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The Representation of Chronic Illness in Young Adult and Children's Fiction

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Abstract

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This research focuses on representations of chronic illness and chronic illness experience in young adult and children's fiction. The goal of this work is to raise awareness of the simultaneous near lack of chronic illness experience in these genres as well as the contradictory and unrepresentative stereotypes of this experience when it is present.

The work highlights two novels that exemplify these depictions: *The Fault in Our Stars* by John Green and *House of Robots* by James Patterson and Chris Grabenstein. Chapter 1 addresses how Green uses chronic illness tropes such as illness as identity, gendered performance of illness, and the metaphorizing of illness experience. Chapter 2 emphasizes the lack of research of a specific chronic illness in *House of Robots*, the gendered suppression of illness experience, and the psychological impact of illness experience on children in the novel as well as on readers. Chapter 3 explains how the ideas of narrative medicine are applicable to fiction reading. Reading popular fiction can cultivate empathy and theory of mind just as narrative medicine and other forms of literary fiction can. Moreover, reading fiction about chronic illness can provide therapeutic benefits for those with chronic illnesses as well as teach readers without chronic illnesses how to better understand those with chronic illnesses. Arguments in this thesis are supported by the work of disability theorists, feminist theorists, and healthcare theorists.

The purpose of this analysis is not to censor writers in the way they represent chronic illness. Rather, it is to encourage writers to research chronic illness and its consequent experience in order to raise awareness of the way chronic illness exists in society. The research aims to promote discussion of the way chronic illness is represented in these genres and increase public awareness of how chronic illness experience in novels can influence the way healthy people treat those with chronic illness in society and how those with chronic illnesses view themselves.

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Introduction

My honors thesis focuses on representations of chronic illness in young adult and children's fiction. There is an absence of chronic illness and of subsequent literary analysis of chronic illness in these texts. Moreover, when physical illness is depicted in these genres, it is present almost only in ill young women, not ill young men. The rare descriptions of illness exemplify tropes of ill young people as heroes or as victims, dependent upon both illness type and gender. These tropes are influential in young adult and children's fiction. Authors' use of these tropes demonstrates a lack of understanding of the potential for illness to be simply another component of a child's life. Rather, whether it be positive or negative, illness is seen solely as an inhibitor of a 'normal' childhood. I question why chronic illness is used as a romantic or heroic characteristic that improves these young characters, as this depiction excludes the possibility of valuing children in these novels for their innate qualities separate from their illnesses. I intend to contrast this portrayal of chronic illness in young adult and children's literature with the perception and treatment of chronic illness asserted by healthcare professionals and theorists. Moreover, disability studies in literature and the ideas of medical theorists, such as narrative medicine, are often considered to be opposing fields of thought. The two theoretical schools have differing opinions on chronic illness, specifically regarding treatments and cures. How do we reconcile these countering views of chronic illness in children?

To clarify, I define chronic illness as any illness that is currently incurable, although the ill person is relatively stable for the foreseeable future, usually due to life-prolonging treatments. I do include some terminal illnesses in this definition, but only those treatable with new technologies in a manner that could prolong the ill person's life for a long period of time. Illnesses such as diabetes, schizophrenia, bipolar disorder, cystic fibrosis, autoimmune disorders,

and certain forms of cancer are examples of this definition. In my analysis, I will be focusing on physical chronic illnesses specifically, which I define as chronic illnesses that have a primary impact on the body, not the mind (although the mind usually is affected secondarily due to coping with a chronic illness). From the above illnesses, diabetes, cystic fibrosis, autoimmune disorders, and certain forms of cancer would be classified as physical chronic illnesses.

There is currently a lack of fictional stories about physical chronic illnesses, especially in children's literature and young adult fiction. However, I intend to analyze two examples of the current literature available to address my concerns: *The Fault in Our Stars* by John Green and *House of Robots* by James Patterson and Chris Grabenstein. *The Fault in Our Stars* is a contemporary young adult novel that has a widespread influence on young people, so much so that the popular movie adaptation grossed over three hundred million dollars (Bush). The novel centers on a female teen protagonist who is suffering from metastatic thyroid cancer. She falls in love with a teenage boy who is in remission from osteosarcoma. He appears to be healthy and strong, but he later relapses and ultimately passes away. This novel requires analysis because it retains a large public presence yet lacks critical examination in the literary sphere. It is important to consider how the depiction of chronic illness in this novel shapes young people's views and treatment of people with chronic illnesses that they see in their daily lives. At the moment, *The Fault in Our Stars* is not critically connected with present-day illness narratives, with popular opinion of illness, or with healthcare theorists' recommendations on how to treat chronic illness in young people. Therefore, approaching this popular novel with a critical lens will greatly benefit the literary community, the healthcare sphere, and the general public. I also want to address the romanticizing and heroizing of cancer that occurs in this novel, such as viewing illness as a quality necessary for love rather than appreciating someone for their innate

