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“NEURODIVERGENT DIAGNOSES EXPLAINED IN ABSTRACT METAPHORS IN
LAUREN SLATER’S *LYING: A METAPHORICAL MEMOIR*.”

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THE DEPARTMENT OF ENGLISH
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BY

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ABSTRACT

“NEURODIVERGENT DIAGNOSES EXPLAINED IN ABSTRACT METAPHORS IN
LAUREN SLATER’S *LYING: A METAPHORICAL MEMOIR*.”

BY ANA OVSEPYAN

A metaphor can be used to simplify complex ideas and make them more palatable to readers. It is a tool that can bring words to life—literally.¹ The use of a metaphor is not just a literary technique, but a psychological one because a writer can manipulate words in order to connect to their reader, controlling the way their readers perceive what they have written. Metaphorical language takes imagination, to write, and understand. This allows a writer to convey their emotions in a much more creatively historical way. This technique reveals emotions and experiences when no standard vocabulary exists, enabling abstract readings. This is what Lauren Slater does in her book, *Lying: A Metaphorical Memoir*. Slater takes a neurodivergent disorder, epilepsy, and uses it as a metaphor to describe the tumultuous relationships and traumas she has experienced. Using a cripistemological lens, I will explore how this technique inspires readers to grasp the complex relationships that she has, and how it helps them gain a greater understanding of a disorder that is difficult to appreciate and comprehend without metaphor.²

¹ Imagine a metaphor for purity symbolized by a flower. Not only does that add a creative touch onto your writing, but it quite literally brings your words to life.

² Cripistemology is the coined term for the lens of thinking and education that is based on an individual’s experience of time, space, and place shaped by their diagnoses or illnesses.

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enchancing, like auras. Except this enchantment is not full of fairies and elves.⁶ It is one of dangers that leads you into a dreadful feeling of déjà vu, where you are floating in a fishbowl, and everything is distorted. But you can hear faint sounds, like the alarm bells warning a town of an oncoming hurricane. Ones that felt uncomfortable, strange, almost indescribable, and completely *unreal*.

The only way I can even try to describe what my physical experience of an epileptic fit is like is through the etymological meaning of the word metaphor. As I “carry across”⁷ the very few recollections that I attempt to remember, I find there are no words to describe what I feel or what I experience, the only way to truly “transfer” meaning, is through the metaphor. The illness narrative has evolved throughout the years, through autobiographical memoirs to more abstract and ambiguous memoirs; ones that match the author’s diagnosis, symptoms, and emotions. As my own experience with my mysterious disease has morphed and evolved into an indescribable one, my curiosities for disability studies, the illness narrative, and epilepsy metaphors has grown to match.

When I was growing up, I used to look at other families and well up with tears. My father was a drunk, and we left when I was young. My sisters followed in his path and my day-to-day was constant chaos, chaos I thought could never get worse—until now of course. I was sixteen

⁶ For further reading on the definitions of major types of seizures see: *Types of Seizures | Epilepsy | CDC*. 30 Sept. 2020, <https://www.cdc.gov/epilepsy/about/types-of-seizures.htm>.

⁷ The etymology (root) of the Greek word, *metapherein*, means to “carry across,” or, “to transfer” which is also what the verb “translate” means.

years old when a few friends of mine from my home meeting decided to go to an Ala-teen⁸ convention called AFG. The convention lasted three days and two nights. I was with my closest friends, crying and laughing all weekend—nothing could make me happier. We had a round of meetings all day with breaks for chain-smoking cigarettes and chugging down energy drinks to keep up with our constant neuroticism. On Sunday, our very last day, I woke up to the kiss of an angel. The room was white. Like, hurting your eyes and incredibly bright LEDs white. I was blind.

“Do you know where you are?” I heard him ask.

Where I am? I can't even see you. How am I supposed to know where I am?

My mouth was raw. I couldn't talk. I had cuts on my tongue, my cheek was torn to shreds, and my lips were so cracked I was waiting for blood to start dripping out of my mouth.

“Are you on drugs? Are you pregnant? Have you ever had any seizures before? Are you on any medication?” I was hit with thirty questions in what felt like thirty seconds—all my answers were no by the way. I was terrified. I didn't remember anything from hours before the seizure, and honestly, the entire morning was a blur too. But they ran some tests, and everything came out normal. “Might have been those energy drinks” they said, and my mom took me home.

Could it really have been all those Red Bulls?

⁸ Alateen is a program like alcoholics anonymous; it is a place for teens affected by someone else's alcoholism to come together and share experiences, discuss difficulties, encourage one another, and to help each other understand the principles of the Al-Anon program through the Twelve Steps and Traditions. Meetings are specifically for ages 13-21. I got into Ala-teen early on as a teenager; I was fourteen when I started going and I went to my first major convention that summer.

Scot. “Teen Corner (Alateen).” *Al-Anon Family Groups*, <https://al-anon.org/newcomers/teen-corner-alateen/>.

It has been 8 years and I still wonder.

In this thesis, I will critique and defend the use of illness as a metaphor by primarily using three books: Lauren Slater's mock-autobiography *Lying: A Metaphorical Memoir* (2000), Susan Sontag's critical theory book *Illness as Metaphor* (1978), and Sontag's companion book *AIDS and Its Metaphors* (1989). To deconstruct the linear confines of the genre referred to as illness narratives, I particularly focus on how illness as a metaphor does not follow any precise guidelines as an illness narrative; it is not straightforward but a situational slope. This technique can be seen as a troubling way to use language to describe disorders and the people affected by them, while simultaneously being a helpful tool to those diagnosed with ambiguous conditions as a way of creative expression. Contrary to critics such as Sontag, I do not believe there is a specific way to de-mythicize a condition like epilepsy that does not have a clear etiology. There is no verbal definite to a condition like epilepsy, so there can be no definite to the ways in which an author can write about it—whether or not they have such an affliction. Lauren Slater's book, *Lying*, is a fictional autobiography that uses epilepsy as a metaphor to approach her emotional experiences in life, however, Slater does so in a manner that directly aligns with the true experiences an epileptic has. Slater's seizure metaphors are likely based on what she has been told by someone close to her, referring to these experiences as a “dreamy... and double mental state—a negative and positive element together.”⁹ While it may be easy to regard Slater's *Lying* as a disservice to those who have epilepsy, I argue that there is no true certainty of an epileptic

⁹ Wolf, Peter. “Epilepsy and Metaphors in Literature.” *Epilepsy & Behavior*, vol. 57, Apr. 2016, pp. 243–46.

DOI.org (Crossref), <https://doi.org/10.1016/j.yebeh.2015.12.029>.

diagnosis because, in up to 70% of cases, the cause of a seizure is unknown—a diagnosis of epilepsy simply means a person has had two or more seizures.¹⁰

Epilepsy is usually diagnosed with a good patient record of witness recounts along with a neurological examination. However, long-term video EEG monitoring is essential given the “ambiguity of the clinical signs and symptoms.”¹¹ While an EEG and an MRI are common tests for people who report seizures, they do not always show evidence of multiple seizures, they can come back normal, leaving both the doctor and patient with no physiological evidence for a diagnosis.¹² There is customarily an existence of doubt in patients about their own diagnosis because there is no absolute way to know if you have an incurable illness. Epilepsy is a difficult illness to talk about because there is no sufficient vocabulary that can describe the feelings or sensations caused by a seizure. A metaphor, however, is the perfect literary technique a writer can use to describe such phenomena. Authors with epilepsy who do choose to write about this diagnosis in a metaphor use reports received from “afflicted persons.”¹³ Since epilepsy does not have an empirical basis, an illness metaphor works well as a means of explanation, illustration, and articulation. Autobiographical accounts of patients with epilepsy are not numerous, no two

¹⁰ For further readings on the specifics of epilepsy see: “Epilepsy: What It Is, Causes, Symptoms, Diagnosis & Treatment.” *Cleveland Clinic*, <https://my.clevelandclinic.org/health/diseases/17636-epilepsy>.

¹¹ Forcadas-Berdusan, M. I., and E. Valle-Quevedo. “[Ambiguous epileptic syndrome: from the point of view of adults].” *Revista De Neurologia* 43 Suppl 1 (October 10, 2006): S173-176.

¹² To read about the different exams to diagnose epilepsy read: “Epilepsy.” *Mayo Clinic*, Mayo Foundation for Medical Education and Research, 7 Oct. 2021, <https://www.mayoclinic.org/diseases-conditions/epilepsy/diagnosis-treatment/drc-20350098>.

¹³ Wolf, Peter. “Epilepsy and Metaphors in Literature.” *Epilepsy & Behavior*, vol. 57, Apr. 2016, pp. 243–46. *DOI.org (Crossref)*, <https://doi.org/10.1016/j.yebeh.2015.12.029>.

are exactly alike, my epilepsy is mine, and although there are similarities to others with this same diagnosis, no two epileptics and seizures will align completely. I will use my personal lens along with critical theory readings to close read Slater's *Lying* and Sontag's companion books to explore the confines of illness narratives and how to differentiate between the ableist nature of metaphors and necessary expression.

Epileptic Texts: Critical Readings of Illness Narratives

Since I will be concentrating on the cripistemologies¹⁴ of neurodivergent disorders—mainly epilepsy—I know I must dive into the basics of Disability Studies and Theory, as well as other articles or essays in the same realm of academia such as the medical humanities.

In *Disability Theory*, Tobin Siebers historicizes disabled bodies and critiques the metaphor because this technique often converts disability into something else in literature entirely, like a romanticized version of the troubled lived experience which can take away from the existing perspective one may try to share.¹⁵ However, many neurodivergent disorders remain undefined, considering we know truly little about the brain. Siebers explains:

My objective here is to address the two audiences at this convergence point: on the one hand, to demonstrate for critical and cultural theorists how disability studies transforms their basic assumptions about identity, ideology, politics, meaning, social injustice, and the body; [and] to theorize the emerging field of disability studies by putting its core issues into contact with signal thinkers in the adjacent fields of cultural studies, literary theory, queer theory, gender studies, and critical race studies. (1)

Understanding the often exclusionary and ableist nature of the illness metaphor means Siebers has a great point. However, we have come far enough in literature, disability studies, and theory where I would argue, we can both formally use metaphors, as well as consciously and intentionally grow the lived experiences of those with any “disability” or neurodivergent disorder. Couser explains, “[f]or me, then, the ethical crux of *Lying* is not that Slater may be

¹⁴ Siebers, Tobin. *Disability Theory*. University of Michigan Press, 2008. *HathiTrust*,

<https://catalog.hathitrust.org/Record/005933256>.

lying about having epilepsy, but that in exercising prose license she commits herself to an essentializing and mystifying characterization of a still stigmatic disability (“Disability as Metaphor,” 142). However, I would argue that the “mystifying characterization” of Slater’s epilepsy, whether she has it or not, is the reason she utilizes the metaphor. That constant uncertainty, fear, paranoia, and true discomfort is something most epileptics feel. Despite having epilepsy, I am still skeptical, and that is really the point.

