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By

Kayla Davis

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Abstract

The purpose of this thesis is to identify common themes presented in several illness narratives with specific attention paid to the relationship between patients and their physicians and patients and their families. Only illness narratives written in America and Western Europe were used for this thesis so the topic could be narrowed to the experience within the western biomedical field. While most research on illness narratives focuses on defining illness and illustrating the importance of introspective work, this thesis identifies patterns in a way that can shape the future treatment of chronically ill patients. This thesis also allows me to creatively explore a personal illness narrative, reinforcing these themes and contributing to the discussion of what physicians and families can do to make the illness experience more bearable for the patient.

Background

Since the introduction of the field, the overall goal of anthropology has been to expand upon our own interactions (Geertz 14). Narrative anthropology, a relatively new field of anthropology, is no different. It allows the anthropologist doing fieldwork to tell a story based on their findings in other cultures, expanding on this human discourse. This narrative delivers the information learned through fieldwork in a more cohesive structure, one that is easier to read but, perhaps, more difficult to write. Ultimately, narrative anthropology aims to observe and analyze everyday activities in order to document the experience in writing (Reck 9). This lived experience is inclusive of the experience of the fieldworker, the person observing the culture that they will eventually write about. The methodology used in narrative anthropology has shifted from "participant observation" to the "observation of participation" and has improved the understanding of these narratives by allowing the anthropologist to become more reflexive (Tedlock 69). This reflexivity comes naturally to most anthropologists who recognize that the only way to learn from people is to become involved with them and their world (Rosaldo 181).

The human race has created the significance that surrounds them, building their culture and giving it meaning. Therefore, the anthropologist must not treat people as an experiment that can be defined by laws but rather this significance must be interpreted to find the existent meaning (Geertz 5). Anthropologists use stories to discover and interpret meaning in different cultures. In narrative anthropology it is important that, because we are a "story-telling animal," we must hear and actually listen to the stories that are told (Reck 9). These stories are important because they can offer insight on the meaning behind human actions rather than simply speaking about the physical movements (Rosaldo 129).

Anthropologists aren't the only people that can benefit from using narrative anthropology. We see that narrative anthropology, when analyzed in a clinical setting, can deliver a better examination of the experiences a patient has compared to the clinical description that boasts objectivity (Reck 8). Patient narratives allow for more of a physician-patient relationship because these narratives elicit lay meanings among patients to allow practitioners to better access unspoken worldviews.

Introduction

The term illness is often interpreted as a person's experience of sickness in contrast to a physician's perspective, typically focused on a more quantifiable "disease," or biological disruption. Illness narratives then showcase a patient's reaction to their own bodily functions, situated in a specific individual and cultural worldview. These narratives comment on the medical system and the patient experience. This perspective is unique in that a patient is working at an emic angle while they are at an etic disadvantage. Ultimately, the most important perspective when it comes to illness is the patient's.

Our society's perspective of medicine is largely influenced by current cultural norms and expectations of the medical system. Kleinman suggests that "the pursuit of happiness," viewed as a human right, has been transcribed in medicine as an assurance that one will not suffer from pain for extended periods of time (23). The way our biomedical system is structured creates an expectation that all patients, once through the system, will be free of pain. However, patients and physicians both ignore the fact that suffering is a natural part of life. Part of the illness experience, when dealing with pain, is having hope and expectation that the pain will cease. But the patient begins to feel hopeless when the pain is persistent over long periods of time. It is not an easily grasped concept that the western medical world cannot cure all ailments, perpetuating a frustrating and difficult relationship the patient has with their bodies and with the medical system as a whole.

To add to the frustration, western society is notorious for medicalizing natural occurrences like pregnancy and menopause, things that affect all women globally, but have unique cultural significance. With this process of medicalization, many of these illnesses are condemned and stigmatized within western society. The fact that we denigrate processes such as acne and balding illustrates the narcissism that exists in western society (Kleinman 25). This creates generations of people that cannot be happy with their natural selves. Lucy

Grealy, a woman that writes about her childhood cancer of the jaw, worried more that her chemo therapy made her bald than she did about the cancer and drugs destroying her body. This baldness indicates to society that she is different and it is something that she cannot hide (Grealy 99). Beyond her baldness, because of the many surgeries she had on her face, she failed to obtain normative beauty, showcasing the narcissism ingrained in her by society, adding to her illness experience throughout the rest of her life.

Furthermore, the distinction between stigmatized, contested illnesses and those that are accepted within our society are distinguished by social beliefs rather than biological reasons (Conrad and Barker S69). In western society, mental illness is often disregarded or seen as unreal. Our cultural definitions of mental illness, whether we believe that those that suffer from them are “crazy” or imagining things, operates to perpetuate a social hierarchy that allows the majority of society to marginalize those that they cannot or will not comprehend (Conrad and Barker S75). This marginalization is only increased when an illness cannot be hidden, when it is displayed on the “exoskeleton.” The illness becomes a symbol of difference within our society that attaches the patient to an identity that they cannot escape (Kleinman 22).

Just as we give meaning to marks and sickness, we also “create ourselves” to present to the rest of the world and we create the words we use to showcase our illness (Kleinman 16). By this logic, people experiencing the same symptoms, the same social backlash, the same self-doubt, will describe what they are going through in completely different ways. For example, Oliver Sacks, a world renowned neurologist and best-selling author, describes his experience with illness by comparing his body to a ship and his mind to a captain such as: *“It was not just that some of the stout timbers were rotten and infirm, and that the good sailors were deaf, disobedient or missing, but that I, the captain, was no longer captain. I, the captain, was apparently brain-damaged—suffering from severe defects, devastations, of* *memory and thought"* (Sacks 46-47). Lucy Grealy also describes her reaction to chemotherapy in metaphor: *"I felt the lining of my stomach arc out and pull spastically back into itself like some colorful disturbed sea anemone"* (Grealy 65). When the patient is knowledgeable enough to explain their symptoms medically there isn't a problem. However, lay expressions, those used by most patients due to their lack of a medical degree, can be problematic when one is not able to adequately describe what is happening to their body. For example, Grealy described that her "sinuses swelled and ached, but knowing nothing about sinuses, [she] could only report that [her] nose hurt" (Grealy 67). The way we describe our pain and discomfort directly affects how we are treated by physicians and how our illness will be viewed. These "lay expressions" can quickly transform into confusing statements by those suffering from mental illness. The given information is unhelpful in allowing the doctor a glimpse into the patient's symptoms and creates more problems in treatment (Vanthuyne 2003). In some cases, it can be almost impossible for physicians to achieve a holistic examination of their patient. Therefore, when it comes to those without a medical degree and those suffering from mental illness, the illness experience can never accurately be conveyed.

When the physician becomes the patient, there involves a process by which they view the medical system in which they work. For example, when he breaks his leg, Oliver Sacks in *A Leg to Stand On*, describes his time in the medical system and experience with his injury as an awful journey. Only during this experience can he truly identify the limitations of the medical system. He begins to feel helpless and realizes that the doctor's demeanor is less than comforting. Surgeons, for example, are "touching places so private that this person has never even seen themselves," but they aren't taking the time to consider this fact (Alvord 111). Western medicine has progressed to a highly systematic, tightly scheduled environment that prioritizes efficiency over the well-being of patients. However, the flaws of this system are being exposed as these limitations are brought to light (Morris 8). This biomedical model is being further questioned as more research is being produced elaborating on the social and cultural aspects of issues such as chronic pain (Morris 9). Since pain is not a simple biological process, the illness experience is multi-faceted and cannot be simply stated in impersonal, medical jargon.

Even as I write this paper, trying to objectively discuss what I have researched in terms of illness being tied together with culture, I recognize that my own cultural beliefs and predispositions are influenced and biased by my own experience and worldview. If "the meaning and experience of illness is shaped by cultural and social systems," then my own perspective of other people experiencing illness is also being affected by the cultural systems that surround me (Conrad and Barker S67).

