that, to a certain extent, he is sometimes free in that he doesn't have a body – for all intents and purposes. In order to become the “butterfly” he has to move his mind away from the body, so to speak, in order to find some freedom. This experience is much like that of Robert Murphy, the anthropologist who became a quadriplegic, whose “solution” to his ill-functioning body is described in the following passage. Speaking of himself he says:

Murphy's brain is similarly sitting on a body that has no movement or tactile sense below the arms and shoulders, and that functions mainly to oxygenate the blood, receive nourishment, and eliminate wastes. In none of these capacities does it do a very good job. My solution to this dilemma is radical dissociation from the body, a kind of etherealization of identity.

(101)

Murphy's text is yet another example of disassociation caused by the trauma of illness or injury. He sees his body in a somewhat separate manner from his self. He has to do this in order to find a “solution to the dilemma.”

Disassociation is a survival technique.

In addition to a phenomenological analysis of Bauby's text, another question remains that comes back to the heart of this dissertation and that is the question of the effectiveness of the literary artist: Is the literary artist in a better position to impart to an audience and then gain reaction from that audience these

feelings related to the consciousness of one's body more so than ordinary people telling their stories? When Bauby describes eating meals and visiting places and imagining Eugenie speaking to him, his use of his imagination and literary skills as a writer give the audience a fuller experience and therefore a deeper and richer understanding of disassociation and embodiment of the self. We are there with him. We can see what he sees. This perspective gives us the opportunity for empathy.

He writes with a wry sense of humor about how his only nutrition is a bag of brown fluid that travels through a tube inserted in his stomach. For the simple pleasure of enjoying food, he says he turns to the "vivid memory of tastes and smells, an inexhaustible reservoir of sensations" (36). The imagery is palpable. "Now," he writes, "I cultivate the art of simmering memories:

If I do the cooking it is always a success. The *boeuf bourguignon* is tender, the *boeuf en gelee* translucent, the apricot pie possesses just the requisite tartness. Depending on my mood I treat myself to a dozen snails, a plate of Alsatian sausage with sauerkraut, and a bottle of late-vintage golden Gewurztraminer; or else I savor a simple soft-boiled egg with fingers of toast and lightly salted butter. What a banquet! (36).

Bauby's literary skills as well as his imagination provide a better venue to channel his frustration, pain and sense of bewilderment about the circumstances in which he finds himself. His use of such vivid imagery to evoke all his senses while

cooking and eating in his imagination is certainly remarkable. But more than just being remarkable it is a way for him to escape the confines of the diving bell. His ability to conjure up images, to travel through his memories and to imagine himself elsewhere – these acts constitute his “butterfly.” In this way, he is the butterfly who temporarily escapes the diving bell. Because he is a prisoner in his own body, he is able, through his imagination, to separate his mind from his body in order to travel to past experiences where he physically feels those sensations again. This is no small feat and very difficult if not impossible, except in deep dreaming, to experience physical sensations so real and so intimate.

But he refers to the butterfly as a metaphor in another part of the book, as well. He recounts how on his birthday his speech therapist, Sandrine, coaches him to say the entire alphabet: “It was as if those twenty-six letters had been wrenched from the void; my own hoarse voice seemed to emanate from a far-off country [which] left me feeling like a caveman discovering language for the first time” (41). Sandrine also helps him stay in touch with his loved ones and, though it is frustrating for him, it is they who must do all the talking during which Bauby “intercept[s] and catch[es] fragments of life, the way you catch a butterfly” (41).

Being able to speak again will enable him to break free from the prison of the diving bell. And certainly it does free him because he writes the book and puts the narrative and all it represents out into the world. He must have felt a great sense of relief when he finished, knowing that he had broken through the walls of the diving bell. Writers like Bauby, through imagination, talent, and experience

transform illness into creative narrative that moves the audience yet avoids sentimentality. They cannot, then, be called chaos narratives when, in fact, they are actually ordered – in a way art can be ordered and deliberative. Therefore trying to categorize a narrative like Bauby's into one of Frank's categories cannot be done unless we use more than one category. He writes in a very deliberate and ordered way, even claiming to memorize every sentence he wants to dictate before his transcriber arrives, and yet he writes while in the throes of his illness. Frank has acknowledged that all narratives cannot be so simply categorized because narratives often fall into more than one category. Writers of these creative non-fiction narratives also use their imaginations to get themselves through the illness – or in Bauby's case – not exactly through, since his journey ends in death – but as a way of coping in the world with something that seems rather otherworldly.

His coping enabled him to acknowledge others who are in the hospital with him. Perhaps these are people he would not have given a second thought in his previous life. Most of us do not acknowledge those confined by illness or disability unless we are forced to. Nevertheless, Bauby's own illness has brought him empathy for those who are like him who are forced to live in a world as surreal as his own. Though some of the patients there have been in accidents and are recovering, he focuses on the patients who are like him:

And to complete the picture, a niche must be found for broken-winged birds, voiceless parrots, ravens of doom, who have made our nest in a dead-end corridor of the neurology department. Of course we spoil the view. I

am all too conscious of the slight uneasiness we cause as, rigid and mute, we make our way through a group of more fortunate patients (32).