Disability Studies scholars often support the investigation of the lived experiences of disability *over* metaphor, hence the en masse critique of Lauren Slater’s *Lying: A Metaphorical Memoir*.¹⁶ The diagnosis of epilepsy and its included symptoms have a general baseline, but the rest is a guessing game and remains unknown. So, describing such an ambiguous condition and the narratives that come with it may be best explained with such a metaphor since there are no other logical, rational, or factual ways of describing the lived experience. The metaphor is as close as it gets to recounting one’s lived experience when no standard vocabulary is found, it is a subjective writing choice that is inherently born through neurodivergency and its ambiguities. The general field of disability studies is shrouded¹⁷ in arguments that disability overall is a social construction and, if disability is a social construction then the speech, fabrication, and metaphorization of epilepsy is legitimate. If there is no standard norm for a brain, how is one neurotypical or neurodivergent?

¹⁶ To name one, Tobin Siebers in his book, *Disability Theory*.

¹⁷ I used the term shrouded because, to me, the verb has such a negative connotation, one that can come across to the reader as constricting or even uncomfortable. A synonymous feeling to those with epilepsy, or those in the general field of disability studies to begin with who have so much to say but have no place to say it.

Epilepsy and the general act of writing literature have two extremely important things in common: obscurity and subjectivity. Both are enveloped in emotions, choices, manipulations, aesthetics, language, and metaphors—one can only imagine why “epilepsy metaphors”¹⁸ are so prevalent. *Lying* explores how epilepsy is the “remystification of a condition still in the process of [actually] being demystified” (Couser, 128)¹⁹. As Slater so accurately illustrates in *Lying: A Metaphorical Memoir*, epilepsy is a perplexity, it is a mystification, “epilepsy is energy [and] it’s a windstorm in the brain (54).” Epilepsy relates to all things magical and equivocal: a windstorm, lightning, a rollercoaster, a car crash—it is all those and more, which only adds to the complexity of its metaphor in Slater’s book. Although I begin with Susan Sontag and their critiques of metaphor, this is a position aligned with disability studies, and I will continue to question this throughout my thesis.

Susan Sontag is a controversial and equally celebrated critic who has contributed a lot of work to the notion of illness as a metaphor and as a narrative. Sontag’s *Illness as Metaphor* and *AIDS and Its Metaphors*, combine to make a harsh critique on the overall principle of using illness as or in a metaphor. In the preface of *Illness as Metaphor*, written ten years before its successor, *AIDS and Its Metaphors*, Sontag starts off by using a metaphor to describe the way illness inhabits the lives of the ill:

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick... [S]ooner or

¹⁸ Coined term by Eleana Vaja in *Epilepsy Metaphors: Liminal Spaces of Individuation in American Literature 1990-2015*.

¹⁹ Couser, G. T. “Disability as Metaphor: What’s Wrong with Lying.” *Signifying Bodies: Disability in Contemporary Life Writing*, University of Michigan Press, Ann Arbor, Michigan, 2010, pp. 110–129.

later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. I want to describe not what it is really like to emigrate to the kingdom of the ill and live there, but the punitive or sentimental fantasies concocted about that situation: not real geography, but stereotypes of national character. My point is that illness is not a metaphor, and that the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to metaphoric thinking. (3)

In the first paradoxical statement in her book, Sontag describes being ill as holding “dual citizenship,” which maintains that we will all eventually be ill and that such citizenship is the position of being a recognized subject in a state of the able-bodied or disabled body; we will all eventually take space in that illness. Her writing critiques the use of illness as a metaphor, yet she begins her book doing exactly that. Sometimes, metaphorical thinking is necessary for illnesses, such as an ambiguous one like epilepsy, to accurately describe something that is indescribable. It is said that “in the majority of cases, there may be no detectable cause for epilepsy.”²⁰ How can an illness as vague as epilepsy resist metaphoric thinking when there are only a few facts, in terms of physiology, anatomically, and/or psychologically? How could one who uses their “passport from the kingdom of the well” reside in that of the ill with no such understanding of their illness? Not every illness is easy to differentiate or diagnose, and it is because of our lack of knowledge and understanding of such illnesses (like those neurodivergent disorders: OCD, Epilepsy, Alzheimer’s, and more) that require metaphorical thinking due to a lack of adequate vocabulary.

²⁰ “Epilepsy: Causes, Symptoms, Diagnosis and Treatment.” *Nationwide Children’s Hospital*,

<https://www.nationwidechildrens.org/conditions/epilepsy#:~:text=There%20are%20many%20possible%20causes,no%20detectable%20cause%20for%20epilepsy.>

Sontag analyzes the sometimes harmful and always controlling power of illness metaphors—those for AIDS and epilepsy in particular—where an abundance of illness metaphors is assumed to make up for any lack of knowledge. The turn to illness metaphors stems from the dangers of the unknown and Sontag identifies this approach as a surrogate for such uncertainty. As Eleana Vaja describes in her book, *Epilepsy Metaphors: Liminal Spaces of Individuation in American Literature*, epilepsy not only has a history of metaphors already within its definition and etymology such as: falling, sleeping, attacks, or danger, “but also describes a characteristic..., that of being ‘epileptic.’” Most of the associated metaphors come with a negative connotation and fit into ableist metaphors, those which rely on the assumed normative and universalized experience of a healthy abled body and stigmatize even the slightest deviation (Vaja, 60). Although Sontag believes cancer is a “scandalous subject for poetry; [one] that seems unimaginable to aestheticize” because of its rarity, I argue it is for that reason exactly that epilepsy can be metaphorized and mythicized. It is not rare, but its treatments and symptoms are, they vary for each person, and there is no cure.

Sontag’s focus of the first book, *Illness as Metaphor*, concentrates on two illnesses: tuberculosis, and cancer. She points out the commonalities in the metaphors that were often inspired by TB and cancer:

The fantasies inspired by TB in the last century, by cancer now, are responses to a disease thought to be intractable and capricious—that is, a disease not understood—in an era in which medicine’s central premise is that all diseases can be cured. Such a disease is, by definition mysterious... TB was thought to be an insidious, implacable theft of a life. Now it is cancer’s turn to be the disease that doesn’t knock before it enters... a role it

will keep until, one day, its etiology becomes as clear and its treatment as effective as those of TB have become. (5)

Epilepsy is *still* mysterious. Its etiology is still unknown, its treatment differs for everyone, and there is hardly ever a “cure.” You may control one’s seizures, yes, but epilepsy stays there. It too, is a “disease that doesn’t knock before it enters.” Even Sontag’s descriptions cannot escape the metaphor—cancer becomes an entity that must knock and get permission, like an unwarranted stranger at your door. She argues that such diseases bring up a sense of power just from their very names, as does epilepsy. Except its fantasy does not come aligned with some sort of intoxicating feeling as TB does, it comes with a seizure—a taking of one’s body in which, for a moment, it is not theirs anymore; they cannot control it. Like the etymology and definitions of TB and cancer, seizure and epilepsy are quite similar: all-consuming, forcibly taken, grabbed, taken hold of; and in this case, like TB and cancer, it is of the body. The roles of TB and cancer change within *Illness and Its Metaphor*, TB was the mysterious ailment that cancer became. Now, it is epilepsy’s turn to take on that role. Like the characteristics of TB, epilepsy has many “deceptive symptoms,” and, it too is “unchanging” (13). To Sontag, cancer has only “true symptoms,” as in, symptoms that are not fantastical or deceiving (13). So, I understand the hesitation in metaphorical thinking towards cancer, even TB, due to their now clear etiology and treatment, but the lines are blurred when referring to a neurodivergent disorder—there are fewer facts, and more fabrications. What may seem like a symptom of temporal lobe epilepsy may

appear to be psychological or psychogenic attacks as well: mythomania, borderline personality disorder, night terrors, and more.²¹

Epilepsy is defined as a “neurological disorder that causes seizures and/or unusual sensations and behaviors.”²² Some children outgrow it, some do not. Some are controlled with medication, some are not. Some die from their seizures, a fatal complication of epilepsy such as Sudden Unexpected Death in Epilepsy (SUDEP), while others can live a long and happy life. Aestheticizing or metaphorizing epilepsy works because of how ambiguous it is. With no basis of facts other than a lived or witnessed experience, aestheticism works in its favor, as a means of explanation, representation, and expression. Sontag uses the “true” symptoms of TB and cancer as a gateway into the “true” disease, arguing that metaphors create a fantastical and false view of the disease. However, what an illness metaphor can do, for some, is to allow one to question what we do not know. Not every illness or condition is easily expressed or explained with “true” symptoms. Some need to use metaphors to understand something that does not have “true” answers. If “the modern conceptions of the two diseases, [TB and cancer] could not be set until the advent of cellular pathology,” how does Sontag expect epilepsy, a disorder with no specific way to “grasp [its] distinctiveness” to become less mythical and more physiologically defined (Sontag, 10)? For epilepsy, seeing is believing, but believing is not seeing. One cannot view their own seizure, only a witness can, which is one of the very first things a neurologist will ask.

²¹ For other commonly mistaken diagnoses read: Smith, Philip E. M. “If It’s Not Epilepsy . . .” *Journal of Neurology, Neurosurgery & Psychiatry*, vol. 70, no. suppl 2, June 2001, pp. ii9–14. [jnnp.bmj.com](https://doi.org/10.1136/jnnp.70.suppl_2.ii9), https://doi.org/10.1136/jnnp.70.suppl_2.ii9.

²² Smith, Alice. “History of Epilepsy: The History and Stigma of Seizures.” *Medungle*, 23 Feb. 2021, <https://medungle.com/history-of-epilepsy/>.

Sontag recognizes how the assertion of worth and station through notions of “illness, [TB and cancer are] (a kind of interior décor of the body) [and how this] became [a] trope for new attitudes toward the self;” a seizure does exactly that, it is seen as a “manner of appearing” (28). Even if you have a witness who can corroborate the physical seizure, how then, do you know you have epilepsy for sure other than a doctor diagnosing you? Especially if there are no visible signs on tests or “true” symptoms? Epilepsy operates on a spectrum; it is not linear. Often, it cannot visually be seen without a seizure. It lasts forever but is only seen momentarily.

A normative medical paradigm, such as cancer and TB, has a “widely accepted explanation for a group of biomedical or other phenomena that become accepted as data accumulate to corroborate the paradigm’s explanation or theory.”²³ The reason why Slater’s *Lying* is questioned so heavily is that she forces the reader to become an active participant in her diagnosis, we are her witness, and as such, we prove that she does indeed have this disorder. Slater does not need physiological evidence, epileptics do not either, all we need is a witness. Epilepsy, and most other neurodivergent diagnoses, have a much harder focal point for data. Other than EEGs or MRIs—which can come back normal even if one is still suffering fits—the only data source is a first-hand witness or experience recount. Thus, the medical paradigm of epilepsy remains mystified in the unknown. Even the cognitive experiences doctors and patients do know of, such as auras, fear, or déjà vu, are *nearly* impossible to describe.

