

Symptoms of Self-Image: Medical Diagnosis in Contemporary Narrative

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Symptoms of Self-Image: Medical Diagnosis in
Contemporary Narrative

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Introduction

Illness touches all of us, both directly and indirectly, and to respond to a reality with physical and psychological ramifications, we turn to diagnosis for answers. The role of diagnosis is to place a name upon a bodily disorder, giving a patient some idea of what has gone wrong in his or her body, and how life may change. At its essence, diagnosis renders a mysterious set of symptoms into a tangible, understandable disease that can, ideally, be recognized and treated. Yet this perspective can seem strangely simplistic. How can a single word or phrase encapsulate the variable and far-reaching effects of illness on the complicated lives we live? And what are the effects of the application of the phrase to a patient's life: a comforting awareness, an estrangement from healthy society, or something in between?

The narrative of illness often deviates from the simple symptoms-diagnosis-treatment-health story, especially when chronic, terminal, or unknown diseases manifest in the body. Chronic disease changes not only physical aspects of health, but also the way individuals perceive themselves and their position in family and society. When faced with serious disease, some turn to writing to chronicle their experiences, and these illness narratives provide a uniquely personal window into the relationship between illness, diagnosis, and

self-image. Additionally, fictional accounts of illness provide societal perspectives and reveal useful frames for understanding these ideas.

A suitable place to start is with HIV/AIDS in the 1980s, which combined the reality of a very serious, fast-moving disease with strong societal stigma resulting from the overrepresentation of HIV/AIDS in fringe groups such as gay men and IV drug users. Dr. Anthony Fauci, current director of National Institute of Allergy and Infectious Diseases, a part of the National Institutes of Health, was a leading infectious disease researcher during this time. He illuminates the surprisingly quick and simple creation of a diagnostic name: Dr. Fauci and five other leading scientists sat down in a room at a scientific meeting and chose “human immunodeficiency virus” because a virus compromised patients’ immune systems, and “acquired immune deficiency syndrome,” or AIDS, because this virus caused sudden and massive loss of immune function. Yet the quick creation of a name for this illness had long-lasting effects, as the view of patients toward their disease shifted from “horror” before the terms “HIV” and “AIDS” existed, to feelings of “depression and dread” once these terms became known (Fauci). The scientific function of naming this disease was accompanied by psychosocial effects, giving afflicted patients a label for the reason their bodies were failing. While the name tamed the horror in patients’ view of their disease, the terms “HIV” and “AIDS” quickly became socially charged, carrying with them assumptions of contagion and impending mortality.

Moments of diagnosis are often incredibly powerful scenes in AIDS narratives, and commonalities in language appear in almost all of these scenes.

This particular diagnosis is one that has “blasted the world apart” and leaves HIV positive individuals completely unprepared for drastic termination of normal life, replaced by the constant presence of illness (Doty 139). Yet diagnosis is intriguing beyond just its power to reshape and end. It allows for a refocusing as well, a sudden urgency to discover what truly matters before it is too late. The stigma accompanying HIV/AIDS makes this diagnosis all the more complex, shaping both the social perspectives of those afflicted in these fringe groups (mostly gay men) as well as the personal identities of HIV positive individuals from socially “unexpected” places. In Abraham Verghese’s *My Own Country*, the middle-aged, devoutly Catholic, heterosexual Mr. and Mrs. Johnson must grapple with how to approach the presence of HIV in their bodies, as well as discover how it will change their social position (240-251).

Although a diagnosis can place an individual in a socially marginalized group, as occurred with HIV/AIDS, it also provides belonging and comfort in that same group. This comfort is unattainable for those who are sick yet have no name for their disorder, and another important reality to discuss is the complete absence of diagnosis for a chronic disease. In this situation, the illness narrative becomes an all-out search for diagnosis to name the disorder occurring in one’s body, yet this pursuit is often in vain. An uncomfortable tension exists in knowing something in one’s body is amiss, yet finding no affirmation in the medical sphere. Meghan O’Rourke, in her 2013 *New Yorker* essay “What’s Wrong with Me?” describes this situation as a concern she will be labeled one of the “worried well,” healthy individuals falsely claiming to be ill. Who will believe her

when the seemingly omniscient and invincible realm of medicine can't confirm her illness through a diagnosis? To what level does even she then question the presence of a disorder in her own body, as time goes on and she forgets what being healthy feels like? The traditional "medical narrative" begins with symptoms and moves linearly to diagnosis and treatment, yet some patients hang in the balance between the steps of symptoms and diagnosis, and utilize narrative to discern how they see themselves and their disease, as well as where they stand in the realms of illness and health.

Perhaps the opposite of an unnamed illness is the well-known cancer diagnosis, which carries serious implications of mortality as well as dependence, being a disorder generally involving lengthy and expensive treatments at best and, at worst, total loss of life. Paul Kalanithi's *When Breath Becomes Air* details his unique journey from neurosurgeon to terminal cancer patient. Although objective biology and medicine dominated his life until he learned of his cancer, data and survival curves gave Kalanithi no solace when he suddenly became a patient himself. He highlights a paradox of diagnosis, that before his diagnosis, "I knew someday I would die, but I didn't know when" and afterwards, "I knew someday I would die, but I didn't know when. But now I knew it acutely" (Kalanithi 132). The moment of diagnosis may physically change nothing, yet at the same time it changes everything. Echoing Mark Doty's explanation of the AIDS diagnosis as one that "blasted the world apart," Kalanithi's diagnostic moment was "as if a sandstorm had erased all trace of familiarity" (Kalanithi

121). The word “cancer” has this immensely influential effect, and literature both describes and responds to the life-changing power of both illness and diagnosis.

In chapter one, I will investigate how the HIV and AIDS diagnoses consume a patient’s identity and position them in a narrative that directs them towards physical and mental deterioration. Collectively, theoretical works by authors such as Julia Kristeva, Susan Sontag, and Sander Gilman express exactly how a diagnosis can infect a patient’s self-image with a sense of horror and separation from health and society. I will then analyze the nonfictional narratives *My Own Country*, by Abraham Verghese, and *Heaven’s Coast* by Mark Doty; through analyses of these works, I will show how diagnosis both ostracizes patients and fences them in with their symptoms. Through exploration of these books, along with other short stories, essays, and works of photography I will elucidate how the lives and identities of AIDS patients are split into two distinct segments, the *before* and the *after* of diagnosis, and how the sense of living, yet dying, shapes their reality.

Chapter two addresses the fact that although all sick patients seek diagnosis, often this is unattainable when the medical world is unable to provide a name for a specific person’s set of symptoms. The absence of medical terminology to classify a disorder can have lasting effects on an individual whose life is being altered in a major way by disease, yet this same disease can’t always be proven or acknowledged by modern medicine. Alan Lightman’s *The Diagnosis* speaks to how precisely this lack of a diagnosis leads to a loss of agency for a patient. My analysis of this novel is followed by a discussion of Joshua Ferris’ *The Unnamed*,

as well as theoretical works by Annemarie Jutel and Michael Foucault, which show how patients, without the assistance of diagnosis, must determine for themselves where to construct boundaries between sick and healthy in their own bodies. The dehumanizing nature of this self-analysis leads to a conversation of how unnamed diseases appear to patients; the indescribable nature of these undiagnosed disorders gives the disorders themselves a mysterious, all-encompassing personality of their own that continuously pulls at the seams of a patient's identity.

In chapter three I will extract meaning from the experience of a cancer diagnosis. Works like Lorrie Moore's short story "People Like That Are the Only People Here: Canonical Babbling in Peed Onk" and the videogame *That Dragon, Cancer* show how illness affects an entire family. In these stories, parents of children diagnosed with cancer try to reduce diagnosis to something tangible that they can understand. This chapter explores how diagnosis promises, yet ultimately fails, to encapsulate the multidimensional experience of illness in a single phrase. The theory of Susan Sontag exposes the role of narrative in depicting and comprehending disease—the very existence of this thesis is based on the power of narrative to represent disease and diagnosis. In this chapter I will show how narrative can accompany, or even replace, diagnosis in providing meaning and sense to those whose lives have been reshaped by cancer.

Chapter 1

The HIV/AIDS Diagnosis

The intersection between health and disease maintains a constant presence in human life, resulting in both physical and psychosocial effects—those non-tangible, yet undeniably present and important impacts that our views upon disease have within our lives. They shape how we frame ourselves, each other, and the world around us. The complex methods we consciously and unconsciously use to grasp breakdowns in health are difficult to quantify, yet through discussion about them we can learn about how and why we react to disease the way we do. This discussion begins with utilizing literature concerning patients afflicted with HIV and AIDS in the 1980s and early 1990s, a period during which these disorders left behind a wake of destruction and societal stigma.

Important distinctions exist between the experience of having an illness, and of living with a diagnosis. While the two occur simultaneously, having an illness is characterized by experiencing a specific set of symptoms, whereas living with a diagnosis involves constantly carrying the weight of a label. A diagnosis is an attempt to transform a disorder into words, labeling a patient with a term or phrase that carries assumptions linked with the disorder. Through investigation of diagnosis in contemporary narrative about HIV and

AIDS, I have found that the effects of a diagnosis upon a patient's self-image distance patients from their communities, and box them in with mental images and associations of their illness's manifestations in the human body. The frame of HIV/AIDS both isolates the afflicted from society and eliminates their imagined distance from mortality and disintegration. This diagnosis also changes the space of an individual patient's body and immediate surroundings into a reductive zone, in which others search for evidence of HIV and AIDS while ignoring this person's humanity. HIV/AIDS patients don't just live with their syndromes; instead, inhuman, deathly symptoms emanate from their bodies, and symbolize a terrifying tension between where the living ends and the dying begins. The diagnosis abducts the identity and places the person on a path towards a specific physical and mental destination, often holding the individual captive on a journey towards disintegration and isolation.

When we think of HIV/AIDS in the modern era, we think of a chronic, yet manageable disorder obtained through sex or intravenous needle use. But it is important to realize that our perception of these disorders has shifted drastically in the past few decades, due to medical improvements and changing societal stereotyping of those with HIV/AIDS. In the early 1980s, most people viewed an HIV positive diagnosis as a death sentence, which was not an illogical view at the time. The first effective drug, which only slowed the effects of AIDS, didn't appear until 1987 (History of HIV and AIDS Overview). Additionally, the disorder was viewed as one that afflicted mostly homosexual men, with intravenous-drug users and hemophiliacs affected to a lesser extent. In reaction

to this epidemic, societal constructions emerged of the disorder and those afflicted by it as a distinct, unnatural *other*. This social view of HIV and AIDS had both purposeful and subconscious roots, and the construction of this frame is addressed in Sander Gilman's book *Disease and Representation: Images of Illness from Madness to AIDS*.

One of Gilman's most compelling arguments is based upon the idea that when humans face a threat, we naturally seek to distance ourselves from it. This distancing is not just physical, but also mental. It is impossible to ignore our mortality in a world so full of injury and disease, so even when someone sick doesn't pose a specific threat, their very existence serves to illuminate our own impermanence. The "terror of potential disintegration" is something humans live with yet hope to keep far away from present circumstances (Morantz-Sanchez). The first step to remove one's self from harm's way is to define those who are in danger, so those afflicted with disease are labeled the *Other*, a group distinctly separate from those who are healthy. Here, they are conveniently detected with the presence of the specific HIV/AIDS diagnosis (Gilman 1).