characteristics, and the potentially detrimental effects on readers' understandings of chronic illness experiences.

The protagonist of *House of Robots* is Sammy Hayes-Rodriguez, a young boy whose mother works as an engineering professor at Notre Dame University. His mother also builds robots, and one of them, named E, is an artificially intelligent robot that attends school with Sammy for the majority of the novel. At the end of the novel, the reader learns that E's true purpose is to serve as a proxy for Sammy's younger sister, Maddie, to attend school. She has Severe Combined Immunodeficiency (SCID), an immunodeficiency disorder that prevents her from ever leaving the house; it is too dangerous for her to get sick, even with a common cold. This novel is crucial to my analysis because just like *The Fault in Our Stars*, it has a large public presence, this time in the children's fiction sphere. *House of Robots* is in fact a trilogy. I am analyzing the first novel, but the second novel is titled *House of Robots: Robots Go Wild!* and the third is *House of Robots: Robot Revolution*. The second novel introduces another robot that is more advanced than E, and the third novel focuses on the other robots in the Hayes-Rodriguez household. All three novels mention Maddie, but I will examine the first novel and its introduction to her illness experience. Children are highly impressionable, so readers are likely to adopt the representation of chronic illness in children that *House of Robots* asserts. Moreover, one of the co-authors, James Patterson, has a large following not only in children's literature but also in young adult and adult literature. To clarify, a children's novel would be for those under the age of 14, and young adult literature targets people between the ages of 14 and 18 (Sullivan). Nevertheless, any novel Patterson writes is likely to be read by a wide audience. Therefore, his novel's representations of chronic illness need to be analyzed and compared to the current medically-based theories of how to treat and understand chronic illness experience in children.

I will utilize disability studies, feminist theory, and philosophies asserted by healthcare professionals and health theorists to support my arguments, and I will provide a brief explanation of why I intend to use these viewpoints. My overarching reason for using these theories is to help readers understand the research behind my assertions about chronic illness perception and representation in children's literature and young adult fiction.

Disability studies provides a unique perspective on the purpose of illness in young adult and children's fiction. Disability studies centers on analyzing disability as a social phenomenon rather than a biological condition as well as the impact of stereotypes on those socially identified as disabled. These theorists encourage the public to embrace and include those with disabilities rather than label them as separate from the norm. In her essay "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," theorist Susan Wendell defines disability as a "socially constructed disadvantage based on impairment" (Wendell 164). She adopts the United Nations' definition of impairment for this description, which is "any loss or abnormality of psychological, physiological, or anatomical structure or function" (UN 1983, I.c., 6-7) (Wendell 164). Disability studies scholars critique the idea that disability is purely biological. Rather, they discuss how society creates the narrative of disability and argue that society needs to become more accepting and inclusive. Another important aspect of disability studies is that the theory acknowledges chronic illness as a form of disability. Susan Wendell defines chronic illness as a type of "unhealthy disability," or a disability that also results in medical problems. In contrast, a "healthy disability" would be when "physical conditions and functional limitations are relatively stable and predictable for the foreseeable future" such as deafness (Wendell 162). I will use this categorization of chronic illness throughout my analysis to connect its representations in my primary sources with arguments from disability theory.