These observations suggest a need for change. While a good first step is recognizing that the patient suffering from a disease is also experiencing an illness, the next logical step is to learn more about the illness. This is when ethnography becomes a vital part of medicine. Of course, illness narratives cannot solve all of the problems that exist within the western biomedical field, this thesis aims to address the way that illness narratives can help mend and strengthen relationships between patients and their physicians as well as patients and their families.

Literature Review

Although there are many different relationships that can affect a patient's illness experience, for the sake of length and clarity, the only relationships explored in this thesis are those between the patient and their physician as well as the patient and their families. These two relationships are discussed separately and further split into prevalent themes.

Physicians and Illness

The role of the physician is often interpreted as the most important part of a patient's treatment. The physician is the person that the patient goes to and sticks with throughout the entire illness and their advice is taken above all, seen as fact and the most intelligible source of information. The relationship, although usually described in negative ways, can be the only outside contributor to the patient's illness experience. The relationship is described through the following themes: the physician lacks humanity, the physician is idealized, the regulation of feelings, the physician treats disease not you, the physician creates fear, noncompliance, and disappointment, and the exceptions to the rule.

The Physician Lacks Humanity

Doctors are in a unique position of power in which they have the ability to heal patients, but they also have the power to worsen the patient's experience. One patient says to Arthur Kleinman, "I had to stand before those medical students like, like a thing to gawk at. Damn that doctor for putting me through that. He never considered how I might feel. All I am is 'an interesting case'" (164). This experience, although it is necessary for the education of medical students, is almost never executed in a way that makes the patient comfortable with what is taking place. The patient is addressed in the third person, as if they aren't even in the room, and the onlookers are indifferent to the patient's own perspective.

Throughout these illness narratives, doctors were portrayed as lacking humanity by not listening to their patient. When the patient feels that they are unheard, their frustration and desperation rises. Sacks, lying in a hospital bed, was hoping for the understanding and support of his doctor but received nothing from him. Sacks explains that the doctor has taken away his “human foothold” that can be interpreted as the necessary communication between two people (84). The absence of this communication results in suffering on the part of the patient. While the doctor likely does not actually lack humanity, when they step into their professional role, they distance themselves from the patient’s experience.

In terms of children, communication becomes even more important. When Lucy Grealy was going into one of her many surgeries as a child, she “begged them to stop, but no one responded” and she went under anesthesia with a heightened heart rate and utter fear (166). Perhaps if she had been aware of what was happening through careful communication, then her fear would have been better managed. However, if we can’t find the humanity within doctors, we can’t form the relationships necessary to heal through the illness experience.

The Physician is idealized

When we begin to believe that our doctor is an invincible, all-knowing “superhuman,” we are setting ourselves up for disappointment (Williams 122). Already there is an expectation that when you enter into a doctor’s office sick, you will come out healthy or, at the very least, with all of the tools to make sure you become healthy. Williams, working from a physician’s perspective in his book *The Doctors’ Stories*, explains that patients believe doctors to be on a level close to God (61). Unfortunately, doctors are neither taught nor prepared to reach this level of expectation. Williams challenges this view by exposing the practice of one of his colleagues. He explains that his medical technique was to try different medicines until one of them worked. Only at that point can a doctor know what the patient’s problem is (Williams 2). Although this can’t be considered the general workings of medicine, it illustrates the fact that doctors shouldn’t be held to such a high standard by their patients.

The more patients view doctors as superhuman, the more doctors feel the need to present themselves as such (Thompson et al. 2001). This false portrayal of themselves illustrates the present dichotomy that exists between doctor and patient. While patients expect this level of perfect health, they also expect to have a personal, honest relationship with their doctor. This contradiction leads to frustrating results as neither side can live up to their expectations.

The Regulation of Feelings

Doctors tend to believe that they understand how a patient should be feeling when presenting particular symptoms. When the patient is displaying emotions not congruent with these beliefs, doctors try to correct their reaction. A common theme within *A Leg to Stand On* is that of doctors and nurses, in an attempt to be relatable, assume the patient's feelings before asking the patient how they are feeling. For example, the physiotherapist asks if Sacks' leg "hurts like Billy-O" expecting a response of yes or no, implying that she does not want to listen to any personalized complaints (Sacks 39). The fact that Sacks was never able to describe his feelings was one of the main reasons that his frustrations grew, contributing to the delayed use of his leg. If physicians were able to enter a patient's room with a clear mind and listen to what they had to say, they could hear their complaints and begin addressing them in order to help the patient.

Ruth Behar, a Cuban-American anthropologist, broke her leg in a car accident when she was 9 years old. She went to a hospital and was told to stop crying and to be happy that she had a broken leg because the woman next to her would be paralyzed for life (Behar 106). From the doctor's perspective, the patient could always be in a worse condition and, therefore, should not complain about their misfortunes. Doctors expect you to show just the right amount of pain so as not to inconvenience or annoy them. This idea truly resonated with Lucy Grealy through all of her trips to the hospital because she always "looked for praise as a 'model patient'" (171). This idea, to not show more emotion than expected, made her keep a lot of her complaints to herself, knowing that if she spoke up about them she would be scolded. Ultimately, because she wanted the praise, the doctors would treat her disease while she took on the role of handling the experience on her own.

The Physician Treats Disease, Not You

According to medical anthropologists, the term illness refers to the subjective experience of suffering, while disease refers to the quantifiable symptoms of suffering. In medical interactions, these two conceptual worlds often create tensions (Kleinman). By ignoring the illness, doctors focus all of their attention on the disease, forcing patients to deal with the emotional and cultural aspects associated with the disease on their own. A patient's whole lived experience is reduced to a biological occurrence as soon as they step into the doctor's office.

One example of such a tension is a patient's feelings of objectification. Sacks explains that he wanted to tell his surgeon what had happened since breaking his leg in order to ensure that they were on the same page about what was wrong with him (65). Sacks really wanted his doctor to tell him that he understood that his experience with this broken leg was more than just the muscle that wasn't working. However, his surgeon was adamant that he couldn't spend time with "experiences" because he was a "practical man" completely invalidating the needs of the patient (Sacks 82). When physicians refuse to listen to their patients, they are prohibiting any type of relationship from forming. When physicians and patients don't have a relationship, healing cannot occur.

In many cases, physician's inattentiveness to the illness experience results in condescension, making the patient feel stupid. After months in the hospital, Sacks moves to a rehabilitation center in which he meets many patients that have been through traumatic physical alienation. Once getting to know these other patients, he realizes that many of them also felt like their doctors believed them to be stupid (Sacks 141). This accusation is brought up after learning that these other patients felt the same feeling of small-ness brought on in a hospital setting. Throughout Grealy's experience with the medical system she refers to doctors who "smiled condescendingly after each inquiry," something she saw throughout all of her visits to many different doctors (13). The dichotomy that exists between the "all-knowing specialist" and the "know-nothing patient" creates an atmosphere of frustration as the patient tries to rise above their pre-determined status and attempts to gain the recognition they need (Sacks 81).

Condescension can also be illustrated by doctors omitting information from patients or "dumbing-it-down" for their supposed benefit. In one situation, the patient asks, "what's the matter with me?" and the doctor responds, "don't worry" as if the information isn't relevant to the person the sickness is affecting (Williams 15). Sacks' doctor told him more, but still not enough, when he said, "Nothing to worry about… You've torn a tendon. We reconnect it. Restore continuity. That's all there is to it…nothing at all!" (30). Doctors either believe that patients aren't smart enough for the full story of their diagnosis or in-depth explanations are inconvenient and too time consuming for the doctor. Regardless of their reasoning, these patients are left in the dark about what is happening to their own body, creating confusion and frustration that negatively affects the illness experience. This is an especially prevalent theme when discussing children's cases. Often times, doctors (and parents) will discuss a child's illness without any input from the child and, likewise, the child will not hear about any decisions or observations. Grealy says, even years after she became cancer-free, "I didn't understand that what was happening to me was important or dangerous" (57). Keeping children oblivious to medical facts and decisions can make a child's life easier in the sense that they don't have to suffer through worry, but it can also make them take a situation too lightly and put themselves at risk for worsening their illness experience. When

Grealy found out that an infection would prevent a chemo treatment, she tried really hard to make herself sick, not understanding that getting sick would be worse than taking the medicine because no one ever told her that her life was at stake.