The above passage is witness to the loneliness of patients such as Bauby who have been caught in the unfortunate position of being trapped by their own bodies. They are poignant images of how others avoid them and are uncomfortable even just seeing them. The “dead-end corridor,” “voiceless parrots,” “ravens of doom,” all connote a sense of loneliness and hopelessness; they are the ones living beyond the boundaries of the rest of the world.

Bauby’s only outlet is the narrative he transcribes using his one eye. The very act of thinking about what to write, memorizing the paragraphs, and then transcribing through his blinking provides him with a cohesiveness and control that he does not have otherwise. The narrative brings his broken sense of self together. His sense of self – of who he really is – has been severed from his body. The trauma he undergoes every day when he wakes up and finds himself in this locked-in condition must be tempered somehow. By writing his illness in the text he creates a continuity that is now missing in his life since a narrative starts, continues and eventually ends. Through narrative, the ill person interprets disruption in a new and novel way. The fragments and disruption are brought together into a cohesive synthesis and “express[es] development over time” (Becker 26).

Without the ability to form a narrative, and therefore some cohesive sense of self, Bauby's imprisonment would have been much more profound. His construction of the narrative is the process by which he is able to make some sense of the fragmented ill self. The narrative becomes the synthesis of all his experience and it is outside himself, yet still part of him.

The last chapter of Bauby's book is entitled, "Season of Renewal." The tone of the last chapter suggests that Bauby has found a sense of order in his new life and it can be argued that the completion of the narrative has brought this order to him. He and his transcriber, Claude, have spent July and August of that summer working on the book. Now that it is autumn and the book is finished, Bauby notes that summer is ending. Vacation time is over and everyone will return home to their jobs and professions. He writes with a tone of resignation and acceptance, noting how everyone else will return from vacation and go back to their professional and student lives:

I am savoring this last week of August with a heart that is almost light, because for the first time in a long while I don't have that awful sense of a countdown – the feeling triggered at the beginning of a vacation that inevitably spoils a good part of it. (130)

Bauby has been living, per se, with a "countdown" since his stroke. So there is a parallel in the countdown of vacation time and the countdown he must undergo every day as he contemplates his death. This is not to say that Bauby is

obsessed with thinking about death. It is ironic given that he is not on “vacation” and that he actually feels “light.” Perhaps this is also a reference to the butterfly. As the summer ends, his narrative draws to completion bringing with it a sense of freedom. He feels free because the act of writing the narrative has given him peace. He has placed his illness into the world with the act of writing it. He can now view it more objectively with the result being an integration of aspects of the self that have been scattered because of the trauma he has experienced. This act has brought back more wholeness to the self and the ability to escape the diving bell. He is not consciously aware of what the writing has brought him, but the title of his last chapter, “Season of Renewal” and the fact that he can ask the questions he poses at the end of the book is evidence that he has moved to a different place, perhaps achieving a kind of transcendence. He says: “Does the cosmos contain keys for opening up my diving bell? A subway line with no terminus? A currency strong enough to buy my freedom back? We must keep looking. I’ll be off now” (132).

Bauby died two days after the French publication of *The Diving Bell and the Butterfly*. The relief he sought came from the construction of the narrative and being able to see the part of himself that was ill and broken, he was able to maintain some sense of integrity of the self that had been so traumatized and shattered and with that achieve transcendence.

CHAPTER FIVE

Oliver Sacks

A Leg to Stand On

An illness is like a journey into a far country; it sifts all one's experience and removes it to a point so remote that it appears like a vision. -- Sholem Asch

The neurologist and author Oliver Sacks' experience is different from the writers discussed in the previous two chapters because he did not have a disease or illness. Instead, he severely injured his leg on a mountain in Norway when he was frightened by a bull. However, Sacks' loss of sense of self caused by a loss of feeling in a part of his body, and his writing of the experience in retrospect, can be analyzed within Merleau-Ponty's phenomenological frame as well as Franks' narrative frame.

Sacks fell while running away from the bull and was dragging himself toward the bottom of the mountain when he was rescued by some villagers. His narrative, *A Leg to Stand On*, recounts his traumatic experience of surgery and rehabilitation which often found him in great physical and emotional pain.

Through the ensuing weeks, he discovers that he has no feeling or “image” of his leg. It has disappeared.

The fragmentation of the self is very evident in Sacks’ narrative. After surgery, he is helpless, surrounded by doctors who refuse to acknowledge that there is actually something wrong with his leg. He describes an almost Kafkaesque scene in which the surgeon, Swan, comes in with his juniors and his students while making “Grand Rounds.” When Sacks tries to tell the doctor that he has difficulty locating his leg the doctor’s response is:

“Nonsense, Sacks,” he said sharply and decisively.

He held up his hand, like a policeman halting traffic. “You’re completely mistaken,” he said with finality. “There’s nothing wrong with the leg. You understand that, don’t you? (81).

After his encounter with Dr. Swan, and when he received no reassurances from the doctor, he describes himself as being in a kind of hell in which he feels he has fallen into a hole:

By saying “Nothing” he took away a foothold, the human foothold I so desperately needed. Now, doubly, I had no leg to stand on; unsupported, doubly, I entered nothingness and limbo . . . The word “hell” supposedly is a cognate with “hole” – and the hole of the scotoma is indeed a sort of hell . . . The quality of timelessness, limbo, is inherent in scotoma. This would be tolerable . . . if it could be communicated to others, and become a subject of

understanding and sympathy – like grief . . . I was thrown into the further hell – the hell of communication denied. (84-85)

The injury caused him to experience severe trauma, which included a loss of sensation in the injured leg, and caused a serious disruption in his sense of self. He could not will his leg to move or to feel. Part of his body was no longer under his control and it left him floundering for understanding:

What was happening with me? I couldn't *try*, I couldn't think, I couldn't recall. I couldn't think or recall how to make certain movements, and my efforts to do so were delusory, derisory, because I had lost the power to call to a part of myself, the power to call *on* a part of myself . . . I felt abysses opening beneath me" (46).