To analyze depictions of chronic illness from a disability studies perspective, I will rely on essays from Susan Wendell and other disability studies theorists such as Rosemarie Garland-Thomson, David Mitchell, Sharon Snyder, and Tobin Siebers. Rosemarie Garland-Thomson is one of the primary creators of the disability studies field in literature. Her work focuses on defining disability and identifying the influence of society on disabled people's views of themselves. She also discusses the intersections between disability and feminist theory. Susan Wendell additionally emphasizes that illness is not only suffering. Instead, it should be considered simply another aspect of someone's life. I aim to utilize this idea to subvert the view that illness is socially inferior to health. In my analysis of my primary sources, I will also adopt Wendell's theory of illness as complementary to life rather than contradictory to life. In addition, David Mitchell and Sharon Snyder explain in their essay "Narrative Prosthesis" how unhealthy disabilities in literature often advance a plot by isolating a character from the rest of society. Similarly, in his essay "Disability and the Theory of Complex Embodiment," Tobin Siebers delineates the creation of the ideology of ability versus disability and how it impacts society's perception of the disabled and its depiction in literature. I plan to use these analyses to criticize the exploitation of chronic illness in literature as a sole definer of a person's character.

Feminist theory addresses the disparities between men and women in our society and encourages fostering an equality between the genders. This effort to achieve equality includes critiquing gendered illness representation and perception. In an optimal description of feminist theory, Lois Tyson writes that: "Feminist criticism is concerned with '...the ways in which literature (and other cultural productions) reinforce or undermine the economic, political, social, and psychological oppression of women'" (Tyson) (Purdue Online Writing Lab). I intend to utilize feminist theory to analyze the gendering of chronic illness that is present in young adult

and children's fiction, specifically in *The Fault in Our Stars* and *House of Robots*. Through a feminist critique, I will demonstrate how authors in these novels perpetuate the societal conception of females as both sicker and weaker than their male counterparts.

I will rely on both qualitative research and analytical feminist theory for my gender-based argument. For example, I will utilize the research of Chris Saad to provide statistical evidence of gender inequalities in illness literature. In his dissertation, *The Portrayal of Male and Female Characters with Chronic Illnesses in Children's Realistic Fiction, 1970-1994*, Saad interviewed readers of fifty-four children's novels and qualitatively analyzed the novels along with the readers' beliefs about sexist, racist, and general views of chronic illness in children's literature. Saad argues that statistically, girls are depicted with chronic illnesses more often in fiction than boys (Saad). This inequity in the representation of illness is a result of the stereotype of females as the supposedly inferior and more submissive gender (Saad). I also intend to draw upon the analysis of Judith Lorber and Lisa Jean Moore in their book *Gendered Bodies: Feminist Perspectives*. Lorber and Moore discuss the development of societal inequalities of gender and how they came to be associated with illness and disability.

The Fault in Our Stars and *House of Robots* both exemplify gender inequalities in illness. In *The Fault in Our Stars*, there is a male ill character; however, he is not the main character of the novel, and he passes away before the novel's end. Moreover, other characters describe him as a hero, while the female main character sees herself as a victim of her illness. *House of Robots* represents chronic illness in a different, yet still problematic, gendered light. The main character is male and healthy, while his younger sister is ill and gets very little voice in the novel even though her illness propels the story. Furthermore, the male robot has a complex personality and is more involved in the plot than the ill younger sister. Using feminist theory to examine these

distinctions between genders will be crucial in my argument for raising awareness about the current depiction of illness in young adult and children's literature.

Similarly, healthcare professionals and philosophers assert their own views on chronic illness in literature as well as in reality. I aim to acknowledge and compare the views of Susan Sontag, Sander Gilman, Rüdiger Kunow, and others with those of the above theorists. One of the main texts I will focus on to support my argument is philosopher Susan Sontag's *Illness as Metaphor*. Sontag claims that society's romanticizing and metaphorization of chronic illnesses, such as cancer, negatively impact the perception of illness and thus have a detrimental effect on those who suffer from the illnesses. For example, identifying someone as their illness negates the value of their other characteristics. In addition, Sontag examines how cancer results in the separation of cancer patients from the rest of society because the public labels it as "the disease of the Other" (Sontag 68).

Two other healthcare theorists I will mention in my argument are Sander Gilman and Rüdiger Kunow. I intend to adopt Gilman's views of chronic illness's perception in society in my argument, specifically regarding Gilman's claims in his book *Disease and Representation: Images of Illness from Madness to AIDS*. Gilman discusses how society has come to impose the binary of inferiority of the ill and superiority of the healthy. He explores the internalization of this binary within those who are chronically ill. In *Material Bodies: Biology and Culture in the United States*, Kunow connects both disability studies and cultural healthcare theory by placing disability in both a healthcare and societal context. He analyzes how disability and illness are depicted in literature and popular media and how this depiction has developed through societal normativity. He also outlines the story of cancer in literature and society, similar to Susan

Sontag, Gilman's and Kunow's theories will aid my discussion of the societal derivation of illness experience.