In *Illness as Narrative*, Ann Jurecic recognizes Sontag’s importance, as well as her controversies: “Sontag’s body of work reveals a deep and sustained exploration—with many turns, conflicts, and contradictions—of the ethics of reception, how audiences regard and

²³ *Paradigm* | *Definition of Paradigm by Medical Dictionary*. <https://medical->

[dictionary.thefreedictionary.com/paradigm](https://medical-dictionary.thefreedictionary.com/paradigm).

respond to representations of other people's pain" (67). Sontag cannot control how other people decide to characterize their pain, nor how such representations will be perceived. Although Sontag attempts to critique the ethics of representation regarding illnesses, she does so in a way that is one-sided and personal, so it does not adhere to the standards of every illness but only the ones she can personally relate to. Jurecic also acknowledges the immediate tension that Sontag causes by using a powerful metaphor in the opening of the book:

...[Sontag's] argument that disease is 'without meaning' is indicative of tensions in the argument of *Illness as Metaphor*... She struggles with the ambiguities and conflicts that, to this day, preoccupy literature and criticism about the representation of illness, risk, and pain... The continual challenge she poses to herself as a writer is to find ways to get closer to the real. *She never finds a resting place.* (68-9)

In *AIDS and Its Metaphors*, Sontag reveals that twelve years ago (a mere two years before *Illness as Metaphor* was published), she too became a cancer patient. She describes how enraging it was to see how the very "reputation" of cancer added to the suffering of those who had it. "[My fellow patients] seemed to be in the grip of fantasies about their illness by which I was quite unseduced" (100). Although Sontag had good intentions with *Illness as Metaphor*, it was written harshly, emotionally, and with lots of complications. She acknowledges in the preface of *AIDS and Its Metaphors* that she wrote *Illness and Its Metaphors* quite quickly, and with "...anxiety about how much time [she] had left to do any living or writing" (101). Her intentions were to spare fellow patients from evading treatment due to irrational fears of chemotherapy. She "wanted to offer other people who were ill and those who care for them an instrument to dissolve these metaphors, these inhibitions" (102). However, the metaphors I (and many of my fellow patients) associate epilepsy with, are not harmful or "enrage[ing]" but the opposite, these

metaphors provide a safe and free space to envelop our language in ways that might be understandable to a layperson without a diagnosis. Sontag might have found it harder to be “seduced” by such fantasies because she had answers. Hard answers sure. But answers nonetheless—what kind of cancer, where it is, treatment options, and her odds, this is why she wrote *Illness and Its Metaphor* with such intense emotion and fear of when her illness would take her with finality.²⁴ What if her fellow patients that were “seduced” were hanging on by a thread, and that very thread was their fantastical thinking? It may be “dangerous,” to some, but others need their own thinking to survive. Not everyone can come to terms with their illness so rationally and easily. Especially one as ambiguous as epilepsy, or even cancer.

Sontag explains that,

[Her] aim [with *Illness as Metaphor*] was to alleviate unnecessary suffering—exactly as Nietzsche formulated it, in a passage in *Daybreak* that I came across recently... ‘To calm the imagination of the invalid, so that at least he should not, as hitherto, have to suffer more from thinking about his illness than from the illness itself—that, I think, would be something! It would be a great deal! (Sontag 100-1)

It is not practical or realistic to calm one’s own “imagination” especially when it comes to thinking about their own illness or learning to live with it. Not everyone’s fantastical thinking is harmful, just as much as it is not always helpful. Sontag expresses that her intention was to “calm the imagination, not to incite it. Not to confer meaning... but to deprive something of meaning” (102). As we will see in Slater’s *Lying*, this advice was not relevant for the text at hand.

²⁴ She talks about her diagnosis and the angst behind writing *Illness and Its Metaphors* in the first chapter of *AIDS and Its Metaphors*, see pp. 100-101 in the combined edition of the books.

Ten years after *Illness as Metaphor* hit the shelves, Sontag came back with more to say about illness metaphors in her book *AIDS and Its Metaphors*. She begins by acknowledging her controversies, explaining how her intentions were motivated by her own diagnosis:

Rereading *Illness as Metaphor* now, I thought: By metaphor I meant nothing more or less than the earliest and most succinct definition I know, which is Aristotle's in his *Poetics* (1457b). 'Metaphor,' Aristotle wrote, 'consists in giving the thing a name that belongs to something else.' Saying a thing is or is like something-it-is-not is a mental operation as old as philosophy and poetry, and the spawning ground of most kinds of understanding... and expressiveness... Of course, one cannot think without metaphors. But that does not mean there aren't some metaphors we might well abstain from or try to retire. As, of course, all thinking is interpretation. But that does not mean it isn't sometimes correct to be 'against' interpretation. (93)

Sontag emphasizes the importance of Aristotle's mimetic theory of representation and metaphoric function, but she also goes against it—she critiques the function of representation, which is quite standard. By negatively working with these properties of illness representation, she furthers the negative connotations of the illnesses themselves, while I take a positive reiteration and expand those notions further. However, who gets to decide what interpretation is correct or wrong, especially when considering something as vulnerable as one's own illness experience? Even in terms of Sontag, is she correct in her expressions just because she too has cancer? In contrast, am I correct in my interpretation of metaphorical thinking just because I have epilepsy? These questions are all valid and do not have a definite answer because the genre and technique related to these questions are subjective, they do not confine to a specific guideline—it is an individual's choice to do as they please with their self-expression. As Sontag

suggests, a metaphor is often due to understanding and expressiveness [or lack thereof], so then, who can determine which illness can be used as a metaphor and which cannot? Sontag attempts to give a logic for this, albeit a faulty one, and she works within her own set of rules for writing and thinking. Sontag disagrees with TB, cancer, and AIDS being represented by metaphors because of their previous ableist, romanticized, or homophobic notions, but allows room for metaphors of the unknown diagnoses. I can understand the difficulties of having metaphorical thinking when it comes to romanticizing TB or, in contrast, glorifying cancer as a walking death. However, Sontag cannot demand people stop thinking about illness as or in a metaphor, whether it be those who have epilepsy and are trying to explain the mystifying effects of their feelings before and after a seizure, or those with cancer, who need metaphorical thinking to come to terms with their illness. There is no hard line on deciding when and where someone—especially someone with an illness of their own—can use metaphorical thinking to describe, think, or talk about an illness: “[h]ow does one define this genre called creative nonfiction” (Culhane, “Interview with Lauren Slater”)?²⁵ If Sontag, a critic of the illness metaphor, cannot stray from describing their experience of an ailment with a metaphor, how can she expect anyone else to do the same?²⁶

For Sontag, her intentions overpower considerations of other illnesses, such as epilepsy, where one needs a metaphor to describe the feelings that have no words to describe them. To her, “[t]he metaphors and myths, [Sontag] was convinced, kill. [(...[T]hey make people irrationally

²⁵ In an interview with Lauren Slater, Culhane asks Slater what prompted *Lying*, to which she responds by questioning the confines of creative nonfiction, or a creative memoir: Culhane, “Interview with Lauren Slater,” pp. 166.

²⁶ Not only is Sontag a critic of the very thing she often does (using illness as a metaphor), but she is also a patient.

fearful of effective measures such as chemotherapy...)" (102). These issues stem from metaphors surrounding those who are labeled "ill, melancholy, interesting, or romantic" entirely—not just cancer (though of course, each illness is different) (29-32). Due to the structural construction of ableism, most are afraid of being "ill" and not knowing what their diagnosis may be, what treatments or cures there are, and how this will affect them in the long run. Even I was afraid to go to a neurologist after having more than three grand mal seizures. I was terrified to find out what I did or did not have. Was having a concrete answer scarier than having a vague one? Both are terrifying, but one has a definite, and one is repeatedly questionable. Epilepsy, like the brain, is ambiguous. It is seen but not heard, it is experienced but not always seen. Reading *AIDS and Its Metaphors* as a sequel to *Illness as Metaphor*, it is understandable why Sontag's writing is so emotional and harsh as she was trying to come to terms with her own illness. She wanted patients to get the truth from their doctors; to be informed and get reliable treatment because "although *the* remedy does not exist, [there are] existing methods of treatment." Like cancer, there is no singular cure or remedy for epilepsy, and it is hard to be "an informed, active patient" of an illness that simply does not have a lot of linear information.

Whilst writing *AIDS and Its Metaphors*, things regarding cancer had changed, "[g]etting cancer is not quite as much of a stigma, a creator of 'spoiled identity'" (103). However, the same stigma is very alive and well for those with neurodivergent disorders—such as epilepsy—because many have as much to do with the mind as they do with the body. Aside from the disorder's connections to Alzheimer's, Dementia, depression, and other associating conditions in one's future, it is seen as something that can very well still "spoil [one's] identity" and change

their behavior, their emotions, their identities, and more.²⁷ Sontag primarily worked with the societal lens of the era she was writing in, and the motives behind her work were the cultural phenomena that she was critiquing: romantically aestheticizing serious illnesses. She works against illnesses that did not have as much information about them as they do now; illnesses that did not *need* fantastical thinking for explanation, or metaphors for expression. The implication in her work is, once an illness has more information surrounding it, metaphors are no longer needed. So, is a stigmatized illness always tied to a myth or a metaphor? Or is it the unexplainable illness that always comes attached to one? I say it is both. An unexplainable illness will almost always come along with a metaphor, but a stigmatized illness will romantically be described as one.

²⁷ Rodríguez, Karla Mora, MD, and Selim R. Benbadis, MD. “Epilepsy and Psychological Disorders.” *Epilepsy Foundation*, 2016, <https://www.epilepsy.com/stories/epilepsy-and-psychological-disorders>.

The Ableist Metaphor: Disability Studies, Language, and the Challenges (and Rewards) of
Illness Narratives

“Who gets to begin, in the eyes of others, with a body? And who gets to begin, in the eyes of
others, with a mind?”²⁸

The duality of mind versus body is one of years of discussion, and if there is no standard “norm” for a brain, how can humans be so sure of what parameters deviate from it? Why must there always be a binary? A duality? Why must one always conform to or adopt the concepts of the other?

Epilepsy does not operate on a linear spectrum, nor is it something one can easily live with, or even learn to live with. I am not only disabled when I have a physical, witnessed seizure. I live with my diagnosis every day—it is always there, as are its physical symptoms and after lying effects and conditions. Yet, the visual seizure observed by others is what gathers the ableist misconception that confines epilepsy: the disease is not just a symptom.²⁹ Epilepsy is not prevalent when one simply has a seizure, it is always there and will stay there forever. What I did not know however is that my epilepsy³⁰ (and everything that comes with it: medication,

²⁸A brilliant quote on page 176 of the article by Mel Y. Chen: “Brain Fog: The Race for Cripistemology.” *Journal of Literary & Cultural Disability Studies*, vol. 8, no. 2, Jan. 2014, pp. 171–84. DOI.org (Crossref), <https://doi.org/10.3828/jlcds.2014.14>.