The Physician Instills Fear, Noncompliance, and Disappointment

Doctors often instill fear. As a result people stop going to the doctor, not seeking the necessary attention when they get sick. As a result, patients tend to wait to visit a doctor until they are desperate; thus, they are interacting with a physician at their most vulnerable state. In this way, interactions become more problematic, increasing negative responses to doctors and creating a vicious cycle of fear and noncompliance (Kleinman). In this way, the physician becomes part of the problem because they perpetuate the cycle of noncompliance (Kleinman 127).

This cycle may result in a dynamic where doctors are overly harsh and outspoken. There is a belief that patients should be treated sternly because "pitying patients" could make them too dependent on the healthcare system (Behar 113). This "tough love" act can only go so far, especially when medicine is treated as more of a service than a human right. Patients become annoyed that they are handled in a way a parent handles a child, leaving the doctor's office disappointed and frustrated. Jamison describes a visit to her doctor in which she mentioned wanting kids. The doctor responded that she "should not have children" because she has "manic-depressive illness" (191). Such misuse of power further alienates patients, resulting in increased fear and self-doubt.

Exceptions to the Rule

The descriptions that patients use to describe their doctors are largely shaped by the restrictions from the medical system. For example, Jamison describes constraints for physicians as she reflects on her professional role: "there were ninety patients for each psychiatric attendant" (23). The only thing the patient sees is a doctor that doesn't come to their room often enough to check on them. However, this isn’t necessarily the way this physician wants to practice.

Sacks discusses “the isolation enforced by the rigid ‘vertical’ structure of the ‘institution’” in healthcare as a leading factor in a patients feeling of loneliness (133). But he also illustrates the dependency that the medical system creates (137). While in isolation, patients are stripped of their identity and quickly forget who they are beyond the hospital as they adapt to this new, although temporary, life. This loss of identity and isolation is often associated with the physician who, once introduced to the patient, becomes the face of the hospital and the subject of critique. However, this physician is just as restricted by the medical structure as the patient is. When Sacks was first admitted to the hospital for his damaged leg, the nurse refused to be flexible about the necessity of a rectal temperature, even though his leg would hardly allow him to turn over comfortably, saying it was “a hospital rule” and that she had to follow her orders (23). Even though each patient comes into the medical structure under different circumstances and a variety of unique needs, the structure is not set up or susceptible to flexibility.

In many illness narratives, patients address relationships that they believe benefit their illness experience. Jamison thanks her doctor for the compassion and time that he gave her and for the fact that he emphasized, more than anything, that her life “was a life worth living” (118). These narratives clearly illustrate that patients don’t necessarily want to be coddled, but they do want to know that they are being heard and that they are in capable hands. By recognizing that the patient’s world is changed by the disease, the physician can address the issues related to illness (Jamison 102).

When doctors listen to their patients and begin to have an understanding of the patient’s needs, they are comforted and can begin to understand that there is hope of recovery. When Sacks’ Norwegian surgeon came into the room, “he leapt and danced and showed [him] his wounds, showing [him] at the same time his perfect recovery. His visit made [him] feel immeasurably better.” Even for a doctor-turned-patient, this illustrative and artistic dance was more comforting than any technical jargon he could have used (25). This is not to say that every doctor must dance around their patient in some interpretive style, but that the doctor must realize that the needs of the patient far exceed the treatment of the physical ailment.

It is most unfortunate that the doctors that are given praise are far less in number than those who are viewed negatively. It should also be recognized that part of medical school emphasizes the professionalism of medicine to teach students how to not become overly attached to their patients. Some doctors take this too far and remain cold throughout their career while others, perhaps, take these teachings too lightly. Jamison says that it is “those doctors who are the most competent and conscientious who feel the most sense of failure and pain,” which perhaps dissuades doctors from forming relationships that could help with their patient’s illness experience (127). But we need doctors like Sacks who says it best of all: “I myself, as a physician, mysteriously stilled the apprehensions of my patients—not through knowledge, or skill, or expertise, but simply by listening” (70).

Family and Illness

The family plays a large role in shaping the patient's illness experience. They can act as a support group, a crutch, a source of tension, or an acknowledged absence. In the case of a child experiencing illness, the family makes all of the decisions about how the child will be treated. The following information about the relationship between families and patients is separated into themes that include: the family dictating your feelings, family expectations, the family being blamed, and effects on family. These themes, present in almost all of the narratives cited, create a general view of this family-patient relationship.

The Family Dictating your Feelings

The most obvious theme that is prevalent throughout illness narratives is that of families telling the patient how they should be feeling in a particular instance or, more commonly, how they should not be feeling. The idea that there is a particular, "right" way of dealing with a disease or medication is culture-bound, tied up in the notion that there is also a "right" way to present yourself to society. This is illustrated primarily when parents talk to their children. According to Grealy, we teach our children that, if you are "courageous" and "don't cry" then you are somehow a good patient (8). She discusses the many occasions in which her parents told her not to cry every time she went to the doctor's office to receive medicine that would make a grown person cry (68). She continues to explain that her mother said to her, "'you can't let this get you down, you know. I know it's hard, but you can't get depressed by it. Don't give in to it…'" (75) and constantly told her that she "shouldn't get so upset" over chemo treatments and surgeries that caused her so much pain (96).

Ruth Behar discusses, in a similar narrative, an accident that she had as a child in which she was placed in a cast from the hip down and yet her family told her that she "was not allowed to feel sorry for [her]self…and [she] was not allowed to be angry with the young men who had caused the accident because they were dead." Not only could she not feel bad, but they also told her that she “should be happy” because her situation could have been worse (106). Behar, a new patient, was already having an impossible time transitioning into her new identity. Her experience is further ruined by her family members criticizing her feelings and making demands of her to change them. Behar must suffer through the pain of her broken leg and her family’s judgements about her coping methods.

Although most of these remarks, especially those that come from family members, are intended to be helpful, most stem from the idea that these family members can understand what you are experiencing. Jamison remarks that “others would say to me, ‘It is only temporary, it will pass, you will get over it,’ but of course they had no idea how I felt, although they were certain that they did” (111). People generally want to be empathetic with the people in their lives that are suffering. But there comes a time when this empathy becomes problematic simply because it can never be true. Although your family can sympathize with you, they can never achieve the level of understanding required to be able to explicitly tell you how you should be feeling and dealing with your suffering.

When the pressure is increased on a patient by telling them how they should be responding emotionally to their pain, and when the patient’s response comes involuntarily, the patient becomes “ashamed of [them]selves” and they begin to think that they have disappointed those around them (Grealy 74). Sometimes parents will even try to create shame to make their child act in socially and medically appropriate ways. Dr. Williams describes in his *Doctor’s Stories* that he regularly heard parents ask their children: “aren’t you ashamed to act like that in front of the doctor?” Parents and other family members force the patient to live with repressed emotional feelings in order to preserve their status in front of the doctor.

When parents, or other family members, talk to the patient about their illness, they try their hardest to be understanding and helpful. However, most do not realize that, although many of their phrases might be forgotten, there will be a few that stand out to the patient and will never be forgotten. In Grealy's case, her mother tells her that she "should conquer [her] fear by not crying," automatically, she begins to associate crying with being afraid and will always be ashamed at the tears that come to her eyes (69). Patients remember the things that affect them the most and being told to manipulate the way you feel is definitely one of those things that you aren't likely to forget.