Sacks suffered paralysis in his leg and his inability to control a part of his body left him feeling that he not only had a "lesion" in his muscle, but, as he says, a "*lesion in me*" (his emphasis, 46). Even trauma to one limb, one part of the body causes a loss in the "me." The body is no longer whole. In the phenomenological thought of Merleau-Ponty, the body is the way we engage the world. We cannot know it otherwise. Sacks' lack of feeling in his leg, his feeling that there was not a limb there, caused him to question his sense of reality. He says that the "leg was there objectively, externally" but it had "disappeared subjectively" (53). With part of the body gone, Sacks lost his ability to feel whole.

At one point when he was lying in a hospital bed and his leg was in a cast a nurse admonishes him for being half out of bed. Sacks has no sensation of the fact that his leg has fallen off the bed, even though his leg was no longer in front of him but had fallen to a ninety degree angle to the side. He writes:

I had a sudden sense of mismatch, of profound incongruity – between what I imagined I felt and what I actually saw, between what I had thought and what I now found. I felt, for a dizzying, vertiginous moment, that I had been profoundly deceived, illuded, by my senses: an illusion – such an illusion – as I had never known before. (48)

Sacks' experience of being fooled by his senses is reminiscent of Reynolds Prices' description in his book, *A Whole New Life*, of his sense of self while living with paralysis caused by a spinal tumor. He writes that he had a sensation of being overwhelmed:

[I was overwhelmed] by a rising sense of disassociation from my whole body. My mind would seem to leak out, rise above my trunk and limbs and gaze down at them from a helpless nearness. *When can I live again in my body? And where I am now?* As much as any specter in a ghost tale, I felt like a spirit haunting the air above is old skin that had suddenly, and for no announced reason, evicted me and barred my return. More than once I felt even worse – like a butchered steer, hooked up in space above my old home. (31-32)

Sacks writes in a similar vein when he talks about his feeling of being disconnected from his body – that he has no sense of where his leg is. He uses the term proprioception to describe what he is feeling because “it implies a sense of what is ‘proper’ – that by which the body knows itself, and has itself as ‘property’” (50). The body senses itself and knows its position in the world. He has a discombobulated feeling that the leg had disappeared: “I gazed at it, and felt, I don’t know you, you’re not a part of me, and . . . I don’t know this ‘thing,’ it’s not part of anything” (53). The trauma he experienced was so severe that he writes as if he doesn’t recognize the leg as part of his body. “The flesh . . . no longer seemed like flesh,” he writes, and as he succumbs deeper into the trauma he says that the more he “gazed at it, and handled it, the less it was there, the more it became Nothing – and Nowhere, Unalive, unreal, it was no part me – no part of my body...It didn’t ‘go’ anywhere. It had no place in the world” (52).

The leg that disappeared but is actually still there is the opposite condition of the well-known phantom limb phenomenon. Sacks’ experience mirrors the condition of anosognosia, an unawareness or denial of a disorder. But Sacks is experiencing paralysis and rather than being unaware of his disorder, he rejects it as not being part of himself because it seemed a nothingness to him. This rejection because of paralysis causes him to have what Merleau-Ponty calls “regions of silence” (82). Merleau-Ponty writes:

The body is the vehicle of being in the world, and having a body is, for a living creature, to be involved in a definite environment, to identify oneself with certain projects and be continually committed to them. (82)

If part of that body is gone or paralyzed, the person has a void that keeps him from feeling whole. This is the disruption of illness. Certainly Oliver Sacks had such a disruption and struggled throughout his treatment and convalescence to recapture the leg that he felt was no longer part of him. It is a cutting off of the body and to be able to sense that which causes such fragmentation in the ill person. The seamless flow of being for the world and being in the world has been disrupted. Writing the story helps to put order back into the chaos of illness. Sacks may not be aware of this. He does not directly state this in his work. However, and objective reader can see, I think, those things the writer can see or maybe won't acknowledge.

Sacks wrote the book after he recovered; however, it can be argued that he still needed to write the narrative to heal another part of himself, since the leg itself was healed. Writing the illness memory is a way to purge the memory of the fear, horror and feelings of inadequacy that came with the injury. Writing the memory is also a way to share the experience with the outside world so that in the future anyone reading about the experience could be moved by it.

Oliver Sacks' experience as a patient gave him more insight in self-perception and others' perceptions of patients in hospitals, a view he usually

experiences as a physician himself. He writes of finally being allowed to sit in the hospital's garden area during his recovery. It was the first time he was allowed outside to enjoy the plants, the sky, and the fresh air. His joy was short-lived when he realized that he and the other "patients in white nightgowns" were avoided "like lepers" by the other visitors, nurses and students who were also enjoying the garden (134-135). Sacks' analysis of his own experience is pointed and addresses the way that one perceives one's self as well as how others see the ill person. Becoming a patient is a process of removing identity. As he points out, the giving up of one's own clothes for a hospital gown, having a name-tag bracelet to mark the patient, the "removal of individuality, the reduction to a generic status and identity" (135) are all examples of how patients are set apart from everyone else.