The *Other* are afflicted with a disorder that embodies fears society has about its own mortality. *Othering* is generally a non-tangible action, but it is one we all perform constantly. Someone need not be visibly diseased to be seen as a threat to our mortality—the mere knowledge that someone has a tumor or an immunodeficiency syndrome appears equally as terrifying as an individual whose suffering stems from a visible source. Because *othering* serves to separate ourselves from disease, those who appear outwardly healthy and "normal" but

are inwardly sick show that the distinction between health and illness is often difficult to make, and that this imagined separation can disappear as quickly as our perceptions of someone can change.

Phrases found in literature about these *othered* groups show their heightened separation from “normal” society. One 1990 newspaper article referred to HIV/AIDS as “the gay plague,” and implicit in this term is a specific attempt to further alienate this diseased group from the non-diseased public (Bremner). Although initially the majority of those afflicted were gay men, many with the disease were not. By not acknowledging these non-gay afflicted HIV/AIDS patients, heterosexual members of the public could point to their sexuality as a way to assuage their fears of acquiring HIV. Secondly, this article posits that HIV-infected people aren’t just sick; they have a “plague.” It seems backwards to call a disorder a “plague” to reduce fear of it, but now HIV has been framed as a plague affecting only homosexuals. “Human immunodeficiency virus” seemed far more terrifying to heterosexual America than a plague that seemingly affects only the homosexual population. Additionally, referring to these members of society as “plagued” results directly from notions of identifying and distancing those afflicted, and serves to assuage some level of guilt for their psychological, and sometimes physical, exile.

Discussion of *othering* naturally leads to a discussion of boundaries. Centuries ago, how were people infected with the bubonic plague dealt with by the healthy population? Often, they were kicked outside of the castle walls. Because kicking the intimidating, supposedly threatening diseased population

out of our cities is now unethical, the boundaries built are now utilized in the social psyche. Julia Kristeva and Michel Foucault provide an interesting discussion of the complications inherent in constructing these borders.

Kristeva focuses on the psychological difference between the “I” and the “abject,” which includes the non-living byproducts of humanity. Our mucus, for example, is a normal (if distasteful) part of ourselves, yet once it leaves the boundaries of our bodies it becomes something different: clearly non-human. Abjection “notifies us of the limits of the human universe”— the universe physically made up of humans—but the line between ourselves and everything not-ourselves is complicated by disease (Kristeva 11). We naturally seek to view disease as abject, something distinctly non-human. The main method through which we separate ourselves from the abject is our skin, but the physical aspects of disease themselves are microscopic invaders. Often skin is easily circumvented, or even passed through directly by viruses and bacteria. Disease uniquely complicates the boundaries between our bodies and our surroundings.

Foucault poses a different question, which further complicates the topic of viewing disease as something distinctly abject: How can we view disease as an outside phenomenon, when by definition human diseases survive through human beings? “The organs are the concrete supports of the disease; they never constitute its indispensable conditions” (Foucault 10). Foucault’s choice of the descriptor “concrete” emphasizes the idea that humans are not just *a* support that diseases subsist off of; we are the *only* subsistence they require. If our presence feeds and houses a disorder, how separate can humanity and disease

truly be? This is especially true of HIV—the virus physically lives inside the cells of the immune system for years before the massive immunodeficiency called AIDS emerges. It is impossible to frame disease, especially one as intimate as HIV/AIDS, as a distinctly non-human entity. We mentally seek to locate virus and harmful bacteria as outside of our bodies, yet when they cross the physical boundary of our skin suddenly discussion, study, and fear of pathogens begins to involve the human body itself.

Our attempts to distance ourselves from HIV/AIDS, and to construct a border between the healthy and the sick, thus lead us to include the afflicted in our framing of the disease. This leads directly to the construction of stigma around the HIV/AIDS diagnosis. To fully view HIV/AIDS, “to fully grasp the disease, one must look at those parts where there is dryness, ardour ... humidity, discharge, debility” (Foucault 13). Here, Foucault states we must look at the disease’s manifestations in the afflicted to “fully grasp” it. Yet this imposition of a disease’s character onto individuals affected goes beyond giving healthy people a “grasp” of illness. HIV positive individuals have characteristics and limits that cannot be imposed upon the abstract idea of “disease.” Their distinct humanity and emotion, as well as their inability to destroy a population like an epidemic does, are just a few differences overlooked by imposing disease onto the sick. By melding invisible molecular infiltrators with diseased citizens, an unreasonable, yet present, boundary is imposed between HIV positive and HIV negative individuals. In attempting to understand and localize disease, people afflicted with a disorder are also subjected to something Foucault calls the “medical gaze”

(Foucault 9). They are dehumanized, becoming no more than a template through which a disease can be viewed.

In addition to being ostracized at great length by society, people in this *othered* HIV/AIDS category are also fenced in by humanly created boundaries. This construction thus serves to keep healthy, “normal” people out but at the same time further boxes the diseased in along with their symptoms. And the worse these symptoms are, the more impregnable are the walls that the healthy population seeks to construct. This extreme case of *othering* is what was applied to people in the HIV positive community in the 1980s. Not only were these people doomed to die, they would also suffer psychosocial exile as their bodies degenerated. The method of this degeneration wasn’t clear, so the ambiguity in their future symptoms served to add even more reason to mentally separate them from the healthy population.

Specifically from the perspective of people afflicted with HIV/AIDS, the moment of diagnosis is a time when questions arise about consequences of past actions relevant to the disorder. Such a moment is outlined in Mark Doty’s *Heaven’s Coast*, when Mark and Wally learn that Wally is HIV positive, while Mark is not. The story is told as if from the perspective of both Mark and Wally together, and upon hearing the news they were struck with a “sense of an enormous rupture” by this “fundamentally inadmissible, unacceptable” announcement (*Heaven’s Coast* 140). The description of their response is important—the news being initially “unacceptable” shows the mindset that this turn of events defies a cause-and-effect view of their world. The news is

“fundamentally inadmissible” because for them, their karma doesn’t add up to this new reality. Thus, in a way the “enormous rupture” is in their just, causational view of the world which has been torn apart by the initial diagnosis. The world is now “wildly unfamiliar,” as Mark and Wally cannot believe that they could be struck with such terrible news, which they feel defies the benevolent lives they have led (Heaven’s Coast 141).

As much as Mark may try to believe otherwise, the diagnostic frame has encased Wally and Wally alone. It has created a separation between Mark and Wally, a distinction between caretaker and afflicted. No matter how close a caretaker gets, physically or emotionally, he or she can never be the person with AIDS in this dynamic. This new relationship is immediately imposed by the diagnosis. One explanation for Mark predicting that the future will be “wildly unfamiliar” is because he realizes that the diagnosis has sentenced him to a future of caring and empathizing, but never truly existing as Wally’s equal. Diagnosis thus has undeniable and permanent effects the moment it is spoken into existence, due to its ability to render a once-equal relationship into one of caring and receiving, of giving and taking.

In an interesting dynamic, the imposing of the frame of HIV positive onto Wally drastically shifted the way Wally and Mark viewed their world. Especially in these early years of the epidemic, very little was known about how the disease worked. A void in understanding exactly how the disorder was transmitted and wreaked havoc from the inside outwards stoked the desire to delve into questions of whether one’s actions had directly caused their affliction, as the

exact cause of HIV/AIDS had remained elusive to scientists. Mark is struck by such a plethora of questions, wondering if some people were “naturally resistant” and how he didn’t have the disorder when he and Wally had engaged in “unsafe sex countless times” (Heaven’s Coast 141). For him, the sudden diagnostic presence accentuates the innate human desire to find moral causality for the state of the surrounding world.

In a sense, a diagnosis of HIV infection is a forceful and communal one. As Sander Gilman posits, “AIDS is a disease that evokes past casualties” (Gilman 7). This perspective of AIDS stems from the constant, terrifying presence AIDS had in the mass media and American culture when it first emerged as an unknown threat. Driven by the enduring goal of delivering the most sensational news possible, the media conveyed images of people with AIDS that purposefully emphasized the physical and mental suffering of people afflicted with the disease. So when they heard the phrase “HIV positive” drop from their doctor’s lips, Wally and Mark would likely have immediately thought of the “past casualties” they associated with AIDS, both of its horrifying presentation by the media as well as any personal heartbreak they had experienced with the disorder among friends and family affected by the disorder. The moment of diagnosis is characterized by an imposition of these images of suffering onto the currently healthy HIV positive patient, leading to a sense of vulnerability on the patient’s part.

The diction of this scene also emphasizes the permanence of the HIV frame in which Wally is suddenly enclosed. A “rupture” is never simply sealed,

even with time—use of this word implies there is no going back to the previous, whole self that was Wally. This permanent, destructive term is also applied to the boundaries Wally and Mark held between themselves and illness, separating them from death. They may have never before considered such borders, but the acute and unexpected “shattering” of these boundaries has an all-encompassing impact, leaving no room for pretense about the presence of death in their future (Doty 140). The world is now “wildly unfamiliar” as the frame of HIV, and eventually of AIDS, will envelop Wally until his death. The experience of diagnosis has forced this realization onto both Mark and Wally.

Interestingly, hidden in Doty’s proclaimed disastrous shock of the moment, he admits it was “not a surprise” (140). This lone admission must be founded in reality; a gay man like Wally falling suddenly sick in this period was a massive red flag that couldn’t have gone unnoticed by both Mark and Wally, both logical and practically minded about the world around them. This tiny inclusion sheds light on the un-ignorable magnanimity of an HIV diagnosis at this time in history. We all possess the centuries-old concept of a diagnosis. This perception is characterized by an inherent trust in the word of a medical expert, creating his or her ability to reshape a patient’s perspectives towards illness and agency in their lives with a single declaration of a disorder’s name. The diagnosis is unforgettable, undeniable, and permanent.

This realization sheds light on why Doty’s admission of prior knowledge, or at least suspicion, was so slight, hidden between weighty phrases like “enormous rupture” and “a horror” (140). Intriguing interpretations exist here,

one being that Mark recognizes that while Wally's agency will decline swiftly, Mark's own potential remains unscathed, perhaps somewhat checked by his new role as caretaker. Returning to spatial metaphors, perhaps the boundaries separating Mark and Wally from illness and disintegration are not fully torn down. Instead, Wally's diagnosis may place him firmly on the diseased side of the wall, and while Mark seeks to view himself as Wally's equal, he is trapped on the other side of the wall, the one with health and normality and no positive diagnosis. Mark's apocalyptic diction then represents his response to Wally's terrifying new location on the health-to-disorder spectrum, while Mark's reluctance to admit his prior knowledge represents his understanding that Wally's diagnosis creates an insurmountable rift between the two. At the very least, if Mark can enter Wally's space of isolation, he still retains the ability to leave the space to which Wally has been permanently exiled.

The concept of space applied to Rebecca Brown's *Gifts of the Body* allows for an interesting perspective on how AIDS maintains a physical presence around an afflicted individual. This presence includes both the space *of* the afflicted body as well as the space *around* the body, in which interactions between the diseased patient and other individuals take place. The very presence of Brown's narrator, a hospice worker, around diseased individuals signifies their lack of agency and ability, and serves as a reminder of their constant helplessness. When asked how she is doing, one patient repeatedly responds with the simple phrase "I'm fine, I'm fine," and every repetition of this statement is an attempt to resist the sense that her role is not of a giver, but of a

receiver of assistance (Brown 53). As the narrator prepares to leave Ed's apartment, he asks "why did you come here?" and when she responds "to see you," Ed immediately asks "you didn't have to?" (Brown 73). These scenes, along with the images throughout this story of living rooms cluttered with intravenous-bag poles, pills, and medical machinery, reveals the striking shift in the living space of an AIDS patient. As medical paraphernalia builds up following AIDS symptoms, the space of a home is transformed into a lived hospital, an area in which the maintenance of health is the focal point, instead of the comfort of living. Embarrassed about a condom catheter, another patient explains that "everything new is something else you've lost" (Brown 42). Viewing this statement through a spatial lens, we see that the physical space around a person afflicted with AIDS becomes more stifling with every change. The experience of AIDS is one involving a constant medical presence, and the appearance of this presence removes comfort and relaxation from an individual's personal space.