Family Expectations

The expectations that families have for their relatives go beyond the emotional response aspect. Not only was Grealy forbidden to cry but she was also told that "one had to be good" which meant she could never complain or struggle and she was absolutely, under no circumstance, allowed to "show fear" (18). Complaining, struggling, and being afraid were all in the recipe for making your family look bad to the rest of society. The "perfect patient" was one that accepted all information given to them without a fight and presented a front of bravery no matter the situation. If there were any issues you were expected to "[keep] your problems to yourself" (Jamison 39). This further burdens the patient with a sense that they can't exhibit any symptoms or, at the very least, respond to their symptoms in their own ways.

Jamison also discusses how her family and friends expected her to act "normal" once she started taking her medication (91). This idea of "normal" that seems so obvious to most people is a foreign concept to chronically ill patients. It is something that patients may dream about but also something that they can't imagine. Family members expect that it would be a welcomed change for the patient while the patient struggles with their changing identity. This idea of "normal" also transcends to physical appearances that are affected by the illness. Ruth Behar's mother told her that "the boys…were going to see that from the waist up [she] was a pretty girl, but, wow, were they going to be disappointed when they saw what [she] was like from the waist down" (113). Presumably, her mother was worried and trying to motivate her to take care of herself, but from the patient's perspective, physical looks are the least of her concerns. Ultimately, the phrases and attitudes from the families created more problems and worsening symptoms, causing the patient to suffer longer than they would have otherwise (Kleinman 100).

The Family being blamed

It is common that the families, usually the parents, are blamed for causing an illness or not treating the patient with the illness in the most efficient manner. When the patient is a child, a lot of the blame stems from a misunderstanding or a misconception of the situation. However, when that child grows up, they can look back and question their parents just as easily. Grealy says that, looking back, she couldn't understand how her father allowed her to suffer by herself while receiving the chemo treatments (76). As a child, she liked that he left, but as an adult, she began to wonder at his seemingly lack of strength to help her in a terrible situation. Often times these illness narratives illustrate the feeling of not being supported and understood.

Sometimes parts of the illness experience are completely blamed on family members. Patients remember their illness in terms of the "perception of the failures of [their] parents" (Kleinman 116). When discussing the damage done to her depth perception, Behar talks to her mom about the reasons why she didn't move her bed while she was sick. She says "I was making [my mom] feel guilty. I decided I would show her how grown up I was. I'm not accusing you, I said to her in an even voice, I'm just trying to remember. But I was lying. Of course I was accusing her" (111). Patients often understand that their families are doing the best they can but it doesn't mean that they don't suffer from their actions, or lack of actions, woven through the illness experience.

The general environment of a sick child's upbringing is also described in illness narratives, describing how the attitudes and personalities of parents affected the illness. For Jamison, she believed that she "ought to be able to handle whatever difficulties came [her] way without having to rely upon crutches such as medication" and this belief stemmed from the way she was raised (99). This idea that her parents wanted her to help herself and not rely on any "crutches" is a seemingly normal ideology that most parents preach. However, when there is a patient involved, the teaching takes on new meaning. For one of Kleinman's patients, "her parents are accused of overprotecting her so that she was not prepared (and still is not) to meet the practical difficulties of "real life." In the other version, her parents (and others) are accused of not having done enough to give her the time, money, or practical help to recuperate fully" (115). This illustrates the idea that blame, in itself, contributes to the illness, regardless of where it is directed.

Effects on Family

While it is true that the patient is generally the one suffering from an illness, the effects of the illness reverberate throughout the family. One of Kleinman's patients states that "if anyone asks about Alzheimer's, tell them it is a disease of the whole family" (183). As the health of the patient deteriorates, so do the relationships within the family. The illness experience is affected by the family in as much as the family is affected by the illness experience. The economic toll that illnesses cause has led Grealy to write, "I saw the bills, I heard their fights," which is an all too common occurrence for families with a sick member (xvii). Not only is a member of your family sick, the added stress of money and keeping the patient comfortable creates tensions that explode in unproductive ways. This stress that is placed on the healthy members of the family creates a layer of guilt on the illness experience.

The patient usually realizes what this illness is doing to other people. Dr. Jamison wonders "who is being too polite to say what?" and recognizes that the illness has created a loss: "friendships gone or drained, a ruined marriage" (68). There will always be friends and family that can't handle the illness and drift from those who suffer from it. The patient, afraid of people leaving and/or not wanting to be a burden, often pushes those closest to them away.

In her attempts to distance herself from loved ones, Jamison lashes out and specifically hurts people in order for them to leave and not continuously get hurt by her illness (113). It is difficult, for both parties, to have a relationship in which a person experiencing illness is a part of.

The patient, when aware of the effect that their illness is having on their family, tries to protect the family from the suffering that has been endured. Grealy thinks to herself, “if I couldn’t overcome my growing depression, I deserved it, and how unfair of me to inflect it upon everyone else” (86). The patient believes that they must deal with their illness on their own because it is, to put simply, theirs. Dr. Jamison believed that, by committing suicide, she “was doing the only fair thing for the people [she] cared about” (115). Instead of dragging others into their situation, they isolate themselves. Often this attitude prevents the patient from seeking any kind of help with their illness and contributes to the worsening of their symptoms and experience.

After being hospitalized from a fall down a mountainside, Sacks is having a difficult time with his leg. When his friends and family ask how long he will be in the hospital, he responds in a flippant attitude with, “not a minute longer than necessary” (35). He doesn’t mention any of the problems he is having aside from the usual effects of surgery. Patients, much like Sacks, tend to tell their friends and family what they want to hear rather than being honest about their physical and mental condition. Although this could be attributed to the idea that patients are embarrassed about their situation, a more likely explanation for withholding information is that they do not want to burden others with problems they feel responsible to solve on their own.

Grealy also clarifies this approach as she discusses one of her prolonged hospital stays. She explains that in the hospital, she is “in one place” while her family was “in another.” When they came to visit her in the hospital, they were “only pausing” from their everyday lives (48). She was a pit stop they made along the way and, while she was consumed every second with her illness experience, her family was only briefly introduced to it each time they saw her. To Grealy, to make her family feel sorry for her, or to request that they join in on her illness experience by having more knowledge of it, was placing an unnecessary burden on each of them and, therefore, a greater amount of guilt on her.

The best thing that a family member can do is listening to the patient. The comfort that a patient feels knowing that they are not alone can help through all sorts of physical and mental suffering. Dr. Jamison writes that “[she] can never pay back the love, kindness, and understanding” that her brother gifted her, making it “unequivocally clear that if [she] needed him, no matter where he was, he would be on the next plan home” (78). Although his understanding didn’t make her disease disappear, his comfort lessened the burden of her illness and allowed her an outlet to seek help in desperate times. She also had friends who, “despite [her] pleas to be left alone,” would be by her side and “she would be secretly and inexpressibly grateful” for the company they provided in the midst of her suffering (117).

Family can also have the largest impact on the moral attitude of the patient. When Sacks’ friends brought him a record player and an album to listen to, he saw a complete change within himself that contrasted how he had felt when interacting and thinking about his physician. The light-hearted and good-natured visit of his friends also lifted his spirits and got him out of his own head long enough to remember the good things in life. Family also has the special position to bring your perspective out of your illness and back to reality. While Sacks was upset about his surgeon’s attitude, his Aunt tells him to bring his expectations to a realistic level, reminding him that they were both only humans. Without the comforts provided by family and friends, patients can drown in their loneliness and self-imposed gloom.