Though Sacks is talking about being a patient in a hospital and convalescent home, (and he eventually recovered), the setting apart from society those who are chronically ill and disabled is carried over into everyday life away from the hospital. In Sacks' case, recovery was imminent and he would go back to a life much like what he had before. However, for those who are chronically or terminally ill or who live with a disability, this sense of being set apart from the rest of society continues.

In fact, G. Thomas Couser, in his book, *Recovering Bodies: Illness, Disability, and Life Writing*, calls Sacks to task by claiming that Sacks reveals a sense of "self-congratulation" even "self-promotion" (188). Couser claims that because Sacks recovered he cannot possibly understand or put himself in the same

place as the chronically disabled. For Couser, Sacks is claiming, because of his recovery, “full selfhood, rehabilitation in the moral and spiritual sense. How much more difficult is the predicament of the chronically disabled autobiographer, whose experience may fail to conform to such a comic plot, and whose self, by the implications of Sack’s narrative, still remains deficient, who lives perpetually in ‘limbo,’ alienated and marginalized” (188).

Couser is criticizing Sacks for writing a restitution narrative, or the triumphant narrative in which the ill or injured person marches on toward victory over the illness. Though Sacks’ narrative has components of the restitution narrative, it is mainly a quest narrative. But it is a quest after the fact, unlike Bauby’s narrative, written during the illness and finished very shortly before his death. Manguso also writes her illness narrative after the fact, but her story has a more haunting tone because she does not know if the illness will return. Hers was a process that went on for nine years, whereas Sacks’ episode lasted nine weeks.

They are two quite different narratives yet, I think, they use the narratives for the same end: they are an act of self-reflection. Sacks writes his narrative almost like an adventure/biography, with characters popping in and out and with a set chronological order. However, he recounts in very vivid ways the emotional and physical trauma he underwent during those nine weeks. His quest narrative has the three phases of the hero’s journey: the call to action, initiation, and the return. His call is the injury on the mountain while the initiation is comprised of all the pain, the surgery, the mental and physical trauma, as well as the way he felt

marginalized by the hospital staff and healthy people. His return is, of course, his recovery and his integration back into society. This return is not easy as he points out toward the end of the book when he was chastised by a nurse for not walking beyond the gate of the hospital. He realized he had to push himself and actually ran to catch a bus at one point, and went swimming at another point. His reintegration allowed him to write the narrative. Therefore, he has come full circle back – almost an exact mirroring of the classic monomyth or hero's journey.

CHAPTER SIX

Anatole Broyard

Intoxicated By My Illness

Things are not all so comprehensible and expressible as one would mostly have us believe; most events are inexpressible, taking place in a realm which no word has ever entered, and more inexpressible than all else are works of art mysterious existences, the life of which, while ours passes away, endures.

--Rainer Maria Rilke
from Letters to a Young Poet

Anatole Broyard, who died in 1990 from prostate cancer, was a writer and critic for the *New York Times* for nineteen years prior to his death. His illness memoir, *Intoxicated By My Illness*, was published shortly after his death. Born in 1920 in New Orleans, his family moved to Brooklyn when he was a small child. He served as an officer during World War II, and then pursued the literary life after he returned home. Broyard was African-American, but spent his whole life passing as white. He kept this secret even from his children who found out shortly before he died. Henry Louis Gates reports in his book, *Thirteen Ways of Looking at a Black Man*, that Broyard spent his life passing as a white man because he wanted to “be a writer, rather than a Negro writer” (184). Broyard’s wife, Alexandra, writes in the preface of *Intoxicated By My Illness* that he “was a superb storyteller, and at this most difficult time of his life he concentrated his talents in a

way that enabled him to hope and believe that he could outwit his cancer by constructing an alternative narrative that would wither and erase the shadow of death” (xviii). Perhaps he believed that he could fool his illness – as Alexandra Broyard says – “outwit” his illness much like he fooled the many people with whom he had contact most of his life with regard to his race. Gates reports that Broyard was beginning to make a name for himself in 1948, being noticed “not merely for his charm, his looks, and his conversation but for his published writings” (186). In 1954 he published a short story entitled, “What the Cystoscope Said” which was a story about his father’s illness. The story brought him some fame in the literary world. *Intoxicated By My Illness* reveals a charming, vibrant, urbane man with a keen sense of irony and humor.

Broyard, who eventually succumbed to prostate cancer, believed that he had a need, that we all have a need to tell our stories, especially when we are ill and dying in order to keep our humanity:

I sometimes think that silence can kill you, like that terrible scene at the end of Kafka’s, *The Trial* when Joseph K. dies speechlessly, “like a dog.” In “The Metamorphosis,” a story that is now lodged in everybody’s unconscious, Gregor Samsa dies like an insect. To die is to be no longer human, to be dehumanized – and I think that language, speech, stories, or narratives are the most effective ways to keep our humanity alive. To remain silent is literally to close down the shop of one’s humanity. (20)

Broyard's belief in not keeping silent about his illness is echoed by the poet Audre Lord who died of breast cancer. In her essay, "The Transformation of Silence into Language and Action," originally a speech at the 1977 convention of the Modern Language Association, Lord opens by saying:

I have come to believe over and over again that what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised or misunderstood. Thus the speaking profits me, beyond any other effect. I am standing here as a Black lesbian poet, and the meaning of all that, waits upon the fact that I am still alive, and might not have been.