Other spaces play roles in the lived experience of AIDS, such as the waiting room in R. S. Jones' *Walking on Air*. Everyone in the room waits to see the doctor, an AIDS specialist, and they are all aware of their commonality: the AIDS diagnosis they share. But what does awareness do to this physical space? Immediately upon entering the waiting room, William, a patient, studies "the faces around him for signs of deterioration," as they view each other as "reflections of their own disintegration" (Jones 59). Each patient arrives surrounded by an aura of deteriorating health, which is magnified by their collective presence waiting to see a medical professional and validated by

crumbling word choice such as “deterioration” and “disintegration.” But these patients are not just mirrors of each other’s symptoms. William feels “entombed by their contagion,” which adds an interesting dynamic to this discussion of space (Jones 60). Although William claims that it is “contagion” that makes him feel deathly restricted, one wonders whether it is his own mortality.

William already has the disorder, and what is more, he understands that methods of contracting AIDS are very specific and intimate. In reality, William feels “entombed” because by being located near other AIDS patients, he notices their surrounding spaces are inscribed with evidence of pain and anguish, “pale with imminent death” (Jones 60). So it is not simply their symptoms that these AIDS patients see reflected in others with the disorder. They also recognize that their subtle interactions with each other—quick glances and greetings—revolve around their battles with AIDS. They realize that their own situations are the same as those of the other patients in the waiting room, and that their common AIDS diagnosis changes their spaces into ones of mortal struggle. Thus, these patients are reminded of the morbid character of the spaces they themselves inhabit, and this knowledge leads to a sense of entombment, a space those diagnosed with AIDS inhabit until death. The AIDS diagnosis removes a person’s control over his or her image and personal space, changing what was once owned by the patient into an area constructed by a viewer searching for signs of illness.

The main character’s experience in Brown’s work highlights specific aspects of the construction of a diseased space around AIDS patients. Upon first

viewing a patient, the narrator immediately notes that he was the “scariest” to look at, that he “really looked like the plague” (Brown 117). Kristeva’s concept of the abject and its role in human perspective on disease serves to illuminate the ability of these sores to dominate the aura, and character, of an AIDS patient. The narrator focuses in upon quarter sized, “dark purple” sores covering the patient’s body, and this description is swiftly followed by an image of his “dark brown” skin. This colorful imagery is purposeful; contrasting of the “purple” sores with the “dark brown” skin represents another contrast that shapes the experience of AIDS patients, that of inhuman symptoms emanating from a human body. Although originating from a man, these sores are distinctly non-human, unmistakably purple to the dark brown of his human skin. The competing presence of both human and abject is flung in the observer’s face. The condition of AIDS is thus framed here as one in which careful study must be applied to differentiate between the dying and the living aspects of a patient’s body. The sores and lesions act as evidence of morbidity written upon a patient’s skin, etching a sense of lifelessness onto the afflicted, who are still very much alive. So the perspective of AIDS carries with it a unique and terrible insinuation that the afflicted live with death.

The physical line between man and sore is a focus of this horrible fascination, as the caretaker in *Gifts of the Body* specifically describes the “yellow ... edges” between sore and man. This client is “scariest” to look at because his clearly visible symptoms force the narrator to consider the line between human and abject. Brown’s choice of “yellow” as the color of this border is significant, as

yellow often conjures notions of sickness, or a humanity somewhat removed from health. Fascination in the line-drawing between man and sore leads the narrator to find that the boundary is far fuzzier than expected. This is emblemized by the color yellow, which is non-human yet only a few shades away from the hue of healthy skin. The stark realization of the blurriness of this line between humanity and the abject is terrifying.

Viewing this boundary's impermanence, we might imagine ourselves slipping into the non-human other, and we "give birth to [ourselves] amid the violence of sobs, of vomit" (Kristeva 3). The emotion seen in Kristeva's gut-wrenching phrasing is the reality of someone living with AIDS' image. In Jones' *Walking on Air*, the main character describes lesions on a patient as "leeches," that were "travel[ing] across his skin" (60). Here, the abject isn't just lifeless—it is an actual creature. The choice of animal is purposeful, as the blood-sucking leech has a predatory aspect to it. Here, AIDS has transformed this patient's space into one of mortal battle, fighting to hold onto one's lifeblood. With an AIDS diagnosis comes a license to be viewed as partially human, partially abject, and this leads to the shift in ownership of space and perspective.

Beyond the caretaker's first reaction to a specific patient's appearance, Brown chooses to devote a full page of vivid language to this man's sores and corresponding salve, while never mentioning the client's name. Brown chooses to omit this character's name because in the eyes of the narrator, she isn't working with a patient; her role is to work with his sores. His AIDS-induced sores haven't necessarily taken his name, but they have re-structured his natural

human hierarchy, and his sores are more characterizing of his being than his own name. She also isn't working in the space of his home, she is working in a zone of medical salve and symptomatic AIDS. The experience of inhabiting this zone is shown in the description of where her eyes focus while applying salve to the sores. Actually "touching the body," she has delved deep into the client's space (Brown 121). Instead of focusing on her client's presence directly in front of her, she asks him about an exotic African painting above his bed, responding to the uncomfortable experience of being so immersed in an AIDS-afflicted zone by seeking to mentally travel to far-away Africa. Embodied in his uncomfortable physical space, this man's diagnosis and his symptoms have covered his original identity.

This is a new concept in this chapter's discussion of the frame of an HIV/AIDS diagnosis. It is not only the ideological borders standing between someone and their mortality that are restructured with an AIDS diagnosis. Additionally, their self, at least as perceived by others, is eroded away with the appearance of physical symptoms. In a sense, these people are known before they are met—their identity as an HIV positive individual creates a personality in the beholder that may reflect nothing of their actual character. For example, the patient mentioned above is reduced to a battle between man and creature, human and leech (over the possession of blood). To expand upon this experience of being known before having met someone, Brown introduces Roy. An elevator attendant in a client's building, Roy knows the narrator's name before he ever saw her face, and this experience was beyond just "weird" (Brown 88). This

image juxtaposes the previous scene of the caretaker applying salve to a client, as here the elevator serves as the space in which one's identity precedes their actual presence. Roy imposes a pre-determined identity upon the caretaker in the confined space of the elevator, leaving the caretaker very uncomfortable. The full five pages spent on the brief scene between the narrator and Roy also emphasize the strikingly uncomfortable nature of this dynamic.

This serves to emphasize the tensions AIDS patients feel, knowing they are preceded by an identity separate from their own. Living in a social culture, we take solace in our right to shape how we are seen by others. But this right is stripped away, or more exactly it is overshadowed, by the HIV/AIDS diagnosis. The experience of this diagnostic reality is that the label of HIV or AIDS seems so important and weighty that it overshadows the societal expectation that one shouldn't judge someone else by their appearances, that you can't know someone until they are met. The diagnosis removes, in a way, those carrying its label from the social expectations and rules of interaction our society is constructed around.

Brown's narrator's horror at abjection, simultaneously personified in her client while removing his humanness, leads to statements like "everyone who gets it [HIV/AIDS] didn't have it once" (Brown 139). This statement's importance lies in its very existence—once AIDS has claimed an identity, it becomes easy to forget that at one point, this person's name and personality held claim over their identity. In his photographic work *People with AIDS*, Nicholas Nixon attempts to tell the stories of fifteen people afflicted with AIDS to attempt to reclaim these

lost identities. Yet although each patient looks unique in the beginning of their chronological photo series, the images at the end provide no such distinction. The gaunt face suspended above a stark collarbone, holding on to fragile arms, appears at the end of every story. This terrible reducing quality of AIDS is clear in the minds of the afflicted, and Tom Petchkiss seeks to argue against it, stating “I still look pretty good. Not like your typical AIDS patient, anyway ... I just don’t think I fit any preconceived notion of what sick people look like” (2). Although Tom may not mirror the reduced, gaunt image of AIDS yet, this image still exists clearly in his mind. Thoughts like these show that the process of living with diagnosis is characterized by the inevitable sense that one will lose their individuality. This stems somewhat from representations of HIV/AIDS in the media, where the afflicted inhabit the “classical iconographic position of melancholy” (Gilman 259). Tom knows that visual markers of AIDS will come to strip him away, and he is consciously attempting to resist this expected reduction to the image of the AIDS diagnosis itself.

So even before Tom’s appearance has taken priority over his self, he fears that it will. This is what accompanies the HIV/AIDS diagnostic frame, a deeply feared, yet profoundly known, fact that the diagnosis places not only a time limit on one’s life, but also upon one’s perceived identity. Through these abjection-fueled frames of people with AIDS, the experience of an AIDS diagnosis becomes one of fearing both physical and social disintegration. As the boundaries between one’s self and illness and mortality lower, one’s personal identity diminishes. Maybe these actual boundaries aren’t destroyed; instead, returning

to spatial perspectives, perhaps it is that an HIV/AIDS diagnosis shifts one's location to the side of the boundaries that includes mortality and abjection, and excludes power and agency over social identity. Norman Sanger, in *My Own Country*, lived his whole life characterized by two traits, "*courage and dignity*" (Verghese 340). Yet the personality he had built to fight his hemophilia disorder was torn down by the frame of AIDS. His fear was revealed through his confiding in Verghese that "last night, for the first time since I was a little boy, I wondered whether I could keep it up, whether this disease would make me lose it all?" (Verghese 340). Norman's identity was restructured, and he became a "little boy" again, losing control of the social and personal view of himself that he clung to his entire life.

A specific experience of the caretaker in *Gifts of the Body* sheds light on the hierarchical reordering of an AIDS patient's identity. While simultaneously applying salve to a patient's sores and conversing about a patient's past, she notes that "it was like there were four people there," two people "having a normal conversation" and one person "touching the body with the salve" and another "with the body with the sores" (Brown 121). This speaks to the narrator's struggle to navigate a sick man's physical space. She views this zone as one of having and battling against illness, creating the dynamic of touching the body's sores with the salve. Yet at the same time, the normal conversation the two are having shifts the dynamic to one not involving health, one reminiscent of the actions of the "normal." This excerpt posits that although the struggle with

AIDS may take dominance of someone's image, humanity still remains, sometimes surprisingly.

The casual diction of Brown's narrator stands in stark contrast to the unique and divisive idea she posits. She uses phrases like "part of it felt good" and "normal" as well as repetition of words like "conversation" and "body," a simple word choice (Brown 121). And in addition to this colloquial nature and structure, the discussion of a psychosocial split is brief, lasting only three sentences before moving onto the patient's life before diagnosis. Here, the narrative itself is consciously structured as a space, one in which simple, brief diction and description seem to highlight the narrator's distress. More precisely, this narrative space emphasizes the uncomfortable, hidden nature of this split in psychosocial perspective. In getting so close to the patient, the narrator must address the dehumanization of a patient to his symptomatic struggles, and her issues accepting this are echoed in the story's discordant narrational structure itself.