My Illness Experience

As part of this project, I am including my own illness narrative. My aim is to respond to the call to embed oneself in the ethnographic process. In addition to reviewing themes in other narratives, I present my own as a way to reflect on ways in which my experience echoes the themes I established above.

The wooden swing set that sat at the far side of our back yard was used a total of 100 times, although I consider even that an exaggeration, in the 15 years we lived in my childhood home. In San Antonio, Texas, the temperatures are either hot or very hot, and the days that the heat was bearable were few and far between. But on those particular days, the swing set creaked with weather rotted wood as we frantically played and pretended that we had never seen the outside before. My favorite activity was jumping off from the highest point. I would get on the swing and watch my younger brother struggle to get as much height as me and then I would jump like I was some sort of superhero and my brother would stare at me in amazement. When mom found out, it made the jump even more exhilarating. She would scream at me between her teeth from her safe space on the porch and I would giggle and pretend that I didn’t hear. I got right back on the swing for the next adventure, getting higher and higher, nearing the pinnacle. My muscles flexed looking forward to the split-second free fall when I heard my mother screaming at me not to do it. My actions were already set, but that was also mom’s serious voice and if I didn’t listen my night of swinging would be over. I fell straight to the ground. I thought I had landed okay, maybe not as graceful as a cat, but I was definitely still in one piece. The world seemed to be a little fuzzy around the edges but I thought maybe the sun had made its way from behind some clouds. Seconds later I registered that mom was screaming on the porch, yelling for my dad to come quick. I looked down at my arm and realized it was twice the size it should be. Did it hurt?

By the sounds of the screams I assumed it did, so I started crying. Dad wrapped my arm with a kitchen towel and told me to keep ice on it. Mom was crying harder than I was so we waited for her to calm down before driving to the emergency room. At seven years old, this was my first time going to the hospital that I could remember. My night of swinging had come to a halt to make way for several hours of sitting in a waiting room. I didn't even come out of it with a cool cast because it was only a sprain. I wished it had been something more important, something cooler to tell my classmates about the following day at school. Little did I know, my wish for a more serious condition would be granted less than a year later.

I held my right index finger directly in front of my face and tried to decide if it was causing me pain. I might have noticed the swelling and then imagined pain, or it could be that the pain crossed my mind and made me take notice of the swelling. Regardless, the matter deserved the attention of the people with more knowledge than my 8 year old self. I paraded my finger through the house, descended the stairs and approached my mother who was crocheting on the couch. With a smile, I shoved my finger in her face forcing her to gaze upon it. I told her it was hurting even though I wasn't quite sure. My mom squinted at this blurred finger resting too close to her face. With a scowl she took me to the kitchen to scrutinize it in better light. I knew her first response would be to ask me what I did. I smiled because I knew I hadn't done anything, that it wasn't my fault. She didn't seem too concerned and her solution was to have the pharmacist at Walmart look at it since she needed to go grocery shopping anyway. My reactions mirrored my mom's on the inside. But, with a constant need to go against her, I assured her it was very serious and when the pharmacist, later that night, agreed, I passed a smug look her way.

We ended our night at a pediatric urgent care in which the doctor assured the two of us that it was simply an allergic reaction, probably from a spider, that could be cleared up with a few days of Benadryl. Relieved, and exhausted, we went home and I gladly accepted the Benadryl that would put me to sleep quickly. A week passed and the swelling in my finger had done anything but get better. The pain, once I decided it really was painful, would not cease and waking up, it seemed, was the hardest thing I had experienced in my life thus far. Nothing was getting better; the doctor's instructions were failing in healing me. For the first time in my life I started to realize that doctors were human. They are not God, they are not superman, I would say they aren't even right the majority of the time. When we went back to the same doctor I couldn't even show him my disappointment because my eyes wouldn't stay open, my head wouldn't stay up, and I was violently retching because my body was fighting against me in every way.

My pediatrician saw me shortly after this episode and he immediately said that I had Juvenile Rheumatoid Arthritis (JRA). Once he explained it to my mom, it made sense, and we were happy to have an understanding of what was going on. But as life has shown me time and time again, nothing is that simple. I had to go to a hand specialist for a second opinion because apparently a pediatrician isn't qualified to make that kind of diagnosis. The hand specialist decided I had trigger finger which we would find out later manifested as exactly the opposite of what I was presenting (my finger was swollen and wouldn't bend, whereas a trigger finger is bent and will not straighten). Within about two minutes of his diagnosis, there was large needle stuck into the palm of my hand. It was the worse pain I had ever been in. As the second needle was inserted he began talking to my mom about immediate surgery. My mom, flustered and scared, saw my tears and took me out of that building as fast as she could. We got to the car, I had finally stopped with my silent tears as my hand went numb, and my mom started bawling. It is a unique and often off-putting fact about my personality that I do not do well with tears. Even at 8 years old I was remarkably uncomfortable when other people cried around me. Sitting in a small car with a mother who was supposed to be the strong one did not ease my awkwardness. I sat there and stared at her. I watched her dial the phone and I heard the sound of my pediatrician's nurse on the other line. My mom begged to talk to him and, lucky for us, my pediatrician cared, or seemed to care, about my well-being above all else. He told us to get out of there immediately and come straight to his office. My mom calmed herself and I stared at the bruising that would soon envelop my entire palm as we drove silently to his office.

The decision this time would be to see a rheumatologist to confirm my pediatrician's suspicions (why this wasn't the original plan was/is above my head). I don't even remember how much time passed between all of these appointments. As an 8 year old, time didn't mean as much as it does now. Somedays would feel like an eternity then I would sleep away weeks at a time. I used to measure time passing by my days at school but I began to miss so much that that unit wasn't relevant. Eventually I was at the office of Dr. Rosenberg, a rheumatologist for adults. He was a tall, skinny man with squinting eyes that made you question everything that came out of your own mouth. The "examination" consisted of him sitting in a chair watching me walk around the 3 foot by 4 foot room and every once in a while he would yell, "SQUAT." He wrote some notes and a prescription and we were on our way.

We picked up the prescription as soon as we left the office and when we got home my mom put the bag in the refrigerator, leaving it in the bag. At this point I was pretty used to taking pills. I was on a constant diet of Tylenol and Motrin, but neither of those were ever stored in the refrigerator. I asked my mom but, in her usual evasive way, she kept telling me to wait until my dad got home. That always meant something bad. So I waited for hours, anticipating them telling me I was dying or that I was going to have to drink that milky stuff that they forced down my throat before a CAT scan. After an eternity, my dad came home and they ignored me. They went into their room to talk in low voices that couldn't be heard through the door. I laid on the couch, I laid in my bed, I played with the cat, I held a heating pad to my hand, I think I even fell asleep before they finally emerged. My dad had changed out of his work clothes and he looked more distressed than he had when he had entered the house. He went outside while my mom told me I was going to be taking shots and more pills. My dad came back in with our neighbor who was apparently a nurse. They pulled the prescription from the refrigerator and began to assemble the separated piece, swirling the mixture together for several minutes. They pulled the mixture into a syringe and asked: "stomach or leg?" WHAT. YOU WANT TO PUT THAT IN MY STOMACH. I refused to cry but I answered with disgust at such a suggestion.