(1441)

In her essay, Lorde discusses that she knew she would eventually die and realized that being silent about her illness and about whom she is would not help her or anyone else. As with others who are faced with serious illness, Lorde refers to seeing the world with more clarity after she received her diagnosis. She seems to feel a sense of urgency and stresses that language could be converted to action. She says that she was "going to die, if not sooner, then later, whether or not [she] had ever spoken herself"

My silences had not protected me. Your silence will not protect you. But for every real word spoken, for every attempt I had ever made to speak those truths for which I am still seeking, I had made contact with other women while we examined the words to fit a world in which we all

believed, bridging our differences. And it was the concern and caring of all those women which gave me strength and enabled me to scrutinize the essentials of my living.” (1439).

Lorde refers not just to her illness here but also to her race and sexual orientation. However, her need for empathy was not just self-serving. Certainly, in order to gain a better understanding of oneself, one must understand others and try to feel what it must be like to be what and who they are. When Lorde recounts that she was afraid to speak about her illness, her daughter told her she should tell her audience that you’re “never really a whole person if you remain silent, because there’s always that one little piece inside you that wants to be spoken out” (1441).

Anatole Broyard had a *deeply-held need* to tell his story. He writes of having the need to describe his extraordinary experience, a need he says we all have. But he also believed that “[m]aking narratives like this rescues me from the unknown.” He uses the analogy of the novelist who desires to turn his “anxiety into a story” (20-21). The person who is sick, he says, turns his illness into a narrative in order to “detoxify” it (21). Broyard, like the other writers discussed in this paper, writes his journal in order to bear the pain, to put his illness experience into the world where it becomes an essence beyond the self in order to help confront the fear of dying. This action helps bring back some sense of order that helps soothe the disruption caused by the suffering brought on by the illness as well as the fear of impending death. Illness becomes the object in the world

because it is being made into an object in the narrative. He writes in his chapter, “Toward a Literature of Illness”:

My initial experience of illness was a series of disconnected shocks, and my first instinct was to try to bring it under control by turning it into narrative. Always in emergencies we invent narratives . . . Storytelling seems to be a natural reaction to illness . . . Stories are antibodies against illness and pain . . . In the beginning, I invented mininarratives. Metaphor was one of my symptoms. I saw my illness as a visit to a disturbed country, rather like contemporary China. I imagined it as a love affair with a demented woman who demanded things I had never done before. (19 -21)

Illness causes one to see oneself in a new way. Coming to terms with a terminal illness for Broyard must have been very ironic since he lived with hiding the fact he was black so long. He felt he was flawed for being black. It was something, he believed, that would keep him from living the life he wanted to live. Now he fights for his life as he’s writing the memoir and acknowledges after the first state of his illness when his body was working again that simply to be healthy, for the body to be whole is something to be appreciated: “With a cry of joy I realized how marvelous it is simply to function. My body, which in the last decade or two had become a familiar, no longer-thrilling old flame, was reborn as a brand-new infatuation” (7).

Yet he realizes that this is just one phase in what could be many phases in his illness. He acknowledges that the elation he feels “is just a phase, just a rush of consciousness, a splash of perspective, a hot flash of ontological alertness. . . I see now why the Romantics were so fond of illness – the sick man sees everything as metaphor. In this phase I’m infatuated with my cancer. It stinks of revelation” (7).

There were those who knew he was black, of course, or who suspected. Gates describes the relationship Broyard had with Brent Staples a black editor at the *Book Review* during the time that Broyard worked there. Staples writes about how different Broyard was when he was with him:

[H]is whole style, demeanor, and tone would change. I took that as him conveying to me, ‘Yes, I am like you. But I’m relating this to you on a kind of recondite channel.’ Overall it made me angry. Here was a guy who was...probably one of the two or three most important critical voices on literature in the United States. How could you actively or passively, have this fact hidden? He turned it into a joke. And when you change something basic about yourself into a joke, it spreads, it metastasizes, and so his whole presentation of self became completely ironic. *Everything* about him was ironic. (206)

Reflecting on his illness, Broyard writes that he now understands the “conditional nature of the human condition. Yet, unlike Kierkegaard and Sartre,

I'm not interested in the irony of my position. Cancer cures you of irony. Perhaps my irony was all in my prostate" (6).

Broyard was a man of style and charm. His friend, Vincent Livelli, remembers that Broyard's "conversation sparkled, everybody said so. The sentences came out perfectly formed, festooned with the most apposite literary allusions. His high-beam charm could inspire worship but also resentment. Anatole had a sort of dancing attitude toward life – he'd dance away from you. He had people understand that he was brilliant and therefore you couldn't hold [him] if you weren't worthy of his attention" (Gates 185).