²⁹ Epileptics are not thought to have a difficult life, it is the witnesser that becomes overtly traumatized, not the experiencer. Because we cannot see our own seizure, it is thought that we do not feel anything, we just live through it, while those who see it are the ones profoundly affected by it.

³⁰I say my epilepsy because it really is *mine*. My diagnosis and everything that comes with it is different compared to that of others, anyone with epilepsy will tell you that. One seizure is *never* the same as another.

symptoms, affiliated conditions) has been and will continue to affect how I write.³¹ A neurodivergent diagnosis does not define us, we learn how to live with them, beside them. We work *alongside* our “disabilities,” but they control us, our bodies, and our thoughts as well.

In the article, “Epilepsy and Metaphors in Literature,” Peter Wolf describes the most common uses of epilepsy metaphors in different forms of literature: seizures and epilepsy used *as* a metaphor and seizures and epilepsy described *in* a metaphor.³² Wolf states that more commonly, since epilepsy is often referred to as an abstract concept, “...a fictional character may experience a seizure in a context where it serves a metaphoric purpose,” such as Lauren Slater in her book *Lying: A Metaphorical Memoir* (243). There are many different prototypes of epilepsy *as* a metaphor which can be, metaphors expressing deep or strong emotions, religious metaphors, symbols of significant life crises, or indications of weakness and vulnerability—all of which relate to Slater’s *Lying*. J.H. Jackson, “...taking up... metaphors from other patients, would refer to this seizure experience as the dreamy state and describe a double mental state—a negative and a positive element together” (Wolf, 246). What Jackson is describing reflects epilepsy metaphors greatly, they are both a positive and a negative together, they are not one or the other. An epilepsy metaphor cannot be a positive without the negative, and vice versa. As Wolf describes, “[d]reams and overwhelming sensory, especially visual, perceptions are clearly the prevailing literary metaphors for epileptic seizures” (246).

³¹ I did not know my illness would affect my imagination, my creativity, or my writing function when I was diagnosed... I did not know it at all. It took my critical theory professor, Professor Lee, to tell me this, and that is ultimately what inspired this thesis.

³² Wolf, Peter. “Epilepsy and Metaphors in Literature.” *Epilepsy & Behavior*, vol. 57, Apr. 2016, pp. 243–46.

In the conclusion of Wolf's article, he states:

Both the use of epilepsy as a literary metaphor and metaphoric descriptions of seizures in fiction seem, to a large extent, to reflect societal stereotypes. They perceive seizures, in the vicinity of religion and sexuality, as expressions of critical emotions ending in ecstasy or breakdown. Attempts to understand the seizure experience typically refer to either dreams or strong sensory experiences. Not surprisingly, the use of metaphors by writers with authentic seizure experiences differs from writers who know epilepsy only from the outside. Both groups include examples of great literary merit. (246)

There is great importance in Wolf's conclusion, important notions lie in the use of epilepsy in and as a metaphor. Seizures really can be described as thunderstorms, dreams, rollercoasters, and more, and it truly is hard to describe something that is inexplicable without such a metaphor. However, a consequence of describing epilepsy as a metaphor for extreme upsets, possession, or breakdowns is where ableist notions come into play—especially if the writer has never experienced a fit themselves. It is difficult to find the right balance of when someone is reaching much too far out of bounds with their thinking, and when it might be necessary to explain a seizure in the way that they are. Similarly, although parts of Slater's *Lying* may provoke ableist notions, other parts are quite relational to the experience of a seizure.

There are also individual metaphors that describe seizures or epilepsy *in* a metaphor. One of the biggest reasons for seizures described *in* a metaphor is this:

Subjective experiences in seizures and auras often are so strange and unnatural that patients lack the right words to describe them. This is probably the reason... self-reports of epilepsy often are rich in metaphors. Patients talking about their own seizures seem to apply metaphors not primarily for their own sake but as one of several instruments to

provide an approximate description of their unusual experiences. This may be a reason... metaphoric seizure descriptions in the texts of writers with epilepsy are surprisingly rare. For them, metaphoric seizure descriptions perhaps do not primarily serve artistic purposes. (Wolf 245)

Susan Sontag's books, *Illness as a Metaphor* as well as *AIDS and Its Metaphors*, are attempting to draw focus onto the harmful effects of patients, and authors, thinking of and describing their own diagnoses as metaphors. What Sontag does not include in these books is how sometimes it may be for patients to describe their experiences in metaphors, such as the reasons Wolf described. Metaphoric descriptions for patients with epilepsy, and other neurodivergent disorders, are not necessarily using this tactic for a creative purpose as others may. They are simply trying to both explain and understand their own symptoms and experiences which are difficult to explain otherwise. However, it is not always necessary to use metaphors in a less artistic way, as Amy Vidali suggests in "Seeing What We Know: Disability and Theories of Metaphor:"

...A disability approach to metaphor is suggested, [especially one] that engages the diversity of disability; refrains from policing metaphor; encourages transgression from the disability community; and invites creative and artistic reinterpretations of metaphor. This new approach is grounded in a critique *of the metaphor knowing is seeing...* [Vidali] suggests a disability approach to metaphor that is not solely based on critiquing metaphoric disability representations, and [to actively mine] our own stories and artful renderings that play on the diversity of ways that we come to see and know. (34)

Similarly, in Christian Jungersen's *Du forsvinder*, "...the narrator has a kind of atheistic revelation in a daydream and wonders if it could have been a temporal lobe seizure" (Wolf,

246).³³ The thunderstorm metaphor is commonly used by neurologists or epileptologists to explain epilepsy to lay people: “[e]pileptic fits are like thunderstorms raging in the brain: Nerve cells excite each other in an uncontrolled way so that strong, rhythmic electrical discharges sweep over whole brain regions.”³⁴ Doctors and creatives alike cannot stray from metaphoric expression, whether they may be critiqued by others. An unfamiliar and complicated diagnosis such as epilepsy often prompts the use of a metaphor; there are no words to accurately describe the state in which a patient lies or experiences without one.

Ann Jurecic, in a chapter of *Illness as Narrative*, critiques when “personal accounts of suffering” can be used in relation to an illness narrative and when or how it can sufficiently be judged on... is it a writing choice? Is it aesthetic?”³⁵ On what basis can an author judge another’s work on illness narrative—what is the basis of such rhetoric? What is the norm for such work and what is not? Jurecic recognizes the importance of Sontag’s work, acknowledging that “...Sontag has done more than any other single writer to bring attention to how literature documents and shapes the cultural meaning and experience of illness, pain, and suffering” (67).

³³ This can be a common occurrence within those who have epilepsy, sometimes people have feelings of euphoria or otherwise unexplainable feelings and are unsure whether that feeling was a seizure—even I have had a similar impression.

³⁴ This citation explains the often-used metaphor that helps doctors explain this diagnosis to patients:

Ludwigs, Albert. “Epileptic Fits Are like Raging Thunderstorms: Astrocytes Help Reduce Long-Term Damage, Surprising New Research Shows.” ScienceDaily. ScienceDaily, August 7, 2012.

<https://www.sciencedaily.com/releases/2012/08/120807101224.htm>.

³⁵ On the problems of illness as a narrative and its limitations, Jurecic goes much more in depth in this chapter of her book: “Sontag, Suffering, and the Work of Writing,” in her book, *Illness as Narrative*, 67–69. Pittsburgh,

Pennsylvania: University of Pittsburgh Press, 2012.

Sontag’s work “reveals a deep and sustained explorations—with many turns, conflicts, and contradictions—of the ethics of reception, how audiences regard and respond to representations of other people’s pain... What good, she wants to know, is art that arouses sympathy for the suffering of distant others?” (67). Sontag insists that others “speak, write, and think” about diagnoses without any mystical thoughts or metaphors, and maintains that metaphors “distance us from knowledge if we mistake [metaphors] for reality. They shield us from the shock of the real and thus dull the pain and knowledge of our vulnerability” (68). Even if her intentions are for the best interest of her fellow patients, the difference between her metaphor in the opening of the book and her argument that disease is “...without meaning is indicative of tensions in the argument of [her first book]” (68).

Sontag continuously struggles with controversies in both of her books, and “...the ambiguities and conflicts that, to this day, preoccupy literature and criticism about the representation of illness, risk, and pain...” (Jurecic, 69). Although Sontag had the right intentions, her personal experience slips through the critical lens she attempts to write from: “[w]hatever her intentions, the split between her powerful metaphor and her argument that disease is ‘without meaning’ is indicative of tensions in the argument of *Illness as Metaphor*” (Jurecic, 68). It may have been necessary for Sontag to stay away from fantastical thinking for dealing with her own health status, but, as David Rieff mentions in *Swimming in a Sea of Death*, “we tell ourselves stories in order to live.”³⁶ Not everyone explains their diagnosis or symptoms in a metaphor, but for others, it may very well be necessary to survive, to explain, and to accept their future. Jurecic continuously critiques Sontag in relation to “[someone’s] personal accounts of suffering” and questions what grounds an illness narrative can sufficiently be judged on: is it a

³⁶ Rieff, David. *Swimming in a Sea of Death: A Son’s Memoir*. New York: Simon and Schuster, 2008.

writing choice? Is it aesthetic? Slater attempts to answer these questions in *Lying* by engaging with the confines of illness metaphors and creative nonfiction.

Sontag analyzes the sometimes harmful and always controlling power of illness metaphors—those for AIDS and epilepsy in particular—where an abundance of illness metaphors is assumed to make up for any lack of knowledge. The turn to illness metaphors stems from the dangers of the unknown and Sontag identifies this approach as a surrogate for such uncertainty.³⁷ Similarly, Jason Tougaw emphasizes a neurobiological point of view and explains that “nobody can explain how immaterial experience—self, consciousness, memory... emerges from brain physiology.”³⁸ While Vaja, in *Epilepsy Metaphors*, introduces three theoretical means for accounting on behalf of the innovative power of epilepsy metaphors. “Metaphors of this first category are premised on the nexus of the clinical and the normal, pushing forward the question of ‘who is normal?’ This is [because] epilepsy as a disorder, triggers the clinical, becomes visible, requires treatment, and thereby deviates from the normal [while maintaining a physical appearance that *is* normal].” Epilepsy metaphors find themselves in the “liminal space between the two” (69). Within the marks of diagnosis and the clinical perspective of epilepsy come the makings of the binaries of normativity and deviation, exclusion, and inclusion.

As its own subgenre of metaphor, epilepsy metaphors must reciprocate inclusion over exclusion, both for its reader and writer. But, as we have seen in Slater’s *Lying*, applying an epilepsy metaphor takes more than just writing it. It takes a level of mutuality and an even

³⁷ Sontag, Susan. *Illness as Metaphor; and AIDS and Its Metaphors*. Picador/Farrar, Straus, and Giroux, 1989.