I was used to shots. It wasn't that big of a deal. But knowing that I would have to do a shot every week was just a mental stab. Anticipating the needle was the worst thing about my existence and that lasted for several months. One shot every week. But it continued to get worse. The shots were supposed to help me, but every day I woke up with swollen knees. I couldn't sleep through the night and I couldn't wake up in the morning. It was a perpetual cycle of pain and fatigue on top of shots that were obviously causing more pain than they were easing. To make it worse, my mom, who had "learned" how to administer the shots, pierced my skin, went straight through a vein and poked a nerve in one swift motion. My leg had a spasm and I screamed and screamed and kicked and screamed and she didn't stop. Her excuse was that I was just upset because the shot hurt. But as she pulled it out blood literally squirted from my leg. The bruise from that shot was one of the largest I have ever had on my body. She was sorry but defensive and that argument ended with me resigning to give myself the shots from then on. So I was a 9 year old doing the job of a nurse. That became the normal. Every Friday night I would drag a chair into the kitchen, mix up the shot and pull up my shorts exposing the fattiest part of my thigh. Eventually, my parents didn't even accompany me. They would sit in the living room or would be off in their bedroom, it became the expectation that I would give myself the shot quietly and get it over with quickly. In a lot of ways I had become an adult within this first year. I was constantly thinking about pain or medicine and I had little room for the childish things my friends thought of. Of course, this also made me incredibly full of myself and I would often find myself in an egotistical admiration for how strong I was.

Several months after my first shot, I visited Dr. Rosenberg's office and he decided I was faking my pain and that I didn't need my medicine. Instead of one shot a week, he put me on one every two weeks, then once a month. I hated the shots. I loved Dr. Rosenberg for not making me take as many. But walking became harder and harder. I was embarrassed that I was limping into my classroom at school. I didn't like the fact that I stayed in with my teacher and read a book during recess. I didn't like that my teacher constantly asked if I needed to see the nurse because of the amount of pain she saw on my face. The next time we saw Dr. Rosenberg, my mom was fuming, and he was still adamantly against putting me back on more medicine. He told me to do my walk around the room and do a squat. That was the whole appointment and we never went back.

The fear and pain mixed together. But at this point I was hopeful. About 50% of kids that are diagnosed with JRA outgrow this disease when they go through puberty. I knew that I would be that 1 in 2. So all I had to do was wait and hope that I would hit this puberty sooner rather than later. During this time, I started to see Dr. Cole. I had my first examination where all of my joints were tested by bending and maneuvering and tapping. I had to dress into a hospital gown and my whole body was thoroughly examined. I was exposed and confused. I wasn't naked but he was the first person that had gotten so close to my arthritis, testing it and provoking it. After he finished, he told me what medicine he was prescribing and he left the room. There was no conversation. He talked at my mom and treated me like another one of the dozens of children he would see that day. I was put on two shots a week and 8 pills a nights, except for Friday when I took 18. A nurse finally explained that the shots were like a boost of energy and that I wouldn't sleep if I did them at night (a fact I would have loved to know before suffering from years of insomnia). So Sunday mornings became the most dreaded time. Years passed without much change. Eventually I went through puberty and life still didn't change. I was the wrong 1 in 2. Everything seemed hopeless because I could no longer visualize an end. This disease was truly forever, something I couldn't comprehend at the time.

* * *

Every summer, since I was 17, I am a camp counselor for kids with Juvenile Arthritis. The camp helps kids meet others with similar problems and encourages healthy lifestyles to help reduce pain and damage. This one week a year is something that many of these kids look forward to as most suffer far worse than I ever have. They get one week out of 52 to feel like they belong and to be with people that understand. Last year I was in charge of all of the younger girls, aged 6-8, all with varying degrees of the disease. Many of them were at camp for the first time but liked talking to people about their diagnoses, using words too large for a normal 8 year-old's vocabulary. One girl in particular had just been diagnosed a few months before camp. She had to take two shots on that Thursday and she dreaded it and constantly said "there are x amount of days until shot day. I don't want that day to get here." Well Thursday did arrive and she looked down at the floor as we walked over to the nurse. I told her not to worry that it would be over before she knew it and she said "yeah, whenever I am done with 2nd grade I won't have to do it anymore." At 7 years old there is no comprehension of the term "forever." She didn't know that she would have to take shots for longer than a year. She didn't understand that what she was going through wasn't just going to magically stop. As her camp counselor, it wasn't my place to correct her, but that conversation will stay with me forever. Pretty soon she will be done with 2nd grade and I constantly think about who will tell her, her parents or doctor, that this disease continues to 3rd grade?

* * *

Eventually, Dr. Cole thought it would be best to add in another shot. The drug, methotrexate, was the first one I had ever taken but, up until that point, it had always been in pill form. The thought of another shot made me spiral into a deeper darkness mixed with my developing teen angst. I did my first methotrexate shot the day before we left to go visit family that lived a 20 hour drive away. I fell asleep in the car early the next morning and woke up close to lunch time gasping for air. Never in my life had I felt like I was dying. It wasn’t the most pain I had ever felt, but it was a fear that I will never forget. I stretched my torso as far as I could, hoping to expand my lungs and force air into them. I was getting light headed, but eventually I could catch my breath and breathing became less forced. Every few hours it seemed I would sit bolt upright and realize I couldn’t do the one thing that your body is supposed to do without thinking about it. My mom called the doctor and they said it was probably acid reflux and that I should stay away from acidic foods. As an aspiring adult, I realize that most of the things doctors would say to my mom would be a complete guess and most of the time they didn’t even make sense. Just this past year at camp did I realize that what was a happening was a panic attack, a seemingly common side effect of the drug that had affected a significant number of my campers.

I was 14 and had been seen by Dr. Cole for over four years. Mom and I didn’t like him very much but he was the ONLY pediatric rheumatologist in San Antonio and it was a fight with the insurance company just to see him because he wasn’t covered. There were never any surprises when we went to his office. Mom always bought me an overpriced drink from Starbucks, we waited at least thirty minutes, he would ask what had been hurting, adjusted my medicine slightly or said that we would wait another three months and see what happened. I would get my blood drawn from arms that looked abused by needles and we would be on our way. This was my life for years and years, my entire middle school days were eaten up with appointments, medicine, and explaining to people why I had a school elevator pass or why I would have crutches one day but not the next. They were years that I wished to be normal and was reminded, by all the adults in my life, that I did not have it the worst. At least I wasn't diabetic and giving myself shots every day, right? Then I would go to another appointment and be told I needed another shot or more pills. So at this point it seemed like things really couldn't get any worse.

* * *

On our last visit with Dr. Cole, he farted. Even then I recognized that people have bodily functions. I realize that he might have had problems controlling the gas or maybe that he was embarrassed. But a friend would have made a joke, a polite person would have said excuse me, and a person so far removed from humanity would have kept writing as if nothing had happened. Dr. Cole didn't even acknowledge that it happened and my mother and I looked at each other and silently laughed for a brief second. But I remember being beyond uncomfortable and I think, now, it was because I really needed a friend. In medical situations my mom had to be a mother. She had to show me tough love when I was feeling sorry for myself and she had to make sure I continued to live my life and not curl up in bed for the rest of it. She was the one that argued with doctor's offices and the insurance company when they tried to take advantage of our situation. So, although she was a superhuman and beyond patient, I didn't view her as my friend. My actual friends, the ones from school and from my neighborhood, rarely knew about my disease. Between the embarrassment and my desperate attempts to "be normal," I tried to hide the limping and pain that I felt. In my heart I knew it would be easier if I could just talk to someone that understood what I was going through. I wished I could have a friend that enjoyed my company and knew about my condition. It made sense for that person to be my doctor because I saw him so much and because he would have really understood. But instead, Dr. Cole farted and pretended like nothing had happened. We never went back to see him and I'm sure he didn't even recognize it as a loss. I was one of many patients that he dealt with to make a living.