In addition, I will introduce physicians' perspectives of chronic illness by incorporating ideas from Dr. Howard Spiro, a Yale gastroenterologist. He stressed the importance of empathizing with those with chronic illnesses rather than ignoring, shaming, or exploiting them for a distinct purpose. Similarly, Joseph S. Alpert and Stephen M. Wittenberg explain the history of empathy in healthcare as well as form guidelines on how to best care for patients. These medical theorists' ideas will support my explanation of how to best represent chronic illness in literature and how society should truly perceive and treat those with chronic illnesses.

I will also discuss how ideas of narrative medicine and empathy in healthcare can be practiced through reading fiction. I will use the work of theorists Rita Charon, Rebecca Garden, and researchers David Comer Kidd and Emanuele Castano to support my argument that fiction reading can not only improve empathy in the practice of medicine but also help children understand the experiences of other children with chronic illnesses.

Overall, I aim to incorporate these theories throughout my description, critique, praise, and suggestions for illness representation and perception in *House of Robots*, *The Fault in Our Stars*, and other illness narratives in modern American literature and society. In my first chapter, I will address how John Green depicts social stereotypes of illness experience and the romanticizing of illness in *The Fault in Our Stars*. I will rely specifically on feminist theory and disability theory in this chapter to support my arguments. My second chapter will connect *House of Robots* with *The Fault in Our Stars* and compare their associations of illness with identity and depictions of gendered forms of illness experience. However, I will focus on the description of the character Maddie in *House of Robots* in my second chapter. Once again, I will utilize both

disability and feminist theory to demonstrate the validity of my arguments. My third chapter will introduce the ideas of narrative medicine and assert that these ideas are applicable for fiction reading. In other words, fiction reading can increase awareness of illness experience for healthy readers, provide bibliotherapy for chronically ill readers, and help inform doctors on how to best treat their chronically ill patients with empathy and understanding. My goal in this project is to promote reading fiction about chronic illness in order to improve the inclusion of chronic illness experiences and even chronically ill people themselves in society.

Chapter 1: *The Fault in Our Stars* and the depiction of young adult cancer experiences

In his author's note to *The Fault in Our Stars*, John Green emphasizes that the novel is a work of fiction and that "neither novels nor their readers benefit from attempts to divine whether any facts hide inside a story" (Green Author's Note). This statement may mean that Green does not want readers to believe the story he has told is real. Nonetheless, he also claims that "made-up stories can matter" (Green Author's Note). If fictional stories hold importance, then they are influencing readers. Therefore, their contents should not only be appreciated for their artistic value but should also be analyzed for their influence on society. Green himself admits to perpetuating tropes of illness while simultaneously attempting to deconstruct them. He read Susan Sontag's *Illness as Metaphor* while writing *The Fault in Our Stars*, and he says that "her work definitely shapes the way I think about illness (and metaphor)" (Green FAQ). However, Sontag criticized many of the representations of illness that Green perpetuates. Moreover, Green claims that he "wanted Gus and Hazel to be people, just regular nice smart people, who also happen to have a chronic illness," yet in much of the novel, he identifies his characters as their illnesses (Green FAQ). Green's actions do not align with his intentions. In this chapter, I question how Green's utilization of illness tropes in *The Fault in Our Stars*, such as his figurative use of chronic illness, his depiction of the ill character as a hero or a victim, and his gendering of chronic illness, affect the way readers will perceive chronically ill people in real-life society.

In *The Fault in Our Stars*, the two ill characters, Hazel Grace Lancaster and Augustus Waters, both have cancer: Hazel's metastatic thyroid cancer is incurable yet controlled, while Augustus's osteosarcoma is in remission. This means that although Hazel's cancer has spread throughout her entire body, especially in her lungs, her cancer is not progressing. Treatment

appears to have cured Augustus's cancer, but doctors continue to monitor him for potential relapses. They first meet each other at a Cancer Support Group. Hazel believes she cannot become romantically involved with Augustus because she will break his heart when she dies. Hazel claims that she is "a grenade and at some point [she's] going to blow up and [she] would like to minimize the casualties" (Green 99). Nevertheless, Augustus refuses to stay away from Hazel, and they ultimately fall in love. Then, in a devastating turn of events, Augustus's cancer returns, and he passes away. At Augustus's prefuneral (which he organized because he wants to attend his own funeral), Hazel describes their love as "star-crossed" (Green 259). Because of their simultaneous terminal cancer diagnoses, Hazel acknowledges the unfortunate reality that their love will end in heartbreak from one of them passing away from the illness.