³⁸ This citation is from Jason Tougaw, and Joseph E. Ledoux’s first chapter, “Introduction: You Are Your Brain, You Are Not Your Brain,” in the book *Elusive Brain: Literary Experiments in the Age of Neuroscience*, Yale University Press, 2018, pp. 1–38. *JSTOR*, <https://doi.org/10.2307/j.ctt22h6qpr.5>.

further deconstructed format that falls into two categories that Vaja separates: “protometaphors” of epilepsy, and “flexmetaphors” (70). As Vaja explains, “protometaphors of epilepsy exert their stigmatizing power by relying on the notion of the symptom—[the seizure]—as a ‘linguistic sign’ and as a ‘descriptive act’” enabling the stigmatic “clinical gaze.” This association is analogous to epilepsy, meaning that “epilepsy symptoms come to form the signifier and its history comes to function as the signified.” Vaja believes epilepsy metaphors that record the moment of a seizure limit the notion of epilepsy itself, implying the disease’s “[incapability to express] anything other than itself” (76). However stigmatizing protometaphors of epilepsy may be, Vaja believes these metaphors to “transform the text into an epileptic text.” In “contradistinction, flexmetaphors are destigmatizing through the liminal space of the open sign,” one that expresses an understanding of the physiological symptom rather than the pathological one:

It does not designate a scientific onset for further diagnosis, but, rather, marks a being in-between states. It is a stable moment in as much as it abides in this transitory state; it rests in the liminal space... Flexmetaphors of epilepsy require the exercise of this uncertainty. Epilepsy, itself, can be said to function as an open sign on the ‘everydayness’ of the person, because the individual never knows if or when a seizure will occur. In order to sustain the uncertainty of everydayness, these metaphors indulge in that moment of epilepsy that is at the edge of common experience. (Vaja 78)³⁹

³⁹ The pathological symptom defines the science of the causes and effects of diseases, while the physiological symptom refers to the branch of biology that deals with the normal and abnormal functions of living organisms and their parts.

Vaja finds that Slater shows just how epilepsy metaphors redefine the notions of the “liminal” and the “normal” (Abstract). Slater works to deconstruct the boundary of medical diagnosis and the unwritten rules of how one can express or narrate their illnesses—whether or not they are identified. Sontag is not entirely wrong in her books, some narratives can stigmatize, but others, such as *Lying*, “make available new ways of thinking about the unthinkable” (Jurecic, 91).

The troubles of written illness or epilepsy metaphors are not the only ones excluding writing forms in disability or medical humanities literature, it goes all the way down to the basics of illness narratives and the complications of both reading and criticizing them. Ann Jurecic makes the argument in her book, *Illness as Narrative*, “that one cannot fully understand writing about illness without... recognizing the split in critical attitudes toward these works” (3).⁴⁰ There remains a tumultuous relationship between critics and their readings of illness narratives due to a distrust put onto the author, their feelings, and the depth of their writing from critics. Jurecic furthers my argument by paraphrasing theorist Eve Kosofsky Sedgwick’s, *Touching Feeling*, by stating that the “distrust of texts’ errors, lies, and manipulations [have] become prescriptive,” arguing that much of modern criticism anticipates “textual and theoretical problems in advance. Critics must deconstruct their habits of reading, especially regarding illness narratives as that simply furthers the universal assumption of normativity, whether that be physical or mental. Jurecic furthers that any critic or scholar who “trust[s] a narrative to provide access to the experience of another person indicates a naïve understanding of how such texts function.” Both Sedgwick and Jurecic emphasize the importance of reading a narrative the way it should be read,

⁴⁰ Ann Jurecic’s chapter goes more in depth about the illness narrative and specifically, Slater’s *Lying*: “Sontag, Suffering, and the Work of Writing,” pages 67-69 in her book, *In Illness as Narrative*, Pittsburgh, Pennsylvania: University of Pittsburgh Press, 2012

singularly, understanding that one's experience is not always related to another—there is no universal experience to illness—we all experience things differently and no one experience should be ostracized or deemed truer than another. The exclusion of disability studies, medical humanities, and the illness narrative only further the stigmatization of authors who have a lot to say with no safe space to say it.⁴¹ However, Jurecic rewrites such a narrative arguing that critics must understand that their “disdain for or disinterest in illness memoirs suggests, above all, that contemporary critics have become alienated from ordinary motives for reading and writing” (3).

Similar to Jurecic's thoughts on exclusion, in their article, “Brain Fog: The Race for Cripistemology,” Mel Y. Chen emphasizes the importance of a nonconforming society, disabled or otherwise. Chen argues that “for shared epistemologies that can be developed together among differently cognating beings... (172). The sort of intellect Chen is talking about when referring to “comprehension” relies not only on the “finality [and] wholeness of grasp” of the word but relies on the individual yet linked minds among those that are “differently cognitive.” To gather an understanding that to be disabled is not to have a stagnant moment of pain or unconsciousness, it is not a singular moment, it is a linear spectrum and (mostly) everlasting.

To lie is nothing more than to imagine the unknown. To “giv[e] the thing a name that belongs to something else” (Aristotle, 1457b, as cited in Sontag, 1989, p. 93). Fabulation is imagination—it does not mean something is not true, or real. Fabrication is the act of inventing something, of creating it. Yet, the ambiguous duality of truth and lies, real and unreal, stretches out even further, reaching the physical objects moving around in our world. To invent something

⁴¹ Although we are now in the beginning of the expansion of these fields, and they are currently thriving, it has taken a long time to do so—critical disability theory is only now reaching its academic peak, whether or not it has been written about for decades, it is only now becoming a trending topic for academics and researchers.

is to create it. However, in contrast, in its etymological form, to invent something is to come across it, to find it, to lie, falsify, or concoct it. The concept of lying itself is a socially constructed one that limits our attempts of understanding the unknown. The limitations of knowledge are built around this pretense of lying when you do not know the answer to something or when you are trying to hide something. Whether or not the reason is a morally ‘good’ one is not at question. It is those like Michael Foucault, John Locke, David Hume, and more, who have taught others that truth is socially constructed—a relative thing, a power narrative fabricated by those of the right race, gender, and class to perpetuate such privilege.⁴²

I argue, then, that seizures or more abstractly, *epilepsy* can be a metaphor itself.⁴³ It is that “*thing* regarded as representative of something else, especially abstract.”⁴⁴ It is representative of the paradoxes of agency, within one’s own body, mind, and writing. And it is representative of singularity, although sometimes relational, not one seizure is linear or repetitive: there is no evidence of two persons having identical seizures. Epilepsy maintains itself as a gigantic presence; one that is vital throughout an author's daily life. When living with a

⁴² See Michel Foucault and Colin Gordon’s book *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977*, 1st American ed, Pantheon Books, 1980 for more.

⁴³ The difference between epilepsy and a seizure is difficult to explain. A seizure is a burst of uncontrolled electrical activity in the brain that causes abnormalities in muscle movements, behaviors, and sensations or states of awareness. But epilepsy, is a disorder diagnosed when someone has two or more seizures with causes unknown. Someone who has had a seizure does not necessarily have epilepsy, but someone with epilepsy must have seizures.

⁴⁴ Thomas Couser’s work is especially extraordinary since his chapter that I am writing about is the only cultural disability studies analysis of epilepsy in American literature that addresses the issue of epilepsy as a metaphor. See G. Thomas, Couser. “Disability As Metaphor.” *Prose Studies*, vol. 27, no. 1–2, Apr. 2005, pp. 142, <https://doi.org/10.1080/01440350500069013>.

disorder that deals with the brain, it is impossible to understand everything that comes along with it; doctors don't even understand all of it, how could you, or I? How could a writer or a reader ever dare to scratch that surface? Such ambiguity allows for a necessary free-formed or even formless structure in illness memoirs, such as the equivocal and highly criticized mock autobiography: *Lying: A Metaphorical Memoir* by Lauren Slater.

Sometimes, a necessary witness may allow for a writer and experiencer, like Slater, to deal with their pains and emotions. In “Let Seizing Truths Lie: Witnessing ‘Factions’ in Lauren Slater’s *Lying*,” Eden Freedman writes about the importance of memory when it comes to overcoming the trauma of one’s lived experiences..⁴⁵ They emphasize the necessity of “witnessing” the trauma to fully overcome it. They write:

Lying... opens an important question about the reader’s role in traumatic witnessing: how does one respond to the traumatic testimony of an unreliable narrator? ...[O]ne may resist Slater’s memoir, [but] one also [can enter] and engage in her experience. In presenting this opportunity, *Lying* offers the writer-narrator and reader-respondent alike, a way to witness trauma together. (1)

The relationship between memory, trauma, and “truth” is one that is and always will be in discussion. Whether it be in terms of legality and evidence, or whether it be, as Freedman explained, an unavoidable evil, necessary to promote healthy coping, is something to be explored especially considering not only the emotional trauma of epilepsy but the *physical* one as well, not only on the body but the brain.

⁴⁵ For more, see Freedman’s full article: Wales Freedman, Eden. “Let Seizing Truths Lie: Witnessing ‘Factions’ in Lauren Slater’s *Lying*.” *Humanities*, vol. 6, no. 4, 4, Dec. 2017, p. 80; p. 1-12. www.mdpi.com, <https://doi.org/10.3390/h6040080>.

This allows the reader to embark on the journey *alongside* the author, while also giving them the necessary space to progress alongside the author throughout the framework of the memoir; the same way epilepsy does. It is only natural that such a diagnosis, one with no concretely formed basis of knowledge for pathology proliferates as metaphors in fiction and otherwise.⁴⁶ The way that a bystander, someone who is physically standing next to someone who is having a seizure, witnesses their illness at that moment, we do the same for Slater. We are witnessing, observing, and spectating her seizures. We can give proof as an active witness; reading about her experiences and emotions provides us with the evidence we need to confirm she has epilepsy, whether or not she has been officially diagnosed—that is how this illness works.

⁴⁶ See Eleana Vaja's book *Epilepsy Metaphors: Liminal Spaces of Individuation in American Literature 1990-2015*. transcript, Veriag, Bielefeld, 2017 for more.

Destigmatizing *Lying* and Celebrating It: The Limitations of the Unknown

In an interview done by Alys Culhane, Lauren Slater describes that the inspiration behind *Lying* was prompted by her teaching a creative nonfiction writing class for Goucher College's M.F.A. program. Specifically, she talked about how there were a lot of questions going around about how one "define[s] this genre called creative nonfiction" (166).⁴⁷ At the time of her teaching, there were rules that you had to follow in this genre, not compressing time, not making up scenes, "[a]nd yet, [she] found [herself] sometimes doing [those] things" (166). Culhane then asks whether "...this distortion of fact [brought her] self-identity as a writer into question." To which Slater responds,

...I wondered, did my desire to alter literal, historical fact mean that I was a liar? Or did it mean that I was a storyteller?... *Lying* was a way for me to refigure some things that I was really confused about and at the same time create a form that reflected what some of the possibilities for a nonfiction book might be. (166)

Slater took in the confusion she had about creative nonfiction and its rules, as well as her interest in Geshwind's Syndrome, and created a whirlwinded metaphorical memoir. Geshwind's Syndrome is "a characteristic behavioral syndrome frequently described in patients affected by temporal lobe epilepsy, consisting of the following features: hyper-religiosity, hypergraphia, hyposexuality, and irritability."⁴⁸ Essentially, it can make epileptics be histrionic, erratic, and

⁴⁷ Culhane, Alys. "Interview with Lauren Slater." *Fourth Genre* 7, no. 1 (2005): 157–72.