On one dreaded Sunday morning, I was mixing my shots. First, you had to take the syringe and screw it into a little glass vial. In the syringe was a liquid that you pushed into the vial with powder. Then you had to swirl, *not shake*, for about ten minutes. For the past several months, the manufacturer had really been off his game. The little screw part would not stay attached and every shot would come apart at least three times during each mixing. It prolonged the process significantly and frustrated me beyond belief. On this particular morning I was even more aggravated. I woke up annoyed at my life and dragged my feet to the kitchen to retrieve my shots. My dad sat across from me in the living room working on his laptop while I struggled with my mixing. It broke apart for the second time that morning and it was like something inside of me snapped. Anger shot through me and I threw the two pieces, liquid and all, across the room, hitting the wall in front of my dad. His head shot up from behind his laptop and he watched as I broke down and melted into my tears. I was immediately embarrassed and regretful that I had just thrown something that keeps me relatively healthy and costs hundreds of dollars practically into the trash. I was expecting my dad to yell and he quickly got up from his chair and lunged toward me. But just as quickly he was on his knees in front of me with tears in his eyes, seemingly pleading for my sanity to return. This was probably the second time I had ever seen my dad get close to crying. He just kept saying, “what can I do, what can I do?” and I didn't have an answer. All I knew was that I couldn't go on feeling that way. It wasn't that the stupid shot kept breaking, but more so that it was breaking down my mental health.

Dr. Cole hadn’t given me any other choices for medications. We knew that they were out there but, as a patient, you couldn’t just demand your doctor give you something else. At this point, there were still no other pediatric rheumatologists in the area so we started to make the hour and a half drive to just south of downtown Austin. I was grateful (not that I ever showed it) that I could convince my parents into taking me to a different doctor even though I knew that it was a struggle with the insurance. My mom never complained to my face but I could recognize her frustration after long hours spent on the phone, sometimes yelling and sometimes completely silent for an hour as crappy music played on her speaker. But it was all going to work out and I was actually kind of excited about getting to meet a new doctor, knowing that this one had to be better than the last.

Traffic was a nightmare, parking was a nightmare, finding the actual office was a nightmare and my mom had planned for all of it as we were still an hour early. She handed me my paperwork expectantly. Between each line of questions on the paper and questions I had about how to fill out the questions, I looked around at all of the small children on their parent’s laps. I didn’t feel like I belonged in there. Tigger and Pooh were stuck on the walls of the waiting room with little lines drawn under them to give the impression that they were jumping around. I didn’t belong here. I had started my journey through puberty several months before this moment which, in my head, made me an adult which, by default, meant I was too old to be in a kiddy office. But I was still labeled with a juvenile disease, still stuck in a waiting room with toddlers crying about the shots they knew were coming. I felt so much pity. I thought, at the time, that it was pity for all of these children that wouldn’t ever get to experience a normal childhood like I did for 8 years, but I know now that it had a lot more to do with feeling sorry for myself than it did for anyone else. I was supposed to stop having pain after puberty. I was supposed to be normal and go into the adult world healthy. One of the last things that Dr. Cole said to me was that now there was less than a 5% chance that I would grow out of this disease. I was doomed. The only thing that came from growing up was getting to fill out my own paperwork.

When we finally got back to see this new doctor, Dr. Carasco, I was anxious. But he came in and shook my hand, examined my body which I was completely used to at this point, and then he gave us options. He talked about all of the drugs that were available to try, how they were administered, how often they would be taken, and how long each session would last. My mom gave me all the power in choosing because she knew just as much as I did and because she and dad talked about me taking control of the decision-making. All of the options involved needles but some of them were once a month and most of them didn’t involve me doing it myself. I chose a drug called Orencia that was an infusion that would take 30 minutes a month. The first few times were every week then every two weeks and these were in Austin. The drive was annoying but I had just gotten my learner’s permit so mom would let me behind the wheel on the way there. We would get to the same building as the doctor’s office and go into a room with big comfy chairs. People would be sitting with big blankets on their laps and needles in their arms. The first time I got this drug the nurse came in and told me the side effects. I never worried about any of it because none of my other medications ever gave me side effects. But halfway through this first infusion, I was more tired than I had ever been. I barely remember making it to my car afterwards and the drive home was spent sound asleep. For three days after that I only got out of bed for meals and I held my head up with my hands. It is terrifying to be so out of control of your sleeping habits. For the first time in several years I was missing days and days of school. For the first several infusions I slept like this, missing days of my life. But eventually it got better, I stopped feeling the need to sleep except for a few hours after the drugs and we found an infusion center close to our house. I was in a much better state, both mentally and physically, with this new medication and was pretty happy with how my life was going. But several months into the infusions those darker thoughts started to creep in and I couldn't get my mind off of questions like: Why does this have to happen to me? and What's the point of even doing this if I'm just going to suffer forever?

I saw Dr. Carasco for about three years. The first few visits were great because he let me choose new medicine and he seemed to be very understanding. But on several visits he told me that I should lose weight because it would be better on my knees. At this point I was a freshman in high school. I was 5'3" and weighed maybe 130 pounds. I was in no way overweight or fat and I am thankful that I had the self-esteem to not hurt myself and listen to him. I couldn't stop thinking about how, if he had said that to a girl who didn't view herself in the best light, especially at 14, he could have caused a lot of problems. I ultimately shrugged it off and decided that he was probably well-intentioned although misguided. But as I continued to visit him, usually every 6 months or sometimes sooner when I was having problems, he would continue to make comments about my physical looks. On one visit, he asked if he could prescribe me acne medication for my face. I was a teenager that would have hormonal break outs (and VERY slight ones at that). I was appalled. I knew that I had acne sometimes, but I also knew that it wasn't something that age couldn't fix. My mom and I would just laugh at his suggestions on the car ride home, but I think they were actually starting to affect me. The last straw with Dr. Carasco came when he was looking at white spots on my back. It was just an unimportant skin condition that didn't allow me to tan all over. I had already seen a doctor about it and he said it would go away and would probably come back every summer, a way for my body to deal with extra heat. I wasn't that worried about it because it wasn't actually affecting my health and I couldn't see it anyway. But, just the same, he asked if I wanted medicine for it. I declined the offer and told him I wasn't too worried about that. His response was to ask if I wanted boys to think I was a leper. I clenched my teeth and tried not to show how angry I was. How dare he talk to me that way. He was supposed to be my doctor for the arthritis that I suffered from yet he couldn't even do that, he had to interject and tear me down. That was also the day that I had to get a large injection in my hip, which he knew about, and I ended up breaking down by the end of it, unable to recognize any good that I ever saw in that man.

Finally, on Sept. 30th of 2012, there was a turning point in my life. I watched a documentary called Forks over Knives and on Oct. 1st, I declared myself a vegan. I immediately stopped taking all of my medication (except for the infusions that my mom made sure I got to) and I hoped that the diet would work. Five months into it, I had an appointment with Dr. Carasco. He was amazed at how good I felt and how my joints looked. I explained what I had done and he started telling me about a study done in Germany examining the effect of animal protein on autoimmune diseases. He explained that, in the study, there was about a 70% success rate when patients completely cut out all animal proteins. As he was walking around the room, tapping joints and talking about things he has known for ten years, my heart sunk lower and lower. I wanted to run from the room but I stared at the floor and didn't look up until he was gone and we could leave.

I cried and I couldn't stop even as I was gasping for air, the tears kept coming. That study had been done before I was even diagnosed with this stupid disease. Instead of recognizing the pain that the medication was causing me, they kept forcing me to take more or to take something different. I had never even considered a diet change before watching that documentary because I was never exposed to the idea. Dr. Montemayor, Dr. Rosenberg, Dr. Cole, and Dr. Carasco had all spoken to me about this disease hundreds of times and something other than drugs was never mentioned. In that moment, all of my faith in the medical system left my body and I felt empty. I felt like the world was against me, particularly the doctors. I began to think that doctors tried to keep you unwell so that you would have to keep coming back. I started to think about how much money these doctors were making from drug companies by endorsing their drugs. I commenced my hatred for big pharma and for greedy doctors. A switch had been flipped and I refused to trust anymore stupid doctors. I went to my appointments for the next two years completely stone-faced and let everything he said go in one ear and out the other. I was no longer going to be a puppet.