Although most illness narratives focus upon the experience of living with a disorder, many also contain important clues about someone's life before the disorder. In the case of HIV/AIDS, the importance of these clues lies in their ability to paint a portrait of someone's life preceding diagnosis. This technique can be used in Nixon's *People with AIDS* to illuminate a temporal aspect of the AIDS diagnosis, juxtaposing a patient's mindset before and after HIV appeared in his or her life. Tom Petchkiss states that "before I was sick, I never would have considered a project like this one ... to speak out against medical insensitivity"

(Nixon 2). Because HIV was an incurable disorder in the 1980s, a diagnosis was in a way a death sentence. Statements like Tom's were prevalent in HIV/AIDS literature, because an HIV or AIDS diagnosis was, at its heart, the imposition of a ticking clock. This quantification of one's future begins as soon as the doctor answers the "how long do I have to live" question. Because of the inherent life-changing aspect of a terminal diagnosis, the life of someone afflicted is split into two temporal zones; the *before*, a time of health and normality, and the "harrowing, forward-pouring *next*," when a person is identified primarily as a patient, surrounded by a medical and degenerative sphere (Doty 140).

This splitting of one's lifetime into "before" and "after" results in an unexpected and confusing split in identity. If one's life is split in two, then in some sense the life was lived by two separate people. This sentiment is captured in Tom Petchkiss' struggle to tell his own story, as he states that "I was ... I *am* an actor" (Nixon 2). This slip-up echoes an internal conflict within Tom to fight against the tendency to view his post-diagnosis identity as distinct from pre-diagnosis. Perhaps times of health and work appear so foreign to the afflicted that although they may have occurred recently, they are viewed as if they are someone else's memories. Tom's tone, seen in the italicized "*am*," shows his passionate response to this imposed separation of his once-unified identity. This temporal division is an uncomfortable reality, shown in Tom's ardent attempts to resist it. In his *New Yorker* essay *The Way I Live Now*, HIV/AIDS patient and writer David Leavitt elucidates the exact psychosocial effects of this new identity's presence. He notes that many gay writers didn't write on the epidemic

until in “the panicked wake of diagnosis” (Leavitt). Diagnosis here is presented as a destructive event, leaving a “wake” behind it. It is a loud and dangerous incident, almost like a natural disaster. The choice of “panicked” fits in with this idea, showing that the post-diagnosis identity is, at least initially, a frantic and pressured experience. Although we all recognize that our time is limited, diagnosis changes this by not only accelerating the clock, but also making the presence of this ticking motion towards death much more obvious.

The chaotic effects of this omnipresent clock are seen in the sentence structure and diction of Susan Sontag’s *The Way We Live Now*. The sentences are jarringly long and riddled with commas and clauses, echoing the frantic and bouncing stream of thought in the mind of someone recently diagnosed. Perhaps much of this mental turmoil results directly from confusion over the main character’s fractured temporal identity. His revelation is that post-diagnosis, all one can do is “wait and hope, wait and start being careful” (Sontag 8). The repetition of “wait” is seen throughout this section of the story, and shows a constant, looming presence of time in his perspective of his own reality. He also states that “becoming seriously ill was something that happened to other people,” emphasizing that the persona he now feels is something he doesn’t recognize, as he only ever saw or imagined its existence in the lives of others (Sontag 8).

Another, more encouraging perspective of the temporal aspect of an HIV/AIDS diagnosis exists in Nixon’s photographic work, one of devotion and rebirth. Tom Petchkiss’ animated “*I am an actor*” indicates a passion missing

from his pre-diagnosis life. This perspective sheds some light on an interesting statement Mark Doty makes in *Heaven's Coast*, that AIDS acts as an “intensifier, something which makes things more firmly, deeply themselves” (Doty 3).

Perhaps the diagnostic expulsion of one’s past identity creates a chance to form a new character. Specifically, the pressure of time seems to exaggerate aspects of life that mean the most to the afflicted. The experience of diagnosis can be one of opportunity in a way. The writers David Leavitt references, although struggling with fear and confusion in the “panicked wake of diagnosis,” are galvanized to take the opportunity to write on this taboo topic.

Susan Sontag both supports and complicates this notion in *The Way We Live Now*, specifically in her portrayal of the main character’s choice to keep a daily journal. This diary was, in a way, a means of “slyly staking out his claim to a future time,” and “accumulating something to reread one day” (Sontag 15). The choice to keep a diary is an example of re-creation, of taking diagnosis as an opportunity to act in a way that reflects what matters most to the patient. Specifically, the diary is an example of the use of narrative to create one’s self anew. These written words are an extension of the patient, and the writing embodies his rebirth. Additionally, once diagnostically trapped in an identity scarce with time, the main character utilizes this diary to capture the fleeting present. In an interesting way, to battle a lack of time he chooses to encapsulate the time he does have. He now has the ability to access his past by simply opening up the diary at any moment, a newly accessible window into the past. Yet Sontag addresses the reality that this rebirth has a ceiling. As the physical

symptoms of AIDS manifest, the handwriting becomes “less legible” in the more recent journal pages (Sontag 15). This re-creation and embodiment of self in the diary is temporary. The captured time in the diary is ultimately prone to AIDS symptoms of its own, becoming “spidery” as a patient’s mental state deteriorates (15).

The temporally measured nature of the new, HIV/AIDS afflicted self is noticeable to those close to the afflicted. In *Gifts of the Body*, the caretaker learns that her boss, Margaret, contracted HIV and overhears her discussing plans for the “summer after next” at a work function (Brown 146). The caretaker’s eyes suddenly “shot over” to Margaret, who saw her “wonder how long she had to live” (Brown 147). This scene speaks to shifts in both the space of their work and the perceived identity of Margaret. The company office had become a reprieve from the daily presence of HIV/AIDS and other illness encountered routinely by hospice workers. But the mere knowledge of Margaret’s diagnosis shifted this space noticeably. It wasn’t the risk of Margaret’s contagion that caused this change, as every healthcare worker present knows they aren’t at risk just standing near an infected individual. Margaret’s diagnosis has shifted her body, and the space around her, into a place to seek evidence of temporality and disintegration. Michel Foucault’s concept of the medical gaze is useful in considering this context, as it refers to the methods through which a sick individual is naturally viewed by somebody else. This “gaze” is naturally “analytic,” searching for signals of disease and naturally reducing a person to the object of a patient, to a “*spectacle*” at some level (Foucault 109, 108). Margaret

has instantly become an object of Foucault's medical gaze, which the main character is used to applying in her client's homes, but is new to the hospice building's space.

Margaret's discussion of the "summer after next" shocks the caretaker because that conversation defies the very nature of Margaret's new space and identity. One sociological study seeking to describe reactions to AIDS found that the "key question PWAs [Persons With AIDS] asked was: 'Will I be able to function tomorrow?'" (Weitz 275). The prevalence of this question in that study stems directly from the temporal focus of the frame of HIV/AIDS. Those inhabiting this frame are often expected to exhibit a mindset in which the unpredictability of the future leads to a single-minded focus upon the present. Margaret's engagement in discussion of the "summer after next" defies this expectation, and thus her diagnosis brings a temporal focus into the shared office space. Her terminal diagnosis has irreversibly placed ideas of the future into question, and as Sontag showed with her diary allegory, perhaps Margaret's discussion is an attempt to lay claim to her own future, which has been taken from her by her sudden and unexpected diagnosis.

Diagnosis, through contemporary HIV and AIDS narratives, is seen to take on a persona of its own. It envelops human identities, both illuminates and alters the boundaries we erect psychologically between ourselves and our mortality, and imposes a time limit on a patient's specific self-image. Diagnosis takes a man or woman's humanity, and uses it as a vessel to embody the living-yet-dying, frail and symptomatic essence of HIV/AIDS. Although actively spoken into

existence by a medical professional, it shifts from a simple phrase to a being of its own, and this transformation is highlighted in narrative representations of the experience of HIV and AIDS in 1980s America.

Chapter 2

The Absence of Diagnosis

When disease enters a previously healthy body and life, the newly afflicted hold certain expectations for how their illness should advance. These expectations involve a series of transitions, shifts from one perspective of an individual's health and condition to another. One method of understanding personal shifts in health perspective begins with Annemarie Goldstein Jutel's *Putting a Name to It: Diagnosis in Contemporary Society*, which speaks of the differences intrinsic in the terms "illness" and "disease" (63). Jutel, using the frameworks first raised by Michael Balint in the 1960s, posits that illness is the "personal experience of sickness" and results from individual identification of undesirable symptoms in one's physical and social state (63). Upon recognition of these issues, illness displaces health as the self-identifier of a person's current state of being. A state of illness is thus spurred by the unforeseen appearance of symptoms, but defined and expressed by the individual.

This "illness" state is generally assumed to precede the "disease" state. Jutel defines the disease state as "framed by the biological rather than the personal," and because illness is instead framed by personal experience, the ill are best suited to impose this frame upon themselves (64). The labeling of "disease," however, must be left to biological experts such as clinicians. Jutel's

definition helps unmask that the shift from illness to disease leads to a shift in agency from the afflicted to the medical expert, as focus moves from a patient's personal experience to concrete biological clues as defined by physicians. This transferred agency refers specifically to the ability to define one's current mental and physiological position while ill. As writer Julia Neuberger notes about her time at Harvard Medical School, tension and contradiction exist between the terms "active" and "patient" (Neuberger 1999). Patients are socially viewed as physically sedentary *and* reactionary to both disease and physicians' orders, contrary to free choice inherent in the state of health. When the title of "patient" is accepted once a disease is formally noted, the agency of defining one's own mental and physiological situation is handed over to a doctor. While this change is not instantaneous, the moment of diagnosis (the description of a set of recognized symptoms using the language and foundations of biology) signals a major shift. While a deviation from normal health naturally restricts one's physical agency, one's authority in naming their medical and social position remains until complicated by diagnosis. Author Joshua Ferris' *The Unnamed* uses a complete lack of diagnosis to elucidate how the relations between illness and disease shape the patient experience.

As Ferris' main character Tim Farnsworth searches in vain to name his mysterious walking disorder, he tells his doctor that he would "prefer the diagnosis of a fatal disease" over no diagnosis at all, because he'd rather "have something I understand." His doctor then replies poignantly, "do you think you'd understand Lou Gehrig's?" (Ferris 108). This scene addresses an important idea,

that extension of the pre-diagnosis “illness” state seems, to Tim, a fate worse than death. The indescribable nature of his sudden, uncontrollable walking is both socially embarrassing and mentally exhausting, and without some level of understanding of his situation Tim states he would rather be dead.

Stepping back from this scene momentarily, the pre-diagnostic state is logically expected to be temporary, ending with medical understanding and description of disorder. Tim naturally expected his state of illness to be temporary, and his grim reaction to the extended existence of his pre-diagnostic state implies that something about this position is deeply unnerving or upsetting. Jutel provides a useful angle to explain the source of such despair, asserting that diagnosis is the “fulcrum of the medical narrative” (65). Tim, and many who perceive themselves as ill, seek and expect to enter the medical narrative of diagnosis, treatment, and finally, restoration of health. Yet the diagnostic moment is more than just an important step of this journey—it is the “fulcrum,” the most essential aspect of a person’s medical narrative. The expected medical narrative can exist without identifying an ideal treatment, or leading to perfect health, but it is closed off without initial diagnosis. Even a terminal diagnosis allows for the medical narrative to continue, albeit not ending in a final return to health, but still perhaps leading to some palliative treatment to ease discomfort.

Tim’s preference of a fatal diagnosis over none at all begs the question: why is entrance into a medical narrative so desperately sought after? As his doctor astutely points out, this desire goes beyond seeking to “understand”

Tim's biological problems, as the naming of a diagnosis can be merely that, a scientific name for a set of issues not fully understood, such as attention deficit hyperactivity disorder (ADHD). Although an illusion exists that medicine holds all the answers, even the best-researched disorders deny some level of comprehension; their microbial beginnings can only be guessed at, and medicine can never tell the complete story of the breakdown of the infinitely complex human body. Yet diagnosis can provide *some* level of knowledge or structure to the unwell. Through this frame, an image emerges of the undiagnosed sick as hovering in a sort of limbo, unable to return to the domain of health as their symptoms persist, yet denied entry into the domain of medicine that is initially expected, even assumed, by all those who seek medical assistance.