⁴⁸ Veronelli, Laura, et al. "Geschwind Syndrome in Frontotemporal Lobar Degeneration: Neuroanatomical and Neuropsychological Features Over 9 Years." *Cortex; A Journal Devoted to the Study of the Nervous System and Behavior*, U.S. National Library of Medicine, Sept. 2017,

overall unreliable. Slater also speaks about how she herself wondered exactly what the readers of *Lying* do, did she ever have epilepsy? There had been a doctor of hers that “wondered if... there was some component of epilepsy to her childhood diagnosis” (Culhane, 167). But whether she had this diagnosis did not matter to Slater, she used epilepsy as the perfect framework to break the rules of creative nonfiction whilst perfectly portraying the dynamic forces of her family—specifically her mother. Ultimately, *Lying* is an adventure of pain, illness, metaphor, and identity.

The introduction to *Lying*, written by Hayward Kreiger, an extension of Slater and a “professor of Philosophy at the University of Southern California,” provides advice for how to read Slater’s memoir. Kreiger describes the memoir as “disturbing..., exciting..., [and] unsettling,” warning the reader of Slater’s “incrementally rising refusal to state the facts of the illness about which she writes,” establishing them to the idea that epilepsy can be “a meaningful metaphor” to communicate the “unutterable experiences in her life” (x). Kreiger (Slater) states that her insistence on questioning which aspects of her disease are “factual, which symbolic, which real, which fantastical... [asks] us to enter... the truth of the liminal, the not-knowing, the truth of confusion, which if we can... learn to tolerate, yields us greater wisdom in the long run than packaged and parceled facts” (x). This introduction goes entirely against Sontag’s ideas of the metaphor and the fantastical functions of thoughts. To Sontag, this type of thinking regarding the unknown is damaging and negatively crucial, but to Slater, they are necessary and affirmative. Like Slater, my metaphorical thinking keeps me aware, expressive, and heightens the intrigue and curiosity I have about my own illness and experiences.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5565695/#:~:text=Geschwind%20Syndrome%2C%20a%0characteristic%20behavioral,hypergraphia%2C%20hyposexuality%2C%20and%20irritability.>

When reading an illness narrative, there is a relational exchange between reader and writer. The writer is wearing their seatbelt, setting the speed limit as they drive while the reader is the passenger, clenched onto their seat, helplessly sitting by, unprepared for whatever they are about to experience, or for others, witness. By rejecting visual involvement, and actively becoming involved, the witness has testimony, and they can prove what happened more accurately than the one who experienced it—more than the person with the actual illness. Which, ironically enough, is what a seizure is like. Except my brain is the driver, and my body is the passenger. See what I mean? Metaphors that simply rely on the witnessing experience and not the lived one fall into the clinically subjugating and stigmatizing ‘gaze’ that contributes to the understanding of ‘seeing’ as ‘knowing’ (Vaja, 76).⁴⁹ There is so much room in the ambiguity and formlessness of the metaphor; There are no rules to it, just what is. There is no rationality, no true logic. Epilepsy has nothing you can keep track of or focus on, aside from medication of course, and the off chance that you successfully find your trigger only happens if it is as easy to find as flashing lights. But it usually is not like that. Usually, there is no reason, something Lauren Slater learned early on:

I was learning, now, that at any minute I could go in a dangerous way. I was not a girl at all, but a marionette, and some huge hand—my mother’s hand?—held me up, and for a reason I absolutely could not predict, that hand might let the strings go slack, oh, God. (9)

After having a seizure or two with no premonition or symptom of the onset seizure, I started to get incredibly paranoid, as Slater does here, and there is no real descriptor for someone who is rationally paranoid. But what do I even mean by saying ‘rationally paranoid?’ The condition of

⁴⁹ Vaja, Eleana. *Epilepsy Metaphors: Liminal Spaces of Individuation in American Literature 1990-2015*. transcript, 2017.

paranoia denotes the *feelings* of paranoia, which is both meaningful, in an emotional sense, and a logical one, marked by a diagnosis. However, the difference lies in the nature of the accompanying paranoia itself. You never know when you are going to set off a seizure; a focal seizure or a grand mal, you only know it is happening when you cannot do anything about it. However, in this instance, Slater is not haunted by the disorder itself, it is not epilepsy that controls her seizures, but her mother. Epileptics are often seen as larger than life, at the hands of their brain and its misfires, while simultaneously beating their own villain (or brain) and regaining control of their body once again. Slater takes this idea and uses it to her advantage, accurately portraying an often thought-of nervousness—not in relation to a seizure specifically—but to her mother. Here, her epilepsy does not represent the undetectable seizure, but the tumultuous relationship she has with her mother. As Peter Wolf has previously mentioned, there are plenty of prototypes of epilepsy being used as a metaphor, and we can see it here.⁵⁰ This mention of a seizure, for Slater, is used to talk about the background of her personal relationship with her mother. One that is imperceptible and erratic, her mother controls her and keeps her on edge, leaving Slater fearful, the way that epilepsy does for many patients.

The symptoms and sensations described by Slater are increasingly accurate to what many epileptics have and continue to describe in their own experiences—which makes it that much more difficult to recognize whether epilepsy is simply a metaphor or something Slater truly deals with. Slater can do this because the metaphor she uses epilepsy to describe the disorder as well. The paranoia that describes her relationship with her mother can also describe what epileptics feel as well. As she remains fearful of her mother's control over her and her body, epileptics

⁵⁰ Wolf, Peter. "Epilepsy and Metaphors in Literature." *Epilepsy & Behavior*, vol. 57, Apr. 2016, pp. 243–46.

remain fearful of their disorder and its control over them and their bodies—her metaphors work in perfect harmony to describe the disorder while also describing her experiences. She knows this too, in the beginning of the second chapter, she describes the constant smell of jasmine, and how at first, she thought this was normal, so she did not think much of it—she called it the “jasmine world” (4). However, she did not know then that “epilepsy often begins with strange smells... [and that she] was lucky to have a good smell. [While other’s] epilepsy began with bad smells” (4). While this sensation of smells is equative to an oncoming seizure, Slater uses this accurate sensation to describe her relationship with her family:

As the summer went on, the jasmine world grew; other odors entered, sometimes a smell of burning as though the whole house were coming down.

Which, in a way, it was. There were my mother and my father, both of whom I loved—that much is true—but my father was too small, my mother too big, and occasionally, when the jasmine came on, I would also feel a light-headedness that made my mother seem even bigger, my father even smaller, so he was the size of a freckle, she higher than a house, all her hair flying. (5)

When her so-called seizure was coming on, she felt a light-headed aura begin to take form and her mother—the controlling presence in her life—got figuratively bigger, while in contrast, her father got smaller. From this description alone, we can see the dynamic between her family and how separate her relationships are with her parents—one is the more controlling figure in her life, taking on epilepsy’s descriptive quality of being larger than life, while the other remains a minute figure, a mere witness.

Slater repeatedly intertwines her epilepsy and her relationship with her mother, and she uses this metaphor as one of emotional breakdown, and “in extremes, an emotional crisis [ends]

with a person's dramatic breakdown which repeatedly has been expressed metaphorically in an epileptic seizure," are as the diagnosis of epilepsy overall (Wolf, 244). As Slater continues to introduce her depictions of her own life, she states:

I have epilepsy. Or I feel I have epilepsy. Or I wish I had epilepsy, so I could find a way of explaining the dirty, spastic glittering place I had in my mother's heart. Epilepsy is a fascinating disease because some epileptics are liars, exaggerators, makers of myths and high-flying stories. Doctors don't know why this is, something to do, maybe, with the way a scar on the brain dents memory or mutates reality. My epilepsy started with the smell of jasmine, and that smell moved into my mouth. And when I opened my mouth after that, all my words seemed colored, and I don't know where this is my mother or where this is my illness, or whether, like her, I am just confusing fact with fiction, and there is no epilepsy, just a clenched metaphor, a way of telling you what I have to tell you: my tale. (5-6)⁵¹

Just before this, Slater tells us that, "[f]rom [her] mother, [she] learned that truth is bendable, that what you wish is every bit as real as what you are" (5). If this is true than her wish to have epilepsy is as real as what she is—a puppet with no autonomy, one that abides by the ruling force of pleasing her mother. Slater openly tells her audience that this metaphor is simply a way of not just accurately describing what this diagnosis feels like, but a representation of her life, pain, and experience. Perhaps the more important question is not whether she has epilepsy, but whether her mother *is* epilepsy.

⁵¹ Note how she says "my" epilepsy. Just as I explained before, even if Slater does not have epilepsy, each person's diagnosis, symptoms, and treatment differs. It really is their own individual relationship and illness, not a shared one, but one that encapsulates uniquely.

In another section of this chapter, her mother begins to play the piano, and “[Slater] could see the sounds she made...” But she explicitly states, “I don’t mean this metaphorically.” Soon after, she goes temporarily blind, and as she begins to freak out, her mother asks, “How many fingers [am I holding up]? *Think.*” She takes a guess of two, and her mother says “exactly... [sounding] triumphant. And just like that, I started to see again...[H]er words determined the truth” (7-8). Just as Slater needs her mother’s acceptance and approval to see the world around her, she needs epilepsy as a metaphor to explain how her mother has influenced her interpretation of such a world— “a secret world” (9). Epilepsy may be used as a metaphor in many different ways, other than one I have already mentioned (metaphors of breakdown), it may also assimilate as an indication of weakness and vulnerability, something Slater often emphasizes, “...after the seizures began...[a]nything, at any moment, might become unbearable, might be a sign of some absurdity we would never escape” (33). When Slater goes to see a doctor is when the reader can really put together the fact that her mother is her emotional trigger, sparking a seizure, the doctor (Dr. Swan) tells Slater and her mother that, “[o]ftentimes a seizure comes after a period of stress” (35)⁵². Slater uses epilepsy to describe her mother, and her mother to describe her epilepsy: “[s]ometimes, after I’d woken up from a seizure, I felt so sorry for her. I felt it was really she who’d had the seizure, she whose muscles really ached” (37).

Peter Wolf has two distinctions for the use of metaphor in relation to epilepsy—either epilepsy as a metaphor for something else, or epilepsy in a metaphor to describe experiences—I argue that Slater does both. Even though a lot of the metaphors used in *Lying* are just that,

⁵² For those with an actual diagnosis, this remains true, “anything that interrupts the normal connections between nerve cells in the brain can cause a seizure,” see Johns Hopkins Medicine article, “Evaluation of a First-Time Seizure.”

epilepsy as a metaphor for something else, the attributing descriptions, claims, or expressions are aligned with true examples of epilepsy as a diagnosis. You may have a change in a sense of smell or visual changes, or you may feel impending doom, fear, déjà vu, or even euphoria.⁵³ Epileptics too often feel as though they are “just a person with a disease,” who are “horrificed [by their seizures],” and whose seizures are “thrashing humiliations” (Slater, 62). We too feel as if, “no matter how much makeup [we wear], [we are] still a girl with epilepsy, a girl convulsed...” and we too question, “[whether] there [is] a way to make sickness sexy” (65). Epileptics are hardly in control of their bodies, or minds, and we, like Slater, “crav[e] for something safe and solid and absolutely absolute,” and it is something we hardly ever get to feel (69).