I had given up on the medical system. It had failed me and I no longer felt the need to be continually disappointed. As soon as I turned 18 I started to actively avoid the doctor. I called and canceled my next rheumatology appointment and used the excuse of my moving away to college to not find an adult rheumatologist. College gave me an excuse to start over, I could leave behind the sick child I once was and look after myself. As long as I maintained a strict vegan diet then I would be just fine. It wasn’t so easy after leaving home, but I managed as best as I could. I had the occasional flare, especially during finals and even more so when the first winter hit and I got to see snow for the first time (once was abundantly enough). College introduced other ways of feeling better and I took care of myself enough to survive and even thrive. During this time I confirmed my desire to become a physician, to go into the medical field and do a better job than the physicians I had seen. I wanted to practice helpful medicine and I wanted to create healthy people rather than perpetuating patients.

It took three years for me to finally be convinced to see a doctor. The pain hadn’t gotten worse, but every morning that I woke up with a pain I was reminded that it wasn’t just an external feeling but also a very real disease that could be destroying the inside of my body. I dreaded the appointment as soon as I made it and I tried to hide my nervousness from everyone around me, without much success. I asked my mom to join me but made her wait in the waiting room last minute because I was worried that the doctor would say something was very wrong and my mom would somehow force me back into drugs. I paced in the small examining room until the doctor came in. When he entered, I sat down and continued to fidget. He sat in front of me and said that he just wanted to go over my history. So I told him a bare bones version of this narrative and he sat patiently, scribbling some notes, and asking questions for verification. Afterwards he did a brief exam and asked me if I was nervous that he was going to make me take medicine. I was surprised that he could deduce that from my narrative as no other doctor ever could. I said yes which seemed to break the small thread of tension and we both laughed. He said he wanted to get some x-rays and blood work to make sure everything on the inside looked as good as the outside. He even made room in his schedule to go over the results with me before I had to go back to school. He told me repeatedly that he would only recommend medication if it was absolutely necessary. He acted as a counselor and a doctor and even referred to medications as poison in a jokingly way (which I thought was a little over the top considering I know that he prescribes most of his patients drugs but nonetheless it put me at ease). What a relief it was that someone in the medical system was on my side.

Discussion

The last 14 years have been a complete rollercoaster dealing with the medical system. I experienced my lowest points in life when dealing with this disease and I associated these lows solely with the medical system and the doctors. Reading the illness narratives discussed in this thesis, I (finally) realized that I was not alone in these struggles. Many of the patients had the exact same experiences that I did with my family and my doctors. The idea that other people have gone through similar experiences weakens the argument that these narratives are unique. If they are not unique, they deserve to be acknowledged and studied to change the future narratives of unsuspecting patients.

In an age where there is a greater focus on cultural competency, eliciting the worldview of patients is critical. Through these personal, primary sources we become aware of an explicit need for more comprehensive and holistic disease management. The following recommendations are three obvious ideas that can be drawn from this research in order to better the relationship between patients and their physicians and families.

1. Clear doctor-patient communication is necessary for both sides of the relationship. When the patient feels comfortable confiding in their doctor, the doctor has an easier time administering treatment. It eases the severity of the illness experience when the patient feels like they are being heard and understood. Without this clear communication, the patient becomes frustrated and often the experience is prolonged.
2. Prioritizing disease over illness must stop. Putting more emphasis on the experience rather than the physical problem is necessary to understand the experience as a whole. The medical system must stop discounting the conversations the patients want to have about their lives because it will allow them a glimpse of what they need to do to treat the person overall.

3. Physicians and families must allow the patient to cope with their illness in their own way. Dropping the expectations of how a patient is supposed to act in a certain circumstance will allow the patient to express their feelings in an unreserved manner and give the physician and family members an idea of how to treat the patient. In other words, the theme titled “regulation of feelings” needs to be eliminated from both relationships.

Changing the way we listen to patients is important for more productive relationships. However, the research above hardly scratches the surface when discussing family-patient relationships. More research is necessary to make any further recommendations on these relationships. This is especially true for relationships involving children. As an adult, the family plays a much smaller role and can often have a smaller part in the illness experience. However, in the case of children, the family is practically in control of every aspect of the illness experience. This recognition, combined with intensive studies, can provide better recommendations for the relationships between families and patients when said patient is a child.

Conclusion

Taking people seriously is the first step we can take to achieve a more comprehensive healthcare. By using illness narratives we can dive into the patient's experience and determine what kind of treatment they need based on all aspects of their life instead of the traditional approach in which the treating physician focuses on the disease. If we can take a step back and recognize the importance of listening over the idea that the medical system is an all-knowing group of superheroes, and if we can put more value on the patient's stories and devalue the physician's narrow perspective, then we can begin to gain access to a more comprehensive healthcare. Ultimately, we must reshape our own ideas of what a medical system should look like if we want the actual medical system to recognize its faults. How can we pick out the flaws of the system, including patient relationships within that system, any better than to analyze the stories of people who have firsthand experience with it?

Work Cited

Alvord, Lori. *The Scalpel and the Silver Bear*. Bantam Books, 1999.

Behar, Ruth. *The Vulnerable Observer*. Pp. 104-135. Beacon Press, 1996.

Conrad, Peter and Kristin K. Barker. "The Social Construction of Illness: Key Insights and Policy Implications." *Journal of Health and Social Behavio*r, vol. 51, 2010, pp. S67-S79.

Geertz, Clifford. *The Interpretation of Cultures*. Basic Books, Inc., 1973, pp. 3-32.

Grealy, Lucy. *Autobiography of a Face*. Mariner, 1994.

Jamison. Kay. *An Unquiet Mind: A Memoir of Moods and Madness*. Vintage Books, 1995.

Kleinman, Arthur. *The Illness Narratives: Suffering, Healing & the Human Condition*. Basic Books, 1988.

Morris, David B. "How to Speak Postmodern: Medicine, Illness, and Cultural Change." *The Hastings Center Report*, vol. 30, no. 6, 2000, pp. 7-16,

Reck, Gregory. "Narrative Anthropology." *Anthropology and Humanism Quarterly,* vol. 8, no. 1, 1983.

Rosaldo, Renato. *Culture and Truth*. Beacon Press, 1989, pp. 127-195.

Sacks, Oliver. *A Leg to Stand On*. Touchstone, 1984.

Savage, Jan. Ethnography and Health Care. *BMJ: British Medical Journal*. Vol. 321, No. 7273, 2000, pp. 1400-1402.

Skutans, Vieda. "Narrative-Based Medicine." *Anthropology Today*. Vol. 17, No. 6, 2001, pp. 23-24.

Tedlock, Barbara. "From Participant Observation to the Observation of Participation: The Emergence of Narrative Ethnography." *Journal of Anthropological Research*. Vol. 47, no. 1, 1991, pp. 69-94.

Thomas-Hawkins, Charlotte and Donna Zazworsky. Self-Management of Chronic Kidney

Disease. *The American Journal of Nursing*. Vol. 102. No. 10, 2005, pp. 40-49.

Thompson, William, Margaret E. Cupples, Caryl H. Sibbett, Delia I. Skan, and Terry Bradley. “Challenge of Culture, Conscience, and Contract to General Practitioners’ Care of Their Own Health: Qualitative Study. *BMJ: British Medical Journal*. Vol. 323, no. 7315, 2001, pp. 728-731.

Vanthuyne, Karine. “Searching for the Words to Say It: The Importance of Cultural Idioms in the Articulation of the Experience of Mental Illness.” *Ethos*. Vol. 31, no. 3, 2003, pp. 412-433.

Waddell, Gordon, Martin Bircher, David Finlayson, and Chris J Main. “Symptoms and Signs: Physical Disease or Illness Behavior?” *British Medical Journal (Clinical Research Edition).* Vol. 289, no. 6447,1984, pp. 739-741.

Williams, William Carlos. *The Doctor Stories*. New Direction Books, 1932-1962.