It is no wonder, given Broyard's personality, his verve for life, his need to be a part of the avant-garde, that he would write that he wanted his illness to have style and that he wanted to die in style

I think that only by insisting on your style can you keep from falling out of love with yourself as the illness attempts to diminish or disfigure you. Sometimes your vanity is the only thing that's keeping you alive, and your style is the instrument of your vanity. It may not be dying we fear so much, but the diminished self. (25)

He writes in a journal excerpt included in *Intoxicated By My Illness* that a fear that an ill person lives with is:

[the]diminishment and disfigurement of yourself. It's that, more than dying, that frightens you. You're going to become a monster. I think you have to

develop a style when you're ill to keep from falling of love with yourself. . .
And your style is the instrument of your vanity. I think it would be good
therapy, good body narcissism, for cancer patients to buy a whole new
wardrobe, mostly elegant, casual clothes. (62)

I believe that Broyard, like the other writers discussed in this paper, are
living with limits and writing their illnesses gives them a limitlessness. The
psychotherapist, Kathlyn Conway in her book, *Illness and the Limits of
Expression*, points out the following about writers trying to maintain identity
through illness writing:

[W]riting has been a human act by which the mind mimics but also
mediates its desire for immortality. . . authors struggle to tell their story in
order to stay alive and maintain their identity in the face of illness and
dying, but they do so with the awareness that the very illness they describe
can deprive them of their voice and self . . . Literature offers the possibility
of representing the shattering experience of illness, but it proves woefully
inadequate for depicting the nature of physical pain and the dissolution of
the self. (16)

I see the placing of the self into the narrative as a way to see the illness in a
much more ordered way, rather than the chaos that becomes the life of the
seriously ill person. Someone like Broyard, a literary person, writer, critic who is

used to ordering the world of literature through writing about it, now finds himself in the midst of the worst kind of disorder: the disorder of the self caused by terminal illness. The work itself becomes a testament to Broyard's fight against disease and his appreciation of the life he still had.

Although the narrative becomes a shared experience for the reader because of its intimacy with the author who allows us into a very personal space in his life, I do not believe that Broyard's purpose is to gain empathy. His tone is more like the speaker in Dylan Thomas' poem about his father raging against the dying light. This is not to say that Broyard's narrative is a chaos narrative. Arthur Franks' chaos narrative is actually what he calls the "anti-narrative" which he defines as a narrative "of time without sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself" (98). He says that "these stories cannot literally be told but can only be lived" (98). But even Franks says that even though the narrative exists it can give us a glimpse into the chaos (100) which is what I think Broyard actually does. This kind of glimpse is especially evident in the last section of the book which is a collection of some of his last journal entries.

These last entries do not represent an ugly chaos. It is a kind of beautiful one – the chaotic writing by a man who is trying to bear the pain of illness and yet who loves beauty, especially the beauty of words. These last sections are written in one-line, sometimes two-line, or several line fragments:

Isn't there some way to turn dying into some kind of celebration, a birthday to end all birthdays?

You mustn't surrender to illness: Shave, comb your hair, dress attractively, be aggressive, not passive. It's the change in the sick person that embarrasses his friends, and the whole inhibition begins there.

The dying man has to decide how tactful he wants to be.

What a critically ill person needs above all is to be understood.

At the end, you're posing for eternity. It's your last picture. Don't be carried into death. Leap into it.

I wouldn't call my attitude courageous. I'd call it irresponsible. (66-68)

Coming back to the issue of style, once again, in one of his last journal entries, Broyard writes:

I really think you have to have a style in which you finish your life. That's what I'm doing right now. I'm finishing my life. I think one ought to die at a kind of party, the way Socrates died. All of his disciples came to his bedside. When Andre Gide was dying, he was

surrounded by friends and journalists...He wanted to die in his own style, and that seems to me quite reasonable. (63)

Throughout the memoir, Broyard eloquently writes about the constraints that illness puts on those who must navigate through it. Through his writing, like the other narratives discussed in this paper, Broyard was able to put some order into what otherwise seemed like utter chaos in his life. His writing helped bear the pain not just of the physical illness, but the pain of knowing that death was imminent. He wanted to die in style and it seems as though he did, although he never mentions his race in the book. Perhaps the illness was a way for him to appreciate his body in a way he had not ever appreciated it before. Perhaps it didn't matter that he was black. We can only speculate since Broyard did not even tell his own children about their ancestry. Their mother, Alexandra, told them while Anatole was in the hospital in Boston. She felt it was necessary for them to know and preferred he be the one to tell them. However, because of his weakened state and that the two children being away at college, the time did not present itself.

Alexandra writes in the epilogue of the book:

Anatole's long love affair with books and writing had served him well. As a child he had wanted to become a writer. It gave him the reference points, coordinates, metaphors, and attitudes that enabled him to be alive and

himself until that was no longer possible. When he lost the ability to speak, his smile was still radiant.(135)

Anatole Broyard was able to bring to the reader his very personal story of illness in a way that evokes some empathy and certainly a bit of pathos. It was his ability to write the illness that brought him some peace because he was able to bring some order to the chaos of being terminally ill.