On the other hand, seizures are incredibly unique, and are handcrafted for each individual; we all feel them differently, something Slater also caught onto: “I want to talk about the auras, which many epileptics have and agree are truly special states. My auras” (72). Slater’s choice of first-person point of view is truly relatable to a reader with epilepsy. It creates a distance between the reader and the writer, the experiencer and the witness, but it also creates a space for particularity and identity, a space where someone can accurately describe their illness as a narrative in a way that is inviting yet distinctive. The reason why I argue that Slater’s *Lying* be accepted as an illness narrative and why I argue for the use of illness as a metaphor is simply this, she asks the same questions we do: “is epilepsy mental or is it physical,” she makes the same sentiments that we do: “[we] thrash and spasm,” and she expresses herself the same way

⁵³ “Evaluation of a First-Time Seizure.” *Johns Hopkins Medicine*, 19 Nov. 2019,

<https://www.hopkinsmedicine.org/health/conditions-and-diseases/epilepsy/evaluation-of-a-first-time-seizure#:~:text=Anything%20that%20interrupts%20the%20normal,this%20is%20diagnosed%20as%20epilepsy.>

that we do: "...my seizures [are] exhausting" (81-83). Those like Sontag and Couser argue against illness narratives or metaphors because of the claim that they do much more harm than good, but my question is, for who? Sontag found it harmful to think of her illness in such a way, but I do not. So, who is right?

But there is no simple answer. Illness as metaphor or narrative really is situational, especially with one such as epilepsy. What even is epilepsy you may ask? The only consensus for the diagnosis is having two or more seizures with no known cause, and the only way to truly know you are having a seizure is if it is witnessed first-hand. Or, like Slater, you can simply pretend, you can create an illness, "[an] illness [as] a conduit to convey real pain" (88). The conflict of interest lies in societal stereotypes and ableist thinking. Seizures really can be described in metaphors as rollercoasters, dreams, or thunderstorms. But they can also be used in ableist fashion when those notions and metaphors are romanticized and exaggerated. Lying may provoke some of those notions, but overall, Slater's notions are quite relational and accurate to an actual seizure and to epileptics. Slater does not romanticize a seizure (or epilepsy) to create this alluded fantasy of beauty, euphoria, or love, she metaphorizes it in a way that expresses the diagnosis and all its components while manifesting an expression of her life through pain, chaos, and attempted control. The general concept of the unknown known, or cosmic dread, has haunted people for ages creating a multitude of anxieties to the unanswerable "what ifs" and unexplainable "whys" of life. But, think about this, as a writer, if you too had a choice to create a mere glimpse into your questionable experiences, would you not take it?

In the foreword of Jason Tougaw's, *The Elusive Brain*, Joseph E. LeDoux stresses that "our ability to explore how the brain works is only as good as our understanding of what we are trying to learn about the brain" (ix). Relatively, "less is known about how first-person subjective

experience comes about in the brain” (ix). If we are trying to express our own first-hand accounts of our lived experience, then our understanding of our own (singular) brain stimulates how well we are able to explore our brain. It is difficult to try and explore someone else’s unless we fully know what we are trying to learn about. For Sontag, her understanding of her brain, and her fellow patients’ brains, are stimulated by her understanding of her brain—which leaves her at a disadvantage. She is not trying to go about others’ experiences in individual ways, but in a collective way, assuming that her own thoughts and singular experiences equate to all other cancer patient’s thoughts and processes as well.

Throughout Slater’s bout with her mom and her epilepsy, deep down, all she wanted was for her mom to save her. In the middle of the book, it is decided by one of her doctors that she will get surgery to lessen her seizures—something she has admitted to the readers that she can force on command.⁵⁴ Knowing that she does not need this surgery, that “[*she*] is not as ill as [*she*] seems,”⁵⁵ she goes along with it. But part of her wonders, “why [mom], why did you let them do it? Why did you let me go” (93)? Now, I must admit, even I began to wonder just why she would continue lying if she did not need this surgery, and even Slater knew her audience would question this, so she answers simply, simply for those with epilepsy anyways:

I said nothing, half from fear, half from confusion. I had always believed there could be two truths, truth A and truth B, but in my mind truth A sat on top of truth B... In this instance, however, I had epilepsy, truth A, and I had faked epilepsy, truth B, and A and B were placed in a parallel position, instead of one over the other, so I couldn’t decide. (94)

⁵⁴ For an in-depth reading on Slater’s admittance to Munchausen’s and how she can fake her epilepsy and cause a seizure see pages 89-91 of *Lying*.

⁵⁵ Emphasis hers.

At this point, as an epileptic, I have often questioned the same thing, do I really have epilepsy? How do I know? How does my doctor know? I, however, am lucky enough to have witnesses who can corroborate my seizures. But they can do only that, witness. They can only inform me of the exact time of my seizure, what my body was doing, how long it lasted, and what I said or did not say during it. Those moments do not inform me of whether I truly have epilepsy.⁵⁶ My EEG and MRI did not show anything other than slight hippocampal loss—which showed my neurologist that I have had, at least a few seizures—but that is all. This information does not show the extent to which my epilepsy will go. Is it severe? Is it epilepsy? Or are my seizures just caused by stress? My doctor and I may never find out.

Having an illness is difficult enough, but having one with no sufficient evidence or proof of the actual diagnosis sends me, and others, into a further fit of panic, stress, and doubt—something that Slater plays with in such a brilliant way:

As she looked across the hospital window,

Where, I wondered, had Lauren gone? Where, I wondered, had my mother gone? And then I felt what I had not allowed myself to feel, the longing for her love, and the longing for a younger, braver self, a self who had once said a definite yes to living in the world.

(95-6)

Epileptics similarly question themselves and their identity, due to an interpersonal and complicated relationship with body and self. But what they do not do, is force an illness narrative based upon the trauma of their upbringings, or do they? For most, “[t]he cause of epilepsy can’t

⁵⁶ Although epilepsy is diagnosed after two or more seizures with unknown causes, that, for me, is not enough for a diagnosis because it simply does not tell me enough. It is not an easily answered question—or is it that I do not have all the information I want?

be found,” which makes it harder for us as the audience to question Slater, and much easier for Slater to question herself.⁵⁷ Here, the audience finds out, epilepsy is a metaphor for her mother, her familial dynamic, her tumult, and her longing for love and care. It never played a singular part as it does for many others living with the diagnosis, it is just as individually wired for Slater, yes, but it played a symphony of questions, hopes, dreams, and emotions:

I was shaking but it wasn't a seizure, it wasn't a sickness; it was me this time, it was real this time, my sadness and longing coming out and my hands, for once, staying still, not stealing a thing. (96)

Lauren Slater is not the only liar and thief in this mock autobiography, it is epilepsy too. A thief of the body, mind, and soul, that leaves a person questioning their identity, diagnosis, and their truth.

Slater uses clever literary moves in her text that make her pseudo autobiography seem a lot less like an intertwined work of creative non-fiction, and much more like a straightforward work of nonfiction. One of the things she does best is creating figures such as philosophy professor Hayward Krieger, and intertextuality like the excerpt of a “scholarly journal article,” which is just her own fabrication. The article is titled, “The Biopsychosocial Consequences of a Corpus Callostomy in the Pediatric Patient,” and it is written by illustrious figures “Dr. Carlos Neu M.D., and Patricia Robinson, P.T.” and it discusses epilepsy, specifically temporal lobe epilepsy, as both a “seizure *and* a personality disorder... [that] raises crucial questions to the

⁵⁷ “Evaluation of a First-Time Seizure.” Johns Hopkins Medicine, 19 Nov. 2019,

<https://www.hopkinsmedicine.org/health/conditions-and-diseases/epilepsy/evaluation-of-a-first-time-seizure#:~:text=Anything%20that%20interrupts%20the%20normal,this%20is%20diagnosed%20as%20epilepsy.>

relationship between anatomical and psychological phenomena” (98). Slater uses this false intertext as a service to the personal investigation of her memoir and diagnoses, a manipulation to engage with the reader and make them a part of the book as a forced witness. By doing so, she empowers her work by lending validity to the story she is writing by separating between chosen lies and unaware creation: “[p]sychologically speaking, such patients... are so prone to fabrications that they themselves are no longer able to determine where fact and fiction meet” (99). In doing so, she legitimizes Lying while also allowing epileptics a roaming space to think further about their own diagnoses—whether she meant to do so or not. A lot of the article is meant to convince readers that she is establishing herself as a creative who is unknowingly mixing fact with fiction, but she is also drawing a parallel to many of the epileptics’ experiences directly. Epilepsy *is* an anatomical and psychological phenomenon, it both relates to bodily structure—the brain—and affects the mind in terms of the emotional and mental state of a person—depression, confusion, and auras. To have a seizure seems easy enough to describe, shaking, convulsing, and short-term memory loss, but this is only because the allotted vocabulary words are immediately associated with a seizure—but this did not happen until John Hughlings Jackson laid the scientific foundation for what we now call epilepsy and seizures in 1873.⁵⁸ In contrast, it is far easier for an epileptic to describe a partial focal seizure as a “brief burst of rain in otherwise clear weather” (Slater, 109). For us, that equates to saying, everything was fine one moment and the next, I was on the floor and having an unusual sensation, known as an aura.

⁵⁸ See this article for more information on the history of name and the anatomically description for epilepsy and seizures: *The Evolution of the Concepts of Seizures and Epilepsy: What’s in a Name?* - PMC.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7049807/>

Epilepsy as a condition is vague, as are its correlating symptoms and sensations, and Slater knows this, she knows a lot about epilepsy and connects it with her life experiences in a way that comes off as knowledgeable and understandable. After Slater has her surgery to lessen seizures known as a Corpus Callostomy, she goes to see her doctor, Dr. Neu, once again and reports having prevalent auras—something epileptics feel often and are thought to be mild, frequent seizures. In response, Dr. Neu offers a low dosage of a medication known to help with this sensation known as Dilantin—a real prescription medicine that is used to treat certain seizures—but she responds and says no because, “[she] likes [her] auras... they give [her] things” (148). I do too. My auras, like my epilepsy, are mine, and in a strange and incomprehensible way, they reassure me of my diagnosis, as they do hers.