Alan Lightman's novel *The Diagnosis* begins with a sudden onset of symptoms for the main character, Bill Chalmers. While riding the metro to work, Bill is struck by an unexpected bout of numbness and amnesia, as he forgets his stop and even his own name. Near the end of this episode, Bill "held up his hands and *examined* the veins near the surface, fragile and faint like the strings of a puppet" (Lightman 19, emphasis added). Bill looks at his own hand and sees something foreign, something separate from himself. One reading of this moment may suggest that in his amnesia, Bill has simply forgotten what a hand is and what its connection is to him. But Lightman recognizes the importance of this moment, the onset of Bill's fruitless journey to find diagnosis, and carefully shapes the scene to speak to conflicting aspects of Bill's experience of disease without a name.

In this scene, Bill has just entered the realm of illness—he recognizes that something inside his mind has gone amok, that he has deviated from the sphere of normal health. Lightman’s choice to medicalize Bill’s view of himself in this instance speaks to the complicated agency that Bill holds. The choice of “examined” to describe Bill’s purveying of his hand is purposefully scientific and technical. Although he had only begun to exhibit illness that morning, Bill has already medicalized his perspective of himself, viewing his hand as a doctor examines a patient’s symptoms. The odd comparison of his veins to puppet strings is what initially catches the reader’s eye, emphasizing the estrangement Bill feels toward his own body, as something separate and under external control. Yet the strangeness of this scene actually begins with the shift in Bill’s perception of his body as something to be inspected. Possessing the agency to label himself ill leads to Bill’s self-medicalization, as if his symptoms are a problem that must be addressed in a logical and scientific manner by *someone*, and in this case Bill hopes to assume this investigative role himself. In doing so, he seeks to understand or name these symptoms, beginning the search for diagnosis without external help. Even though Bill is the only character in this scene, he still creates a sort of doctor-patient relationship, playing the role of the doctor as well as the source of symptoms. Michel Foucault’s theory of the clinical gaze, the way in which the sick are viewed as a template or example of disease, illuminates this picture—Bill fashions himself as the subject of the gaze, with his hands as the object of the gaze itself. This “fashioning” on Bill’s part highlights the presence of some level of authority, yet at the same time this sense of agency

is complicated by his realization that his hands are suddenly separate, controlled as if by a puppet master.

There is a noticeable absence of the words “amnesia” or “numbness” from this entire scene. These pseudo-diagnoses are hinted at, but never stated, which complicates the image of Bill acting as a doctor to examine himself. Bill’s attempt to construct himself as the subject of the clinical gaze, and his hands as the object, is not as simple as he had hoped. The struggle for Bill to act as the classic subject of the clinical gaze represents more than just a lack of his own clinical experience, as even a lay reader may associate the term “numbness” with such a scenario. Perhaps even with his strange, newfound amnesia and physical desensitization, Bill can’t separate himself from his body in a way that is necessary to name what is clearly amiss inside him. This suggests Bill’s inability to exhibit the third party objectivity needed to use clinical terms like these.

Diagnosis is useful in part because it names a specific aspect of a person that is malfunctioning, transforming aspects of the body into “broken” or “faulty” in the eyes of the beholder, whether that is patient, doctor, or uninvolved observer. By distinguishing the aspects of an individual that are dysfunctional, the rest of the body can be viewed as separate from these problematic areas, and can only then be safely assumed “healthy.” As Foucault points out, the clinical gaze is based on the assumption that disease inhabits specific spaces in the body. The sick spaces must be identified before the healthy ones can be defined, yet as previously shown, Bill is unable to utilize the clinical gaze upon himself. This results in his failure to even mention the medical terms amnesia or numbness;

he is unable to label his symptoms and cannot discover and demarcate the sick from the normal in his own body.

Bill's amnesia contributes to his conflicting perspective, as it suggests Bill's mind itself may be the issue. This is important because it suggests the impossibility of applying a medical gaze to one's self. Although that is the first thing Bill attempts to do, to rationally analyze his symptoms, Bill's gaze is rooted in his mind. How can Bill trust his own judgment while he exhibits a symptom of the mind like amnesia? Bill is forced to recognize that even his mental faculties can't be trusted if he can't identify the location of the disease inside himself.

The interesting description of veins throughout his hands, "fragile and faint like the strings of a puppet," is suggestive of Bill's shifting self-image as well. This striking dehumanization of not only his hands, but also his own blood, stems from the suddenness and inexplicability of his symptoms. The separation seen between Bill and these parts of his body suggests to the reader that some other force may be at play. Not only are his hands and veins separate from his body, they seem to be suddenly subjected to some external control, shown in their comparison to the strings of a puppet. This scene connects directly to Joshua Ferris' *The Unnamed*, a novel about a man whose legs develop a mind of their own and walk for hours at a time. In this story, Tim feels that his body has been "hijacked" by "that thing," referring to his unnamed disease. While Bill's veins-as-puppet-strings scene illuminates the loss of agency in the very beginning of his illness narrative, Tim's scene occurs near the end of the story, after years of searching in vain for diagnosis. The similarity between Bill's and

Tim's use of language is striking, especially given that one would assume Tim is very experienced living in this illness space. Tim refers to his disease as the unyielding commander over his body, and this tyrannical presentation of his disorder may result from years of futile resistance to walking. If Bill's veins are "like the strings of a puppet" then perhaps Bill is similarly referencing his unnamed disorder as a sort of puppet master, albeit in a gentler and subtler way, without years of frustration fueling his diction.

Agency is thus naturally removed from the sick in two ways. Symptoms naturally restrain someone from acting at a normal level—if deviations from normal health increase one's abilities, they are instead termed superpowers (which are much rarer than symptoms in the medical narrative realm). In addition to symptoms being physically or mentally handicapping, agency dissipates from individuals with undiagnosed disease because the un-nameable nature of their disorder gives the disorder itself an untamable identity, powerful enough to "hijack" one's own body. The term "hijacked" echoes the medicalized sense of "examined," as both terms suggest a shift toward viewing one's body as a nonhuman entity. Planes and cars are hijacked, not bodies. Similarly, distinct symptoms are examined in medicine as biological cues, not as subjective aspects of the human experience. The locus of examination provides an interesting tension here, as a vehicle is hijacked from the inside, whereas the body is examined at a distance. As disease gains control, a strange new perspective emerges, in which one's body is something to be manipulated, from within and without.

This concept brings to mind Kristeva's theory of the abject, discussed in chapter one. The abject refers to a failed delineation between self and non-self emanations from the body, such as sweat or bleeding. Analysis of the abject associated with one's body is met with a sense of horror, as one grapples with the futility of identifying differences between themselves and their excretions. For example, sweat and saliva are intrinsic, necessary aspects of our bodies, yet upon expulsion they disgust us. We loathe seeing ourselves in them, because we are, in the end, unable to separate ourselves from the abject. Tim and Bill face the abject as they experience the futility of attempting to view specific diseased aspects of their bodies (or even their bodies as a whole) as entities separate from their perceived identity. This exposes an interesting dynamic in the way we perceive borders between disease and ourselves. Physical manifestations of named disorders, such as lesions from Kaposi's sarcoma, may originate from the body but they are designed and sculpted by AIDS—the body simply serves as resource for flesh. This exemplifies the major connection between diagnosis and the abject, that diagnosis promises to salvage the subject, in this case Tim or Bill, by framing and enclosing the abject. In a way, diagnosis hopes to remedy the fear that ensues from dwelling upon the ambiguous and elusive nature of the abject.

Without diagnosis, ill individuals are left to do the boundary-constructing work promised by diagnosis on their own. One example of this is the dehumanization of one's symptomatic areas in both *The Unnamed* and *The Diagnosis*, which exemplifies an attempt to delineate sick from healthy without the tool of diagnosis. As Tim first loses control of his legs, the narrative begins to

hint that some “other” being is developing inside him. At first, Tim’s body seems to develop its own identity, speaking “a persuasive language of its own” (Ferris 109). Not only is his own body fighting to occupy its own persona, it is denying Tim any level of communication or understanding, seen in Ferris’ choice of “language of its own” to describe Tim’s bodily rejection. After years of searching intensively for a diagnosis, Tim’s view of his body undergoes an intriguing shift. As his body turned on him years ago, Tim finally turns against his body. This is an important distinction—while his legs betrayed him by walking against his wishes, Tim moves beyond blaming his legs, and sets himself against his entire body. Unable to understand why his legs rejected his control, Tim sorts his whole physical being into a foreign entity, one that has maliciously denied him any level of communication or understanding.

The lens of the abject provides some clarity to Tim’s rejection of his physical figure. Fear of the abject is based in the struggle to delineate death from life, and similarly Tim recognizes some non-human “other” inside himself. As diagnosis is unable to identify this unnamed presence, and cannot frame Tim as subject, and the disjointed and diseased within him as the object, he chooses to reject his whole body instead of living with the idea of a contamination within his own identity. Throughout the story, Tim references suicide as a serious option. This discussion of his rejection of his body and disorder together illuminates that although Tim says “suicide,” he views this act as more of martyrdom (Ferris 222). His separation into mind versus contaminated body allows for this distinction—where a malevolent presence exists, the sacrifice of

one's life to destroy it is a completely different mindset than committing suicide just to end one's suffering.

Discussions of bodily disconnect accompanying a mystery diagnosis appear in non-fiction narratives as well. Meghan O'Rourke's biographical *New Yorker* essay "What's Wrong with Me?" describes her struggle to find a name for the mysterious autoimmune disorder taking over her life. This online diagnostic narrative is slightly different than *The Unnamed* and *The Diagnosis*, in that O'Rourke is given multiple diagnoses, which are each proven false by their ineffectual resulting treatments. Yet through this journey of false hope and disappointment, O'Rourke takes a full three paragraphs of her essay to explain her disconnect. Physically, her eyes and face felt like "distinct parts of the body, as perceptible as fingers," reminiscent of Bill's and Tim's experience (O'Rourke). Interestingly, O'Rourke senses a physical separation that transcends what she can see—her vision, usually used to determine the limits and identities of non-self entities, seems itself contaminated or "fraudulent." This language echoes Bill's inability to trust his own judgment, to impose a medical gaze upon himself. Like Bill, O'Rourke felt that "everything [inside her] was wrong" and she "wasn't sure anymore" what constituted her own healthy identity, nor what had been taken by this mysterious disorder. In a way, this frame portrays the body as a sort of battlefield, in which the enemy's identity, strength, and location are unknowable before diagnosis. How can anyone in such a situation not feel like their very identity is eroding away, and not feel "fraudulent" without grasping what is truly them and what's been distorted by disease?

O'Rourke's experience of disorientation extends beyond just the physical, to the "loss of an intact sense of self." This cryptic statement is elucidated somewhat by a line found in the quotation below, where she eloquently mentions that the healthy "have the luxury of forgetting that our existence depends on a cascade of precise cellular interactions." She follows this statement with her shortest sentence, "Not you." (O'Rourke) The weight of this line is palpable, referring to the chronically ill yet undiagnosed experience. Her ordeal seeking diagnosis, like those of Tim and Bill, is characterized by dozens of tests that seek to return her to health; yet these tests overshadow the personal experience of illness, such as patient history and opinion, with intense scrutiny of the body's biological workings. The constant lab tests that accompany diagnostic searching actually remove a patient's humanity from the equation in their search for answers, replacing a patient's subjective experience with an objective frame of their calculable symptoms. This conflict may contribute directly to O'Rourke's mentioned "loss of self." Tim temporarily rejects the diagnostic search, frustrated that it reduces him to a "gerbil" on a wheel (Ferris 8). The exhaustive search to label disease can raise the disease's priority above that of the patient, as the patient becomes a source of symptoms, a "cascade of precise cellular interactions" and clues to reach the pot of gold: not health, which remains a distant goal, but first and foremost diagnosis.