CONCLUSION

It is no wonder that when a person is confronted with critical, chronic or terminal illness, especially illness that results in disability of one kind or another, that perceptions of self and of the world change. In these accounts of illness and its repercussions, over and over again there appears a sense of the fragmented self. Sometimes this sense of self becomes a feeling of detachment from the body with the person imagining himself outside the parameters of the body. Robert Murphy, an anthropologist who became a quadriplegic because of a spinal tumor, recounts the splintered sense of self in his narrative, *The Body Silent*. He discusses how he felt after becoming semi-paralyzed as a result of a tumor in a chapter entitled, “The Damaged Self”:

I had an increasing apprehension that I had lost much more than the full use of my legs. I had also lost a part of my self. It was not just that people acted differently toward me, which they did, but rather that I felt differently toward myself. I had changed in my own mind, in my self-image, and in the basic conditions of my existence. It left me feeling alone and isolated, despite strong support from family and friends; moreover, it was a change for the worse, a diminution of everything I used to be. (85)

Murphy's comment is an example of how important the body is with regard to the self in the world. Because he could not use his legs, he sensed that a part of him had been erased.

It is difficult to get away from seeing the world through only the physical lens. People who experience good health tend not to dwell on their bodies in the same way as the ill. Those traumatized by ill health seem to define everything about their everyday life experiences based on their bodies. Most people have probably experienced having to listen to someone's story about an operation, the illness, or problems with medications, categorized by Frank as chaos narratives. It is because we know the world through our physical senses that we place so much emphasis on the body. Sometimes the ill or disabled are forced to navigate the world differently because of their limited physical condition. Murphy (quoted above) notes that when he tried to enter his "normal" social world in a wheelchair, he felt more than awkward, not being the same height of everyone else at a faculty social function. He was the same person on the inside, but because he was limited by his physical condition, even his colleagues treated him differently (91-92).

The writer Andres Dubus, who lost the use of his legs by being hit by a car as he tried to help a stranded motorist, vividly narrates how his view of himself changed after the accident. A former marine, Dubus had always seen himself as a very strong and virile man. In his collection of essays entitled, *Broken Vessels*, he recalls the on-going struggle to reclaim his former self, identifying himself as

strong husband and father who wanted to be able to take care of his family. He had to come to terms with his physical difficulties, his inability to walk and confinement to a wheelchair. The accident and its aftermath eventually caused the break-up of his marriage and his painful separation from his young daughters except for a restricted visitation schedule.

Not only did he have to live with the physical pain, but he also had to redefine himself and come to terms with the changed person he had become. In his preface to *Broken Vessels*, Tobias Wolff says that Dubus “made his wheelchair a place to see the world more clearly than ever” (xviii). Dubus was initiated into the realities of how society looks at someone whose illness or disability is visible – that they are no longer contributing member of society – that they are somehow needy and different. What is normally taken for granted by someone who has full use of her body cannot be taken for granted by someone forced to use a wheelchair. Going into buildings, riding busses, shopping for groceries are examples of everyday activities that limit the person in an altered body. The trauma of injury or illness and its aftermath rips the fabric of the self apart because the person is in the world, objectified by the world and interacts with the world in a completely different way. Though there are differences in having a chronic illness, being paralyzed, or suffering the loss of limbs, or of having a terminal illness, the ruptured perception of the self in the world, in general, is the same.

The author and poet Reynolds Price went through a long ten years and a rethinking of how he saw himself after he was diagnosed with a spinal tumor.

After his surgery, he writes that almost every day he'd have a sensation of being overwhelmed:

[I had] a rising sense of disassociation from my whole body. My mind would seem to leak out, rise above my trunk and limbs and gaze down at them from a helpless nearness. *When can I live again in my body? And where am I now?* As much as any specter in a ghost tale, I felt like a spirit haunting the air above his old skin that had suddenly, and for no announced reason, evicted me and barred my return. More than once I felt even worse – like a butchered steer, hooked up in space above my old home. (31-32)

Some kinds of comparisons can be made with the other writers discussed in this dissertation with regard to their particular illness places and their use of creativity and imagination to regain a continuity of self. Anatole Broyard certainly doesn't live and his narrative is really a series of journal entries, but they are very self-conscious, nonetheless, with regard to his coping with illness. Given that he was a critic and writer, he must have known that they would be published someday. So he, as well, was thinking of an audience, and his work can be analyzed with regard to how he, the artist, navigated the world of illness and used his writing as a way of reaching some kind of understanding of himself and his situation.

It should be noted that despite the fact that Manguso lived, she was not sure that would be the outcome during her long, nine-year struggle with the illness – an

illness that could recur at any time once she went into remission. However, an important difference between her work and that of Jean Dominique-Bauby and Anatole Broyard is that they wrote their narratives in the present while they were going through their illnesses, treatments, and after effects – while Manguso wrote after she had gone into remission and had tentative thoughts about how the illness could possibly come back. Sacks was also writing after the fact – long after he had recovered the use of his leg and was reintegrated back into “normal” society again. This not to say that one is more effective than the other; but one’s perspective would certainly be different, possibly more fatalistic, while writing during the throes of the illness as opposed to writing after one is healthy again. Frank would categorize the works of Broyard and Bauby as chaos as well as a quest narrative. The difference is that Bauby had an actual ending to his book but Broyard died before there was a final ending to the narrative.

Oliver Sacks’ injury was not life-threatening, but he felt that he had been rendered invisible. His experience cannot be compared with the others with regard to terminality. But his experience is significant for this study because he felt that an actual physical part of him had been severed, and yet he had to somehow maintain a sense of a whole self in order to keep his self intact. However, his perspective was that of the disrupted, injured self and though he sensed a feeling of loss, it was his experience as a patient that enlightened him about how patients are treated, since he was used to being on the other side as a doctor. What is significant is that he didn’t feel whole and he wasn’t treated as a “whole” person.