According to David Mitchell and Sharon Snyder in their essay "Narrative Prosthesis," authors often depict chronic illness to further the progression of a story rather than represent illness for its own sake. This removes value of ill people for their personalities and prevents development of dynamic characters with dimension. It also promotes the idea that ill people in reality are nothing more than their illnesses. Green utilizes the depiction of chronic illness in this manner in *The Fault in Our Stars*. For example, Augustus's relapse propels the plot of the novel; without the worsening of his cancer, the story would remain stagnant and have no other mode of progression. By attempting to subvert chronic illness tropes while simultaneously adopting said tropes and using illness to forward the plot, *The Fault in Our Stars* does what Mitchell and Snyder would call "inevitably punish[ing] its own prurient interests by overseeing the extermination of the object of its fascination" (Mitchell and Snyder 229). Green's use of illness tropes detracts from the positive examples of illness experience that he attempts to convey.

Moreover, illness's purpose in the story is to drive the entire story rather than exist on its own as an additional component of the characters.

Unlike most popular illness novels in which a healthy protagonist narrates and the ill character is secondary, Green's novel is unusual because the narrator is not only ill but also is female. Readers learn how Hazel views her illness experience through her own words, thoughts, and actions. In addition, Augustus is a very expressive character and open with Hazel, so readers see through Hazel's perspective how he experiences his cancer diagnoses. Green skillfully allows readers to enter the mind of someone who is chronically ill. He also consulted a teenage girl with thyroid cancer named Esther Earl before writing the novel and attempts to describe the thoughts and feelings of Hazel based on Esther's experiences. However, it is important to remember that Green is still a healthy male author writing from the perspective of a chronically ill teenage girl. Although a writer does not necessarily need to have the same experiences as his or her protagonist to write authentically, research about the protagonist's experiences can inform the way he or she writes. However, Green's writing may not completely represent a chronically ill teenage girl's experience.

The most poignant, overarching stereotype of chronic illness in this novel is Green's romanticizing of illness with its two main characters. The plot of romance between Hazel and Augustus is problematic because it gives readers the idea that illness is romantic and potentially even a desirable trait that melds with personality. Illness in the novel is romantic because illness sparks Augustus and Hazel's meeting and ultimately results in their falling in love. The novel is almost solely about romance and illness experience, and as a result, most young readers will associate the two due to their proximity and importance in the novel. In *Illness as Metaphor*, Susan Sontag discusses both tuberculosis and cancer as illnesses that are often detrimentally

metaphorized. Society describes cancer and tuberculosis with different metaphors and characterizations. For example, Sontag explains that tuberculosis is “thought to produce spells of euphoria, increased appetite, [and] exacerbated sexual desire” (Sontag 13). On the other hand, people consider cancer to be more internal and less explosive in energy. Although cancer is a form of growth—even called a “demonic pregnancy”—and tuberculosis resembles decay, cancer still appears to remove the energy of those who are sick while tuberculosis energizes (Sontag 14). Nonetheless, Sontag contends that “the most striking similarity between the myths of TB and cancer is that both are, or were, understood as diseases of passion” (Sontag 20). The term “passion” derives from the Late Latin root *passio*, which means suffering. It is interesting to note that the term “passion” has a connotation of romance in American society. Illness inherently involves suffering, as does love. Thus, illness and romance connect through the idea of suffering. Sontag acknowledges that many believe cancer to be “a disease of insufficient passion” while tuberculosis “come[s] from too much passion” (Sontag 21). She counters this argument with the assertion that “these seemingly opposite diagnoses are actually not so different versions of the same view” (Sontag 21). Sontag explains that tuberculosis also is sometimes “regarded as a disease of repression” (Sontag 21). In addition, she believes that people believe cancer is caused by a “repression of feeling” (Sontag 22). Like Sontag, I argue that both diseases can relate to repression and expression of passion. Thus, passion is at the core of cancer in *The Fault in Our Stars*. Rather than viewing cancer as only illness, cancer in this novel is a reason for expression of passion through romance.