The difference between me and Slater, aside from my true diagnosis, is that she has the right words to describe my illness, and I do not. Slater knows how to express the feelings of epilepsy in ways that epileptics do not, she knows what we go through even though she has not gone through it herself:

Epilepsy does not mean to be possessed, passively; it means to need to possess, actively. You are born with a hole in you, genetic or otherwise, and so you seize at this, you seize at that, your mouth so hungry you’ll take your own tongue if you have to... I had the feeling, then, I had the knowledge. I saw my illness as more than a physical thing; It was also a metaphor, and *that helped me make some sense*. (157)

As Slater does so here, I too recognize my illness as a metaphor, and the vagueness of it all makes me try to understand the physicality and psychology of what I am going through—even if I do not fully understand it, as my doctors do not, at least we are able to express it. Notice how Slater says here that it helps her make “sense” of it all, not understand it all, because to

understand something in the brain we must understand what we are trying to learn about it.⁵⁹ To come to terms with a disorder like epilepsy, one must have to get an understanding of their own epilepsy first—we must possess our brains, “actively.” What makes another’s epilepsy different, how does this disorder change our brain and not anyone else’s? The things we question about our illness and the way it affects our bodies and brains only further our understanding of the illness itself.

Toward the end of the book. Slater has a chapter dedicated to a future publisher where she goes into depth explaining the contents of her book and lays out at least four possibilities of what are fabrications, and what are facts, they are as follows:

A) I have epilepsy as I’ve described. Ninety-nine percent of what I’ve told you is accurate, with a few glitches, due mostly to the memory lapses and altered consciousness that accompany the split-brain patient. B) I have epilepsy, but due to the very nature of the epileptic personality, the need to exaggerate all that, you should believe only selectively what I have recorded here. C) I don’t have epilepsy at all, not a shred, not a sliver, but I do have Munchausen’s, and what you have here before you is a true portrait of a fabulist, a sick mind under siege, the webs we weave, the glistening tales, all matter turned to myth, yes. D) I have neither Munchausen’s nor epilepsy nor a TLE personality style, but I did grow up with a mother so wedded to denial, so inclined to twist and even outright lie, that I became confused about reality and also fell in love with tall tales. (161)

As an epileptic, I can wholeheartedly say that A is very plausible since, especially with temporal lobe epilepsy, the thing most affected is one’s memory and emotions. B is also quite believable

⁵⁹ Tougaw, Jason Daniel, and Joseph E. LeDoux. “Foreword.” *The Elusive Brain: Literary Experiments in the Age of Neuroscience*, Yale University Press, New Haven, 2018, pp. ix-xii.

since temporal lobe personality disorder, or Geschwind syndrome is also real, but it is usually not as intense as the symptoms Slater describes in her book.⁶⁰ D is realistically the accurate depiction of Slater's representation of herself and life in *Lying*, and this is something she mentions in her interview with Alys Culhane.). She wanted to deconstruct the confines of a nonfiction book and question whether the alteration to any literal, historical fact meant she was a liar while concurrently being interested in Geschwind's syndrome. In the interview, she explains that to her, *Lying* is not a precise record of what she thinks like, but it captures her true psyche, at least a piece of it, which to her, means that this is not a work of fiction: "[f]or whatever reason I just feel that the personality on the page is who I am, amplified" (Culhane, 167). All she knows for certain is that the witness is there to experience alongside the experiencer, the way that the experiencer does the same with their diagnosis—we attempt to do both, but at best, all we can do is tell our lived experience, even if we cannot witness every moment of it: "[t]ogether we will journey. We are disoriented, and all we ever really want is a hand to hold" (Slater, 163).

In the last chapter of the book, she opens with a quote from Sally McFague in *Models of God* that reads,

What a metaphor expresses cannot be said directly or apart from it, for if it could be, one would have said it directly. Here, metaphor is a strategy of desperation, not decoration.

(169)

Here, McFague perfectly explains the use of illness metaphors, at least when it pertains to experiences with epilepsy. When there are no true ways of expression and when it "cannot be

⁶⁰ To read more on TLE or other psychiatric disorders in patients with temporal lobe epilepsy see: *Temporal Lobe*

Epilepsy and Psychiatric Comorbidity - PMC. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8669948/>.

said directly,” all that is left is a metaphor. Even as a critic of illness as a metaphor, even Susan Sontag could not avoid it. There is no other way to utter the words needed to get feelings off your chest, so how else could you do it if not the metaphor? There is no other way to utter the words needed to get feelings off your chest, so how else could you do it if not the metaphor? Epileptics attract the use of metaphor because seizures, especially partial focal seizures, are so difficult to describe, the closest you can get is to relate the experience to the perceived world around you and somehow relate it to a made-up metaphor.

In the afterword of *Lying*, Slater explains the reasons behind her choice of the epilepsy metaphor:

[T]he text I've created uses... most significantly the metaphor of epilepsy, to express subtleties and horrors and gaps in my past for which I have never been able to find the words. Metaphor is the greatest gift of language, for through it we can propel what are otherwise wordless experiences into shapes and sounds. And even if the sounds are not altogether accurate, they do resonate in a heartfelt place we cannot dismiss. (219-220)

Sontag argues against the use of illness as a metaphor, particularly TB and cancer, while Slater emphasizes the use of it, even when she does not explicitly have epilepsy. However, she does explain that she used to take anticonvulsant medication and has had auras all of her life.

Symptoms that have been diagnosed as consistent with temporal lobe epilepsy by one doctor, has also been described as a borderline personality disorder.⁶¹ The vagueness of multiple neurodivergent disorders, not just epilepsy, often overlap in more ways than one, and without any physiological explanations or outright descriptions of experiences, it is hard for doctors to

⁶¹ Slater goes more in depth about her separate diagnoses as a child in the afterword of *Lying: A Metaphorical Memoir*.

accurately diagnose, and patients to accurately explain. By writing *Lying*, Slater attempts to fill the gaps between the differences between a plethora of neurodivergent disorders, specifically epilepsy, and defying the laws of creative nonfiction in a way that positively relates and accumulates to epileptics who have been diagnosed and continuously question the same things that Lauren Slater does. Are we really epileptic? Are our experiences accurate, and if so, how do we attempt to describe them? How do we know we are having a seizure if we do not have a patient record with a witness recount? These questions are all almost impossible to answer, not only for us as patients, but neurologists as well. The only thing we can do is try to find the most accommodating way to explain to others what we go through, day to day, and seizure to seizure, if we do not have that, what else do we have? There is no other way to utter the words needed to get feelings off your chest, so how else could you do it if not the metaphor? Epileptics attract the use of metaphor because seizures, especially partial focal seizures, are so difficult to describe, the closest you can get is to relate the experience to the perceived world around you and create a closely analogous metaphor.

Conclusion

“A big seizure just kind of grabs the inside of your skull and squeezes. It feels as if it's twisting and turning your brain all up and down and inside out. Have you ever heard a washing machine suddenly flip into that bang-bang-bang sound when it gets out of balance, or a chain saw when the chain breaks and gets caught up in the gears, or an animal like a cat, screeching in pain?

Those are what seizures felt like when I was little.”⁶²

Critics like Susan Sontag, Amy Vidali, Thomas G. Couser, Peter Wolf, Ann Jurecic, Eleana Vaja, Eden Wales, and more have tried to answer the controversial debate about whether writing about illness as a metaphor is morally right and should be avoided, or whether it is a creative, personal choice that does not have to conform to rules. These well-known theorists have varying critiques about this subjective literary approach when it comes to the lived experiences of illness narrative choices; some argue against it, while others praise it. But narratives are not fictional books that are available to critique regarding writing choices, they are subjective and should be treated as such. No two narratives will be the same, each person's experience is theirs to keep and express, in any way they would like. Some narratives and illness metaphors can be stigmatizing, but others open a doorway to a world of understanding what is otherwise incomprehensible.

There is no debate that Lauren Slater took a risk when writing *Lying: A Metaphorical Memoir*; this is something even she knows and states, both in her book and during interviews: “[t]aking risks has enabled me to stretch myself as a writer, to peer over the edge, and that's what

⁶² Trueman, Terry. *Stuck in Neutral: A Novel*. HarperTeen, 2012.

writing should be, at least to me” (Culhane, 170). She notes this in *Lying* during a chapter where she tries to market the book, she gets meta, and she recognizes its risks and faults in an obvious way:

This is a difficult book, I know. The seizures are real or something else. I am an epileptic or I have Munchausen’s. For marketing purposes, we have to decide. We call it fiction or we have to call it fact, *because there’s no bookstore term for something in between, gray matter...* [M]y purpose... [is] to ponder the blurry line between novels and memoirs. Everyone knows that a lot of memoirs have made-up scenes; it’s obvious. And everyone knows that half the time at least fictions contain literal autobiographical truths. *So how do we decide what’s what, and does it even matter?* Question number two: *Is it possible to narrate an honest nonfiction story if you are a slippery sort?... Something can be both true and untrue—it’s a paradox...* I suggest you pitch it to the public as such... *a book that takes up residence in the murky gap between genres, and by its stubborn self-position there, forces us to consider important things.* (159-60)⁶³

Lauren Slater does exactly what she says she will; she raises important questions about autobiographies and illnesses together. What is the structure of a memoir and what is the structure of fiction? They vary and are paradoxical—sometimes even parallel. Each has parts of the other, and truth always contains some exaggeration or lie within. A memoir or an autobiography only has one side of the truth, it is subjective. The way I talk about my experience may not be the way you talk about that same encounter. As the reader continues throughout the book, it is assumed that she does not have epilepsy, but as a witness, along with the experiencer, both continue to question one another. Even if Slater does not have epilepsy—which in an

⁶³ Italic emphasis mine except for the last sentence beginning with the words “a book that takes up residence...”

interview she revealed she does not—the diagnosis represents many of the tumultuous relationships and struggles she, and other epileptics have, with themselves and their diagnosis.⁶⁴ Since her representation of epilepsy as and in a metaphor is so respectfully aligned with an epileptic’s experience, I cannot dismiss her book as an ableist representation or a misalignment of what I and other epileptics go through. Lauren Slater’s *Lying* and its epilepsy metaphors are used as an excellent tool to express what she has and continues to deal with while simultaneously representing what epileptics have and continue to deal with. Like Slater's truth A and truth B, epilepsy and her language are contemporaneous: “[t]his how epilepsy begins. It begins beautifully, and with only slight pain” (9, 94). Together, Sontag and Slater show just how murky it is to debate the use of illness metaphors, they can be detrimental, but they can also be benign. Like epileptics, no two people will have the same experience.

I cannot unequivocally deny illness metaphors altogether, this concept is not that simple. Illness metaphors are not always harmful, nor are they always helpful, they are both combined and remain parallel—they can always be separate, and they can always be one. There is a reason metaphor is used so frequently, they offer a gateway into our imagination, one where we can bring another person into our world and try to make them understand what we are voicing to the absolute best of our capability, and Slater does that in *Lying*. It is not a question of whether she has epilepsy, but how accurately she can encapsulate the experience of having epilepsy, and I say she does so beautifully.

⁶⁴ See Slater’s interview with Alys Culhane pp. 167 for a more in-depth explanation of *Lying* and how she explains why she authored this book and fabricated her diagnosis. It was not the full truth, but it also was not a full lie—her own doctor thought she had epilepsy as a child.

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