He becomes other within the patient/doctor relationship. His disruption of self stems not only from his injury which caused temporary paralysis, but also from the way he was treated by health care providers.

I have been mainly concerned with how the illness narrative provides a transcendent experience for the writer, but ultimately some comments can be made about the experience for the reader. Joseph Conrad, the nineteenth century British writer gives a powerful testimony as to the work of a writer:

My task which I am trying to achieve is, by the power of the written word, to make you hear, to make you feel – it is, before all, to make you see. That – and no more, and it is everything. If I succeed, you shall find there according to your deserts: encouragement, consolation, fear, charm – all you demand; and, perhaps, also that glimpse of truth for which you have forgotten to ask.

Conrad's powerful words emphasize what these writers of illness narratives are trying to achieve. The ill among us are also some of the most marginalized of us. A writer's job is to bring to the reader something that the reader cannot procure on her own. If a writer does the job by opening the mind and heart of the reader, then he has accomplished his task. In some of her correspondence, the American writer, Flannery O'Connor wrote that she believed her task was to make the blind see and the deaf hear. A good narrative – whether fiction or non-fiction – should,

indeed, give the reader that “glimpse of truth.” It is a tall order, but a necessary and important one if the work is worth reading.

Martha Nussbaum notes that stories become important only to an audience who accepts the view of life that what happens to someone else should matter to them. In her analysis of the tragic genre she notes that the genre only works when the audience shares this belief. She discusses the audience’s responses of pity and fear at tragic events:

[They are] are valuable responses, responses for which there is an important place in the ethical life, since they embody a recognition of ethical truths. That other emotions as well are appropriate, and based upon correct beliefs about what matters. That, for example, it is right to love certain things and people that lie beyond one’s own control, and to grieve when these people die, when these things are removed. (17)

The creative expression that the storyteller shares with the audience, in whatever form it takes – fiction or non-fiction – will lead to the same place, as long as the audience is willing to let the storyteller and the story in. Conrad’s “glimpse of truth” offers the chance for transcendence that is possible for the audience when the storyteller is effective.

In a time in which we seem to be getting more and more disconnected from those who inhabit the world with us, reading good, powerful narratives that help us empathize may be an important factor in keeping us more human and more connected with each other. Certainly, illness narratives are a way of also acknowledging a segment of our society that is marginalized, much like Bauby's "dead-end corridor." But one of the most important attributes human beings can have in order to make our world a place of peace is empathy. Maybe reading the pain of others is a step in that direction.

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Teaching Background

Teacher and English Department Chairperson

Our Lady of Providence Junior/Senior High School, Clarksville, Indiana (1991-present)

- American Literature (colonial through modern)
- World Literature (survey of various cultures with emphasis on Latin American, African and Asian literature from the ancient world through post colonialism)
- British Literature (survey from Beowulf through modernism)
- Creative Writing and Advanced Creative Writing
- Film Literature
- AP English Literature and Composition

Adjunct Instructor (dual credit teacher for IUB at Providence)

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 - L202 Literary Interpretation
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Scholarship

Ph.D. Humanities, University of Louisville (2011)

Dissertation: *Embodied Consciousness in Non-Fiction Illness Narratives: A Phenomenological-Sociological Approach*

This dissertation uses a phenomenological and sociological lens to explore how non-fiction illness narratives help us understand how perception of the self is disrupted because of serious illness or injury. Specifically, I use the French philosopher, M. Merleau-Ponty's phenomenological thought concerning the body and the sociological perspective of medical sociologist, Arthur Frank and his types of narratives and how culture helps construct illness. I analyze the works of four different writers: Sarah Manguso, Oliver Sacks, Jean Dominique-Bauby, and Anatole Broyard.

M.A. Humanities, University of Louisville (2000)

Thesis: *The Individual and Community: A Communitarian Understanding of African Values Systems*

The thesis includes the Western debate between liberalism and communitarianism, how the individual has been given primacy over the collective, an idea rooted in Lockean theory. The project examines liberal theories of justice, as well as metaphysical arguments in African perceptions of society including the religious framework whereby African theologians argue for a substantive communitarianism for Africans that advocates the view for the primacy of the community over the individual. The thesis discusses how communities and cultures are constructed and how recent critical theory has given agency back to human beings in the individual/community relationship. The conclusion is that perhaps by incorporating the best of both liberal and communitarian thought, a cure may be found for the ills that plague both systems, at least theoretically.

Conference paper: “Djuna Barnes and *Nightwood*” (Kentucky Philological Association)

Conference paper: “The Works of Flannery O’Connor: Transforming Illness into Narrative”

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Conference Presentation: “Teaching Research and Disabilities Awareness” (Indiana Non-Public Education Conference, Indianapolis, Indiana)

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Professional Activities

- Professional Teacher License – Indiana Department of Education
- IGNITE Chairperson
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- Theatre Department: Properties Director for Spring Musical
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Community Service

- Pilot Club of Jeffersonville, past president: an international service organization that stresses community service: awareness and service projects for brain-related injury/illnesses
- Bliss House Committee (Center for Lay Ministries): a half-way house for women addicted to drugs and/or alcohol in recovery
- Volunteer tutor: Afterschool Literacy Program – Wesley United Methodist Church
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Recognition

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