Moreover, Augustus and Hazel’s romance exists because of their illnesses. The first instance of cancer’s association with their romance occurs when Hazel and Augustus meet at a Cancer Support Group. Their illnesses link them and provide them with the opportunity to

become romantic. Without their illnesses, Hazel and Augustus not only would have never fallen in love with each other but also would never have met.

Hazel falls in love with Augustus partly because she sees him as healthy and strong even in the face of his diagnosis. The first depiction of Augustus the reader gets is one of strength and size. When Hazel meets Augustus, her first impression of him is that he's "long and leanly muscular...he dwarfed the molded plastic elementary school chair he was sitting in" (Green 8-9). These descriptions of Augustus continue throughout the novel, just in a subtler way; Hazel slips in that she sees Augustus's "shoulders fill[ing] out his green knit polo shirt, his back straight" (Green 17). Later in the novel, Hazel states, "You could glance at Gus and never know he'd been sick" (Green 146). He appears healthier and stronger than he actually is.

On the other hand, Augustus only notices Hazel's existence because she looks like his ex-girlfriend who had cancer, Caroline Mathers; he admits that when he sees Hazel for the first time, he thought he "saw Caroline Mathers's ghost in Support Group" (Green 176). It is important to take a moment to analyze why Augustus may be attracted to women who have cancer. Although Augustus is partially drawn to Hazel because of her unique existential beliefs that developed as a result of her cancer, it seems as if his main reason for falling for her is because of her appearance: she looks sick, just as his ex-girlfriend looked sick. Hazel is as sick as she seems, while Augustus's illness is hidden physically other than his prosthetic leg. Augustus's attraction to women with cancer may result from a belief that they share his own experience. As I will discuss later, many chronically ill people feel isolated from the healthy members of society. They feel as if they are noticeably Other. Perhaps when Augustus meets someone who can identify as Other like himself, he immediately believes he can relate to them, and this identification morphs quickly into a connection and then into attraction.

Green also employs the trope of the ill character as perfect, specifically for Augustus, ignoring any or all other character traits other than the positive. Green commonly portrays Augustus as flawless, as discussed above, and it begins with the first moment he introduces Augustus's character. Green immediately describes Augustus with his favorable physical and mental characteristics. When Hazel first meets him, she emphasizes his muscular body and blatantly states, "he was hot" (Green 9). In addition, Augustus's eyes are so perfect that they are super-human: "You could almost see through his eyes they were so blue" (Green 12). Hazel defines his first smile at her as "the little crooked smile of the boy trying to be sexy while he stared at me" (Green 13). Augustus is immediately depicted as a romantic character, an ideal teenage man with whom readers would want to fall in love. Moreover, the reader knows immediately that Augustus will be the love interest of the novel when he says to Hazel, "Goddamn... Aren't you something else?" (Green 13). Augustus's blatant and articulate admirations of Hazel continue to escalate. When Hazel asks Augustus why he stares at her, he explains, "Because you're beautiful. I enjoy looking at beautiful people, and I decided a while ago not to deny myself the simpler pleasures of existence" (Green 16). These statements are not those of a seventeen-year-old boy. Rather, Green depicts Augustus as more attractive, more mature, and more eloquent than the typical teenager, imbuing him with a perfection impossible to reach even far beyond his age.

However, Green depicts Hazel as perfect as well, regardless of her character and actions. Hazel's parents follow this trope when they view her. Because they are her parents, they know her the best. Yet, they still glorify her. Her father says to Hazel, "You are amazing. You can't know, sweetie, because you've never had a baby become a brilliant young reader with a side interest in horrible television shows, but the joy you bring us is so much greater than the sadness

we feel about your illness” (Green 103). From an objective standpoint, none of the characteristics that Hazel’s father lists would make Hazel outstanding, perfect, or more than an average teenager. That is understandable, as most ill people are just people. Her parents demonstrate that Hazel still deserves love regardless of her achievements or illness. They appreciate her for her unique self. However, their adoration also can signify that because of Hazel’s illness, her characteristics of an ordinary person become extraordinary, only because she still possesses them while being ill. In other words, Hazel’s characteristics are outstanding only because she is sick. If Hazel were healthy, her parents may not view her character traits with as much admiration.