A tension is beginning to appear, considering the various proponents and detractors to a patient's agency in the pre-diagnostic stage. Three agency-affecting factors have now been discussed—the natural reduction in a patient's

ability to perform physical or mental actions as disorders progress, the agency inhibited when patients choose to frame themselves within the illness stage, and the projection of some external controller of a patient's physical body. Thus, the push and pull upon patients' abilities to control how they and their disorder are framed is far more complex than it may have originally seemed. This complexity manifests in the contemporary literary representation of living with a disorder but without a diagnosis, shown in the presence of a specific cast of words that appear throughout topical fiction and nonfiction alike.

O'Rourke, in discussing the complexity of autoimmune disorders, mentions "all this uncertainty adds to the *shadowiness* of the experience" (O'Rourke, emphasis added). The intricacies of the immune system merely contribute to the "shadowiness" of her experience—her experience of living in a pre-diagnostic illness state is beyond frustrating, beyond confusing. The testing phase is full of extensive medical imaging, through MRIs, CAT scans, etc. and extensive analysis of a body. But this wealth of discovered knowledge, if it fails to provide a label for one's disorder, actually envelops a patient in darkness and confusion. Every test passed represents a healthy aspect of a patient's body. But there is no comfort found in such an affirmation of health, as the presence of some mystery disorder still lurks and the patient remains in a perpetual state of disorientation, searching for a location and description of what is biologically wrong. Tim refers to his uncontrollable walking as a "specter," and Bill, throughout his degeneration, hears a mysterious, low buzz, which through this lens is seen to represent the disorientation and discombobulation of ambiguous

illness. The term “specter” is important, as it represents the human reaction to the unknown. This anonymous disorder is impossible to accurately represent, yet in seeking to do exactly that it is portrayed as a hulking, cunning, and inherently evil “specter.” Its identity is cemented as threatening and difficult, perhaps impossible, to overcome. Even a named yet deadly disorder like cancer can be visualized through its name, and what is visualizable may perhaps be defeated. But a shadowy specter seems far more threatening, as its likely future course cannot be acknowledged, planned around, or accepted.

The pre-diagnostic experiences in *The Unnamed*, *The Diagnosis*, and “What’s Wrong with Me?” are riddled with numerous tests and scans, searching for something amiss in the body. In addition to reducing a patient to a set of numbers and images to be compared against healthy baselines, when these tests find nothing wrong, an interesting type of diagnostic experience occurs. Jutel discusses the “diagnosis of exclusion,” which is offered when “a panoply of other potential medical explanations fail to explain” various symptoms (77). This is a curious term, as the word “diagnosis” is assumed to emerge from a proven understanding of one underlying cause for a set of related symptoms. Yet “diagnosis” is far more flexible than this simple definition suggests, and the identification and understanding of disease implicit in the term “diagnosis” isn’t always as scientific as it seems. Meghan O’Rourke’s autoimmune diagnosis is an example of such a diagnosis of exclusion, and it exposes the issues implicit in pseudo-diagnosis. An array of tests failed to demonstrate anything wrong in her body, until O’Rourke heard that one doctor strongly suspected she had an

autoimmune disorder. Although this physician may not have realized she was settling for a diagnosis of exclusion, the compulsive search for diagnosis implicit in the patient-doctor relationship makes accepting the first possible diagnosis very tempting, even if that frame is ambiguous and imprecise.

Autoimmunity exemplifies a few classic characteristics of a diagnosis of exclusion. This sort of diagnosis tends to be secondhand and broad—autoimmunity is itself generally a result of some other genetic or viral malfunction, and a wide variety of distinct symptoms can result from an immune system turning on its own host. So often this sort of diagnosis is a crutch, utilized to provide some sort of answer for both the patient and the doctor. It signifies an exaggerated level of progress toward truth and temporarily halts the journey toward a proven and useful diagnosis. O’Rourke, as many patients do, reacted to this diagnosis with relief, and accepted it as the solution to her medical issues. Her blind acceptance of a diagnosis of exclusion was seen as she became “hyperconscious of what [she] ate and what [she] exposed herself to,” cutting many healthy and normal foods out of her diet. It also shows the dangers of settling for a non-specific diagnosis. The vast confidence in modern medicine implicit in a patient’s framing of his or her doctor can lead to expansive, yet ultimately fruitless or even harmful, changes in the patient’s life. O’Rourke’s massive dietary swing alleviated no symptoms, and actually led to inflammation of her digestive tract. Diagnosis should be a path to fixing one’s problems, yet in this case the pseudo-diagnosis of autoimmunity took O’Rourke even further from health.

Jutel discusses another common diagnosis of exclusion that appears in the experiences of Bill and O'Rourke, which has striking effects upon a disease's relation to the assumed power of modern medicine. Psychodiagnosis refers to a disease rooted in the mind, either causing physical symptoms or twisting a patient's reality to make him or her believe certain symptoms exist. This type of diagnosis both presumes and protects the infallibility of the doctor and medicine at large (Jutel 83). The infinite complexity and un-testability of the human brain can serve as a sort of excuse for a doctor's inability to locate a diagnosis. The brain is much better understood than it was a century ago, but we are still far from cracking many of its secrets. So psychodiagnosis is presented as if the unstoppable force of modern medicine is meeting the indecipherable human brain, not as if a physician has failed to find an elusive diagnosis.

Psychodiagnosis is a diagnosis of exclusion, seen as Dr. Petrov informs Bill that because a pile of other tests came back negative, Bill should go see a psychiatrist, Dr. Kripke. Bill is incredulous at this suggestion, and responds "do you think I'm imagining all of this?" Even if the disorder is rooted in his brain, Bill is still sick, not merely "imagining" his debilitating symptoms. Yet Dr. Petrov's response offers no relief, only offering "I will not be able to say that at this point in time." (Lightman 183) Dr. Petrov's focus upon finding a diagnosis has removed concern and respect for Bill's subjective experience, as he sees no reason to correct Bill's worry that his issues are simply "imagined"; his emotionless, automated response instead reflects his real concern, the quantifiable and objective aspect of Bill's symptoms. Moreover, Jutel points out

that this approach toward an unexplained set of symptoms shifts the burden of disease from a doctor back onto the patient. Physical symptoms are framed as out of a patient's control, while psychiatric issues suggest that perhaps a patient can control, or even reverse, a mental syndrome by merely changing the way he or she thinks. Although the body is presented as under complete individual control, it is the mind that both makes up a patient's identity and resists a tangible interpretation. Issues of the psyche thus seem deceptively simple for a person to change or fix, if that individual simply has the will to do so. If the disorder is "just in your head," a patient naturally wonders if they are simply "crazy," if the disease stems from some fault of their own (O'Rourke).

For Bill, beyond the initial psychodiagnostic event, in which Dr. Petrov suggests Bill's issues may lie in his mind, the only diagnosis he receives from Dr. Kripke is strikingly non-medical. Dr. Kripke suggests that Bill is "putting his anger into numbness," which holds interesting implications for Bill's framing of his disorder (Lightman 202). This diagnosis provides none of the structure of a formal medical name, and doesn't seem to move Bill out of the illness stage and into the medical narrative of named diagnosis preceding treatment. Yet this is an answer Bill can understand—regardless of its lack of scientific validity, Bill begins to feel some level of satisfaction from this description of his disease. Maybe even a diagnosis that is not fully medical in nature gives a patient something to point at, some semblance of causation for the new symptomatic troubles in their lives.

While a diagnosis of exclusion is one reaction to the suspenseful nature of the pre-diagnostic stage, another remarkable reaction occurs in all three narratives investigated in this chapter. While in Dr. Petrov's waiting room, discussing a mutual frustration with their respective lack of diagnoses with another patient, Bill hears one unique phrase many times. The patient Bill is speaking to continues using the phrase "pro tem" in normal conversation, an otherwise rare and atypical phrase. This phrase echoes around the reader's head, yet neither Bill nor the other patient acknowledge any strange turn of speech. The implications of this phrase are linked to its meaning, "for the time being." Firstly, this phrase speaks to the experience of a pre-diagnostic state, characterized by a sort of hovering sensation between health and the assurance of a defined medical narrative, which begins with diagnosis. Bill and the other patients in the waiting room are not just waiting to see Dr. Petrov. They exist in a deeper, intangible waiting room, a sort of limbo made terrifying on account of there being no evidence that a diagnosis will emerge anytime soon, nor any suggestion that they will move toward health or progress according to a designated medical narrative.

Derivation of the phrase "pro tem" illuminates another allusion to life within the pre-diagnostic frame. The reader eventually asks why this patient utilizes such a vague, complex term over and over, instead of the simple "for the time being?" It is actually the indeterminate and complicated nature of this phrase that explains its existence in this conversation and in the space of the waiting room. Dr. Petrov has medicalized a simple phrase by giving it a Latin

name, in the absence of a determined, scientifically backed diagnosis. Seeking structure, yet unable to find it via diagnosis, Dr. Petrov's patients find it in the rigid, academic Latin language. The contrast between the reader noticing this strange phrase's repetition and Bill's failure to acknowledge the repeated, strange "pro tem" suggests the effect that this medicalized phrase has upon a patient in Bill's position. Presented with a complex Latin name, the patient accepts it not only because the physician is assumed to be both honest and sagacious, but also because the scientific tone of this phrase may provide some shred of evidence suggesting that the disconcerting limbo period may be ending, or at the very least being demarcated by the frame of diagnosis.

At one point, Tim receives a diagnosis that melds a diagnosis of exclusion with this sort of forced medicalization to create some level of diagnostic frame. As there is "no laboratory examination to confirm the presence or absence of the condition," Tim's doctor labels his disorder "benign idiopathic perambulation" (Ferris 41). Similar to the language of "pro tem," this represents an attempt to utilize the medical language of Latin, which most people are unfamiliar with, to support the image of modern medicine as an unquestionable source of forward progress. Increasing pressure from both Tim and the modern assumption that medicine can fix, or at least alleviate, any disorder leads to this diagnosis. Tim quickly notes that the diagnosis is meaningless, as the term "idiopathic" means "of unknown cause" and perambulation is simply medical terminology for walking. This diagnosis thus gives Tim no meaning, but simply acts as a veil over a void in medical comprehension.

The name given to Tim's disorder (benign idiopathic perambulation), beyond exhibiting an example of a failed veiling of medicine's failure in this instance, both distances Tim from the medical world and shifts the burden for dealing with the disease back onto him: the patient. Here, instead of locating and applying a known diagnostic name, the medical world creates one to apply to Tim's condition. Yet this solution is doomed to fail because a diagnosis defines a condition, linking cause to deleterious effect. Unable to provide such a link, this particular "diagnosis" instead questions the deleteriousness of Tim's symptoms by terming Tim's disorder "benign." But this disorder destroys Tim's career, family, and life, and thus it is the opposite of "benign" in nature, illuminating a limitation in our dependence upon the diagnostic frame. This frame requires a biological understanding of a disease to name it—and thus dooms those whose symptoms are currently unexplainable by modern medicine to waiting, searching for an answer that does not yet exist, while failing to receive validation regarding the severity of their disease.