Green also often conflates illness with identity, which is what healthcare professionals and philosophers emphasize as the most damaging for chronically ill individuals. Susan Sontag asserts best that “in cancer, non-intelligent ('primitive,' 'embryonic,' 'atavistic') cells are multiplying, and you are being replaced by the non-you" (Sontag 67). Green conflates the “you” and the “non-you,” problematically combining illness and identity. Illness is not who someone is; it is part of them, yes, but not all-encompassing. Sontag simultaneously critiques the idea of representing cancer as something foreign inside a person as well as equating a person with cancer completely. Consequently, the healthiest way to think about cancer would be as a part of someone’s identity and formative of their experiences and perception of the world but that person also has unique attributes and characteristics that are inherent to their being, separate from their diagnosis.

Nonetheless, all of the characters in the novel, both ill and healthy, view illness as identity. For example, Green portrays a minor ill character, so minor we do not even learn about her until she is already dead, negatively. Green may give her such an unpleasant personality

because she is Hazel's romantic rival: Augustus's ex-girlfriend, Caroline Mathers. Caroline suffered from brain cancer, which often alters people's personalities. However, Augustus does not view her with any empathy as a result of her involuntary personality change. Augustus identifies Caroline completely with her cancer: "they were inseparable, she and the tumor" (Green 175). Augustus says Caroline had the "Asshole Tumor" type of brain cancer, and Augustus crudely asserts, "she was a bitch" (Green 174). Augustus lists ways in which Caroline was cruel to him and how he wished to leave her. He explains that he had to stay with her because "you can't dump a girl with a brain tumor" (Green 175). One would believe that, as a sufferer from cancer himself, Augustus would empathize more with Caroline. However, Augustus cannot accept the possibility that Caroline's innate personality differs from the one he witnessed as a result of the tumor: "...it was the tumor. It ate her brain, you know? Or it wasn't the tumor. I have no way of knowing" (Green 175). He blames *her* for her behavior rather than her illness.

All the reader learns about Caroline comes through Augustus's voice and through a brief scene where Hazel reads condolences on Caroline's Facebook page. The reader never knows how Caroline felt about her illness. She has passed away before the events of the novel begin, and there are never any instances where Green employs her voice or opinions. In addition, the reader does not know if Caroline was actually cruel or if the tumor "ate her brain," as Augustus crudely describes (Green 175). Green dehumanizes Caroline in this description and identifies completely with her illness.

In *Illness as Metaphor*, Sontag criticizes this representation of illness by delineating the change in its historical representation: "the notion that the disease fits the patients' character, as the punishment fits the sinner, was replaced by the notion that it expresses character" (Sontag

43). Sontag asserts that the public sees illness as an exhibition of personality, and this exhibition is highly problematic for many reasons. The main problem with this view of illness is that anyone can become ill—anyone can develop cancer, not just Caroline Mathers—regardless of their innate personality. Therefore, Caroline Mathers’s brain cancer should not be viewed as a reflection of her character. Green depicts Caroline negatively so Augustus can acceptably move on from his ex-girlfriend with cancer and date someone else, who also happens to have cancer. Once again, illness serves the plot of the novel as Mitchell and Snyder describe in “Narrative Prosthesis.”

As discussed previously, Augustus focuses more on blaming Caroline for her treatment of him than empathizing with her suffering. He even seems to believe her illness and her behavior toward Augustus are her own fault. Green once again portrays the normalized conception of illness that Sontag criticizes: "With the modern diseases (once TB, now cancer), the romantic idea that the disease expresses the character is invariably extended to assert that the character causes the disease—because it has not expressed itself. Passion moves inward, striking and blighting the deepest cellular recesses" (Sontag 46). In other words, Augustus believes that Caroline’s personality caused her illness. Therefore, if her illness causes her to behave cruelly, the illness is simply reflecting character traits that Caroline already possessed.