The idea of a non-medical phrase failing to provide the structure and meaning that patients seek both reflects and contrasts the earlier discussion of diagnosis of exclusion in Meghan O'Rourke's nonfiction account. She mentions suffering from "brain fog (a usual autoimmune symptom)." Here, the un-testable diagnosis of exclusion leads directly to the pairing of a real symptom, an inability to concentrate, with a vague and colloquial title. In a way, it perfectly contrasts the phrase "pro tem," which contrarily hoped to provide meaning and structure through an elegant Latin title where none actually existed. Formal medical

names are often expected to represent concretely understood symptoms, yet this is not always the case. The abstract qualities of a diagnosis of exclusion seem to bleed into very real symptoms, leaving a patient without the structure that comes from naming a diagnosis or even a relatively straightforward symptom like confusion.

Although diagnosis promises to draw borders between what is diseased and what is healthy, the narratives of Meghan O'Rourke, Joshua Ferris, and Alan Lightman expose a unique flaw in this promise as presented in contemporary literature. The indescribability of a disorder does not render it benign, yet our modern world of medicine seems to stall when it fails to find diagnosis. Patients are left struggling with confusing disruptions in agency around their own bodies, and as their diseases worsen, their subjective experiences become less and less valuable in the eyes of medicine, replaced by a blinded focus upon what is objective and quantifiable. The afflicted try and fail to exhibit a clinical gaze upon themselves, attempting to delineate healthy from disordered without the assistance of a diagnosis. Yet the idea of the benign is a strange one itself—in reality health is always a spectrum, as nobody is perfectly healthy, and with enough inspection some aspect of the massively complex human body is always failing on some level. It seems that the modern obsession and reliance upon the diagnostic frame traps the undiagnosed between healthy and being within the “medical narrative,” on a path toward a return to health. Perhaps an acceptance that health and disease are simply different locations on a spectrum of bodily

function would acknowledge or even alleviate some of the identity and agency issues of Tim, Bill, and Megan O'Rourke.

Chapter 3

The Cancer Diagnosis

Cancer, the diagnosis our society may be most familiar with, reveals a unique perspective on the diagnostic effect. Cancer can affect patients of all ages, so when a very young child is diagnosed with cancer, the lived experience of disease extends beyond the child and onto their parents and family, who face a sort of displaced diagnosis as they must themselves grapple with what the disorder means. Diagnosis promises to reduce the distinct aspects of the illness experience (physical, psychosocial, familial, etc.) into a clear-cut medical term, yet this chapter will illustrate various examples in which diagnosis fails to do this. A medicalized term cannot account for all of the dimensions terminal illness assumes in the lives of a patient and their family. Other components of illness, such as the melding of home and hospital, slip out of the attempted diagnostic unification, as diagnosis implies but does not ultimately deliver a unifying narrative including bodily, social, and psychological symptoms that end with treatment and cure. The tension from the promised, yet unattainable, encompassing of an illness experience into a diagnosis is exhibited throughout the cancer narratives discussed in this chapter.

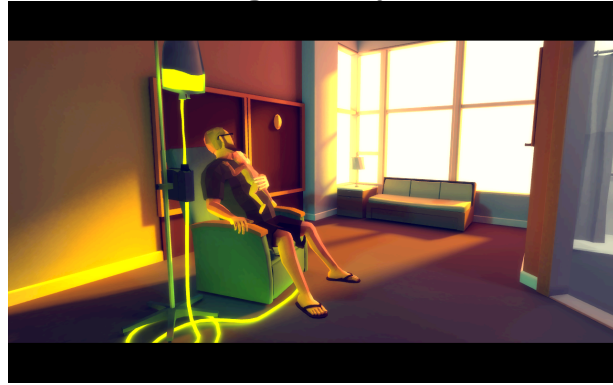
This strain is palpable in Lorrie Moore's "People Like That Are The Only People Here: Canonical Babbling in Peed Onk" (referred to hereafter as

“Canonical Babbling in Peed Onk”). The Mother (unnamed) in Moore’s short story engages in a disembodying attempt to accept the diseased aspects of her child (referred to as “the Baby”) as her own. The malignant tumor that appeared on a scan of the Baby’s kidney, the Mother feels, must have been “*her* kidney” as she was “standing very close” when the scan was performed (Moore 468). Diagnosis specifically identifies the ill, and in doing so creates a boundary between them and the healthy. When faced with an exposure of disorder within her child, the Mother seeks to lessen the imagined boundary between her and the Baby. She attempts to deny this perceptual border by citing her physical proximity, that she was “very close.” Yet Moore’s farcical presentation of the Mother seeking to “make the [Baby’s] blood hers, the tumor hers” exhibits the confusion present in the Mother’s response to a diagnostic frame, as the psychological dimensions of disease cannot simply be swapped out for the physical. Her confusion stems from the feeling of absolute connection between mother and child, which fiercely compels her to take on the Baby’s disorder, yet she is unable to assume this particular burden. Specifically, the Mother’s adjacency to her child cannot eliminate the boundary constructed by a cancer diagnosis between her and the Baby.

Another example of perceived boundaries between cancer and familial relationships is the interactive video game *That Dragon, Cancer*, which allows a player to follow the story of Ryan and Amy Green as their son Joel struggles with cancer. Compared to the Mother’s active, vocal attempts to join the Baby in the space of illness in “Canonical Babbling in Peed Onk,” father Ryan Green’s

experience in the interactive video game is portrayed as more of a passive inhabiting of the space of his son's illness. As he sits holding Joel, shown in Figure 1, radiant green chemotherapy seeps toward both of them yet is never shown entering either body, even when the player moves closer to viewing the pair. Given only this scene, a viewer wouldn't know who is sick and who isn't. Yet the player *does* know that the child is ill and that Ryan is perfectly healthy, and Ryan's presentation as possibly receiving chemotherapy instead of Joel is confusing and somewhat disconcerting. This chapter of the game, entitled "On Hospital Time," is constructed so the viewer is far from the father-son duo and must sweep across the screen to find them. The bare quality of the room pushes the player to focus on Ryan and Joel—the effect of which is that because the entirety of their bodies are in view, the huge size disparity between them is undeniable. Even with their bodies laid on top of one another, the presence of two people, one large and clothed and the other small and in only a diaper, is thrust into the viewer's experience. This scene emphasizes the impossibility of Ryan's attempt to inhabit Joel's perspective on account of both his disorder and his identity, represented by disparities in size and age. Although in this scene Ryan and Joel are blended in the viewer's inability to determine who is receiving chemotherapy and who is diseased, a tension emerges in that a firm distinction between the two

Figure 1: Ryan holds Joel.



simultaneously exists and highlights how Ryan is both in the middle of, yet separated from, Joel's diagnosis.

Later in the same chapter of the game, uncomfortable physical dynamics between Ryan and Joel emphasize Ryan's inability to reside in Joel's diagnostic frame. Lying on a small pullout couch in Joel's room, shown in Figure 2, Ryan seems gigantic. Try as he

might, he cannot fit into a bed so small. He can't fit naturally into this space, because it was built for pediatric cancer, and despite his psychological ties to

Figure 2: Ryan and Joel sleep.



his son's predicament, Ryan's age and health deny him the ability to fully inhabit it. When the player is given the opportunity to play from Ryan's perspective, the only action that can be taken is to stroke Joel's head, and Joel's only response is a sort of giggle. Communication beyond simple physical touch is essentially nonexistent. The player thus feels a sense of Ryan's frustration at being unable to explain to Joel why he feels how he does; he desires nothing more than to explain the situation to his son, which is the purpose and the realm of diagnosis, yet he cannot. Balloons formed from hospital gloves float onscreen, and Joel sees them not as medicinal tools, but as just toys. The complete silence in this scene emphasizes the solitude Ryan faces, as he bears the weight of his son's diagnosis yet cannot utilize it to pass on any meaning or understanding to his young son. Ryan's search for meaning is complicated further as he is helpless to

communicate any understanding of Joel's situation to Joel himself. Diagnosis promises to assist the Greens in constructing a frame for Joel's disease, yet this effect is ultimately limited by Joel's youthful ignorance of language and any meaning it may convey.

The Mother's response to the very moment of diagnosis in "Canonical Babbling in Peed Onk" is an immediate attempt to transform her child's diagnosis into what she finds most familiar: language. The Baby's doctor explains that "what we have here is a Wilms' tumor" and as a writer herself, the Mother immediately responds with "Wilms'? Is that apostrophe s or s apostrophe?" Presented with a diagnosis whose medical meaning is inaccessible for a non-health professional, the Mother tries to break down the disorder into its linguistic pieces. The enormity of the diagnosis, wrapped in the word "cancer," must be understood and framed somehow, so the Mother attempts to utilize her literary toolbox, turning to grammar and spelling because "spelling can be important," the Mother thinks to herself. The term "Wilms' tumor" presents her with no meaning or structure of her child's disorder and its effects, yet she desperately seeks to understand it and tries to use language as a frame. This attempt proves unsuccessful, though, as the doctor replies "S apostrophe," which momentarily promises some meaning; but the meaning is stripped away as he follows with "I think." This hesitation shows that the doctor sees no meaning in specific language, and more importantly, that the location of the apostrophe will transfer no understanding of the diagnosis to the Mother. (Moore 468)

The father in *That Dragon, Cancer*, Ryan Green, has a related yet distinctly quantitatively oriented response to hearing a physician diagnose his son with end-stage cancer. The doctor states “this is a tragedy” and “it is fatal, no treatments are curative,” leaving no room for hope for parents Ryan and Amy. The term “tragedy,” while the doctors likely hoped to express empathy, instead imposes a “tragic” narrative upon the Green’s and their son Joel. Faced not only with a diagnosis, but with the confirmation that their time left with Joel will be characterized by grief, Ryan thinks to himself “size matters: if I know how big it is I can size it up” (*That Dragon, Cancer*). Like the Mother in “Canonical Babbling in Peed Onk” Ryan immediately seeks to find a perspective on the diagnosis that allows him to frame it in a way that he can understand, but he tries to transform it into a physical entity, instead of a literary one, to do so. If given some measure of size, perhaps he can mentally envision Joel’s diagnosis, hold it, and mentally *grapple* with it.

Yet the Greens’ physician in *That Dragon, Cancer*, like in Lorrie Moore’s story, immediately states “the tumor is relatively small; unfortunately, size doesn’t really matter here.” This scenario mirrors the Mother’s situation almost perfectly—Ryan received the type of answer he sought, yet the validity and usefulness of that answer, with respect to absorbing and assimilating the diagnosis, is immediately stripped away. Juxtapositions of the Mother’s and Ryan’s attempts to frame a disorder with a medical professional’s denial of such a strategy reveals the inherent inaccessibility of diagnosis. No literary or quantitative transformation of diagnosis can bring with it psychological

comprehension of a diagnosis' significance: what the diagnosis portends about their future or how Joel and the Baby will be affected. Such attempts to grapple with diagnosis are natural responses to a familiar situation, but they are ultimately in vain. Throughout the powerful scene described above, Joel simply giggles and plays with a colorful toy, yet his parents leave their meeting with Joel's physician with only an inaccessible name, holding little more understanding of the diagnosis than blissfully ignorant Joel does. A diagnosis of cancer gives neither medical explanation nor prediction of how Joel's illness will affect the familial dynamic; if anything, it denies Ryan's attempts to understand Joel's cancer. All the Greens leave with is an affirmation that their narrative will end in Joel's death.

Ryan Green's attempt to understand the meaning of his son Joel's diagnosis through visualizing the size of his tumor appears again in the video game. In one of the most striking scenes of the game, shown in Figure 3, the player watches Ryan floating underwater, surrounded by an arcade game, discussed later, and three thorny, eerie, pitch-black masses. The only sound is a pulsing throb, like a human heartbeat, which the masses move along with. For a minute or two, all the player can do is look around the blue sea and contemplate the meaning of the scene. Even after the doctor's assertion that the size of Joel's tumors doesn't matter,

Figure 3: Ryan submerged.



Ryan and Amy have chosen to portray Joel's diagnosis through the objective form of ever-present and menacing tumors, physically inside Joel but figuratively surrounding them. This scene expresses their lack of agency even within the physical materialization of Joel's diagnosis, which they as parents themselves created in their quest for comprehension and control. Although the tumor-size perspective doesn't immediately give Ryan the framework of diagnosis he hopes for, the mental, and in this case digital, materialization of disorder persists. Perhaps creating physical manifestations of diagnosis is a reflection of a failed struggle to render the meaning of diagnosis accessible.

Although a foreboding and terrifying presentation of tumors and cancer seems natural, Susan Sontag's landmark 1978 essay "Illness as Metaphor" exposes the extent to which social discussion and representational framing, specifically metaphor, has shaped this attitude. For decades, cancer has been portrayed as a disease in which patients are stripped of energy while the tumors themselves are "ferociously energetic," madly multiplying and spreading (Sontag 66). Sontag theorizes that this presentation of tumors shapes the patient experience, which can be seen in Figure 3. There, Joel's tumors literally surround Ryan, pulsing as he floats motionless. This scene also extends Sontag's theory—while Sontag referred to a patient, the video game imagery shows how her theory can also apply to the parents of a cancer-stricken child. In grappling with diagnosis themselves, the cancer threatens not only their child but the parents' way of life as well.

In her own portrayal of tumors, the Mother in “Canonical Babbling in Peed Onk” demonstrates an aspect of the metaphorical representation of cancer that Sontag’s theory protests. Sontag argues that notions of cancer as the “killer disease” leads to “punitive” notions of disorder, in which the “illness is the culprit” and patients are thus represented as victims (54). The Mother views a tumor as “differentiated muscle and bone cells, a clump of wild nothing and its mad, ambitious desire to be something” (Moore 477). The first section of this quote reveals a distinct biological lens that is suddenly terrifying because how can “differentiated muscle and bone cells” be delineated from *normal* muscle and bone cells that make up the Baby? Where can the line between cancer and baby be drawn if a tumor is simply the Baby’s cells that have changed slightly? For this reason, the Mother immediately switches to the frame that Sontag discredits, one of a tumor as a “wild nothing” personified with an “ambitious desire to be something.” Although this frame asserts that a maleficent entity seeks to proliferate and wreak havoc inside her son, it allows her to preserve the image of the Baby as clean and innocent, infected by a specific *other*. In demonizing the tumor, the Mother can save the uncontaminated image of her child.

Writer and literary critic Anatole Broyard, who wrote a series of essays about his experience with his own terminal cancer, disagrees with Sontag’s quarrel with metaphor and supports the role that metaphor can play, as in instances like the Mother’s turn to tumors as “wild nothing.” In discussing only the negative effects of metaphor, he posits that Sontag “throws the baby out with the bath” because “at the very least, they are a relief from medical terminology”

(Broyard 18). Broyard hints at an important idea here, but doesn't reach far enough. The "wild nothing" metaphor goes beyond providing a relief from medical phrases like "differentiated muscle and bone cells." Metaphor provides an escape from an inherently objective scientific reality that cannot be combated or grappled with through words. Metaphor releases the Mother from the black and white, diseased or healthy mindsets of science, and allows her to create her own perspective of diagnosis and disease. While metaphors like the "wild nothing" of a tumor allow for the Mother to distinctly locate the Baby in the frame of cancer, they also provide a flexibility in representation that returns to the Mother some level of control in framing her life and the life of her child.

Sontag argues that terminology about cancer such as "mutant" cells presented as a "demonic possession—tumors are 'malignant' or 'benign' forces" shapes cancer into a disease of the *other* (64). This sheds light upon the role of the arcade game floating near Joel's tumors in figure 3. The player finally floats to the arcade to play "Joel the Baby Knight," where he or she assumes the role of Joel, chased by a demonic, fire-breathing dragon named "Cancer." This game within a video game is a powerful tool through which Ryan and Amy Green express the extent to which Joel's diagnosis has removed their agency and freedom to choose how to live their lives. A player can move through the video game, yet there is no way to win, only to dodge the dragon's fireballs until Joel's fifteen allotted lives are spent. Implicit in the simplicity of this game is the sense that the Greens' lives have been reduced to making their way down a predetermined path, like a level in a video game, dodging fireballs spewing from

the mouth of Cancer itself until eventually the player succumbs. The Greens are a deeply religious family, perhaps leading to their view of cancer as a massive, red-eyed creature reminiscent of the devil. Sontag's theory is useful in this context, showing that although the Greens created their image of cancer as a dragon as a means of externalizing the threat to Joel, the use of a demonic metaphor strips the Greens of agency because cancer's representation as a massive dragon provides only a single (dreading) thought in the player's mind. How can a tiny baby like Joel ever defeat, or even slow, such a beast? The very object of the Greens' attempt to materialize the threat to Joel actually constricts their psychological ability to fight his cancer.

"Joel the Baby Knight" is initially presented as a bedtime story to Ryan and Amy's other children, as a way to explain how cancer has affected Joel's life. Their use of narrative, here of the ancient knight-versus-dragon tale, shows a method of assimilating diagnosis into the Green's' daily life, specifically of staying connected to their other children. The creation of "Joel the Baby Knight," as well as *That Dragon, Cancer* as a whole, exemplifies how turning to narrative can creatively usurp the power that diagnosis and its expected narrative of "tragedy" have stolen from the Green family. Broyard labels his experience of being diagnosed with cancer as a "series of disconnected shocks," and in writing his essays he found a way to make whole again a life that felt utterly fragmented by the unpredictable nature of cancer (19). Medical explanations, though they may provide the most likely series of events, can "flatten the story of illness" (Broyard 66). After diagnosis reduced him to a "cancer patient," and his

experience began to turn into feeling like a laundry list of symptoms, charts, and numbers, his series of essays returned to his life the three-dimensionality and freedom of the human experience. In a sense his life *became* narrative, as his “existence ... had taken on a kind of meter, as in poetry or taxis,” a meter controlled by him that defied the cancer diagnosis’ grip (Broyard 3).

Paul Kalanithi’s *When Breath Becomes Air*, a memoir about his final days as a neurosurgeon diagnosed with terminal lung cancer, approaches the role of narrative creating agency in the face of diagnosis on two levels. Firstly, the book itself is Kalanithi’s method of understanding the transition from doctor to patient, as he figures out how to receive a diagnosis after years of distributing them. But inside Kalanithi’s story is a second turn to narrative to understand living within the diagnostic frame of cancer. Kalanithi, “lost in a wasteland of [his] own mortality” after receiving his diagnosis, began to read literature on the experience of illness such as Tolstoy’s *Ivan Lynch* and B.S. Johnson’s *The Unfortunates* (Kalanithi 148-150). Kalanithi recognized that the certainty expected of diagnosis, that it would teach a patient how his or her life will be altered by disease, could never be fully realized. No “curves of survival statistics” could tell him how to view cancer’s infiltration of his life and his identity (148). Although diagnosis provides a name for the disorder within a body, it can’t explain how the individual experience of a particular illness will change a patient’s identity as well as his or her body. Yet for Kalanithi, literature can begin to answer this question.

Kalanithi explains that in his perspective, patients do not seek “scientific knowledge that doctors hide” but truly search for “existential authenticity” and “oracular wisdom” (Kalanithi 135, 180). Throughout his story, Kalanithi’s motto becomes the unforgettable last words of Samuel Beckett’s *The Unnameable*: “I can’t go on. I’ll go on” (Kalanithi 149). Creating *That Dragon, Cancer* allowed the Greens to discover how to fit Joel’s bewildering cancer diagnosis into their family’s life, because even through the shock and confusion of diagnosis, life must still continue on. Figures 2 (Ryan Green appearing huge on a hospital pullout bed) and 4 speak to how living with Joel’s cancer has removed the spaces of “home” and of “the hospital” and instead given the Greens a strange melding of the two in which to live. Again, the removed, distant perspective of Ryan sleeping with Joel on a tiny bed expresses the impossibility of any hospital ever being a true home. The bare walls emphasize this reality—yet because of the extensive chemotherapy required for Joel’s treatment, the Greens must spend more time at the hospital than their own house.

Figure 4 (next page) shows how the Greens’ house is no longer just a space of living. Diagnosis, although it provided a medical name for Joel’s inner disorder, gave no warning for how the Greens’ image of home would be altered by cancer. Joel’s cancer has shaped his room into, in the eyes of his family, a lonely and isolated space. In the chapter “Adrift” the player is exposed to this image as he or she stands in Joel’s room while simultaneously hearing crashing waves and noticing the beam of a lighthouse over the surrounding sea. This imagery communicates that because of Joel’s extensive treatment and the

unpredictability of his disorder, home is no longer a space of comfort and security, but one of uncertainty. Is Joel's room still Joel's room if he now lives in the hospital? The tension of assimilating a cancer diagnosis into family life is further expressed by a background conversation occurring in this scene, as Joel's brother tells his parents

Figure 4: The Greens' house, adrift



"Disneyland sounds fun, but I don't want to miss school and make up my homework" (*That Dragon, Cancer*). This statement reminds the player that although the undeniable presence of terminal illness distracts from the demands and affirmations of ordinary life, life must go on for the Greens. Although the family sought meaning and some level of prediction from diagnosis, they cannot let Joel's cancer envelop the rest of their reality, even if this reality must occur in a strange new space between home and hospital, somewhere simultaneously known and unexpected.

One scene in "Canonical Babbling in Peed Onk" expresses a similar idea, but through the lens of the Baby remaining a normal child despite his diagnosis. Sitting in the waiting room, the Baby wants to play with another child's toy, Ned's "little deflated rubber ball" with an "intriguing curling hose." The two fight over the toy until Ned's mother runs over, shouting "Stop that! Stop it! ... This is drawing fluid from Neddy's liver!" (Moore 476) In the case of this work, the diagnosis of pediatric cancer has literally become a place: "Peed Onk," short for

pediatric oncology, meaning “children’s cancer.” Yet even in this diagnosis-infused room the Baby is still just a baby, inserting some level of comedy into the midst of the tragedy that has reshaped this family’s story. This scene parallels Joel’s playing with hospital glove balloons in *That Dragon, Cancer* because, although a pediatric-cancer diagnosis changes a child’s life and that of the child’s family, creative narrative demonstrates that some aspects of life deny, or at least disrupt, the serious, medical diagnostic narrative.

That Dragon, Cancer as well as the texts explored in this chapter shed light upon how and why diagnosis cannot give a patient, or his or her family, a concrete image of how disease will permeate their lives. Diagnosis can’t bind singular experiences, emotions, and perspectives into a medical phrase, but expression of experience into a written or digital narrative can encapsulate some of these unexpected aspects of diseases such as pediatric cancer. Through scenes such as the Baby’s attempts to play with a “deflated rubber ball” as a toy (actually a pediatric patient’s liver drawing fluid) and the representation of home as an island at sea, the narratives of “Canonical Babbling in Peed Onk” and *That Dragon, Cancer* provide a way for the Mother and the Greens to discover how to carry the weight of pediatric cancer diagnosis through the continuation of everyday family life.

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