Similarly, once Augustus relapses and his cancer becomes metastatic, every character begins to see him as only his cancer, including Augustus himself. Although Augustus does not admit to applying his cancer to his identity in the same way he does for Caroline, Green’s depiction of Augustus supports this contention. When he reveals his relapse to Hazel, he says, “My cancer is me. The tumors are made of me. They’re made of me as surely as my brain and my heart are made of me” (Green 216). When he passes away, Hazel reemphasizes his illness as

his identity: “Augustus Waters died eight days after his prefuneral, at Memorial, in the ICU, when the cancer, which was made of him, finally stopped his heart, which was also made of him” (Green 261). As Augustus becomes sicker and sicker, both Hazel and Augustus increasingly view him as cancer rather than as the person he was before his relapse. They conflate his illness with his identity, sadly until the day he passes away. This transformation in the view of Augustus supports the idea that physical demonstrations of illness are considered weaknesses. When Augustus appears healthy even though he is not, Hazel sees him as strong. When his illness becomes more physically evident, Hazel not only acknowledges but also focuses on Augustus’s weakness. Thus, the visualization of illness goes hand in hand with identity: Augustus’s strength and Hazel’s perception of his strength change due to the way he appears to be ill.

This evidence demonstrates a change in Augustus’s view of illness; in the beginning of the novel, Augustus discusses his hatred of illness as identity. Hazel cannot think of anything to tell Augustus about herself except her cancer, an example of her illness encompassing her. Augustus responds, ““Don’t tell me you’re one of those people who becomes their disease. I know so many people like that. It’s disheartening”” (Green 32). However, Augustus sees Caroline as her illness and then sees himself as his illness as well. If the intent of writing this scene was to reject the illness as identity trope, Green fails to do so and even embraces this trope in his conclusion to the novel and in his depiction of Caroline Mathers.

Green also follows stereotypes regarding gender and illness. In *The Portrayal of Male and Female Characters with Chronic Illnesses in Children's Realistic Fiction, 1970-1994*, Chris Saad analyzed fifty-four books and interviewed readers about children’s fiction. After qualitative and statistical analysis, Saad found that statistically, authors depict female ill characters in

children's books as weaker than their male counterparts. He attributes this difference to "the traditional societal view that female bodies are inherently pathological" (Saad). In other words, society perpetuates the false notion that females have weaker bodies more prone to illness than men's bodies. Saad explains that his "study demonstrates that illness and femaleness are portrayed as synonymous in children's literature" (Saad). In her work *Extraordinary Bodies*, Rosemarie Garland-Thomson confirms Saad's findings, stating that "the discursive equation of femaleness with disability is common" (Garland-Thomson 19). Thus, females in young adult and children's fiction, such as Hazel in *The Fault in Our Stars*, demonstrate the societal standards for women as the weaker and sicker gender.

The femininity of illness can be deconstructed through Judith Butler's gender theory from her book *Gender Trouble*. Butler discusses how women (and men) often perform their genders:

Such acts, gestures, enactments, generally construed, are *performative* in the sense that the essence or identity that they otherwise purport to express are *fabrications* manufactured and sustained through corporeal signs and other discursive means. That the gendered body is performative suggests that it has no ontological status apart from the various acts which constitute its reality. This also suggests that if reality is fabricated as an interior essence, that very interiority is an effect and function of a decidedly public and social discourse. (Butler 119)

Based on Butler's assertion, authors of children's literature that follow gendered stereotypes reinforce the performative behavior of gender that is a result of societal influence. The performance of gender in *The Fault in Our Stars* reflects that of performing a form of what I would like to call *gendered illness*. For example, Augustus's bravado and stereotypically masculine physical characteristics indicate Green's creation of Augustus's gendered illness

performance. This performance begins before Augustus relapses. He introduces Hazel to a stereotypical “boy movie,” one full of action “very hot” women, when he first invites her to his house (Green 35). When he tells Hazel his cancer has returned and it is metastatic, Hazel begins to cry. However, she says that “even then [Augustus] was strong, holding me so tight so that I could see the sinewy muscles of his arms” (Green 215). Even though Augustus is sicker than Hazel at this point in the novel, he still hides his illness through gendered descriptions of his strength, compared to Hazel’s weakness. Although Augustus’s cancer returns, he hides his physical illness symptoms until the end of the novel, demonstrating how he performs the male gender roles of health and bravery and avoids the gender performance for females as the weaker gender.

Similarly, Green writes Hazel as a character who clearly demonstrates the performative nature of gendered illness that society imposes upon her. Hazel sees herself as much less attractive than Augustus, weaker, and a “grenade” or a burden rather than just a person with an illness (Green 99). It is interesting to note the contrast in the description of Augustus with the preliminary physical description of Hazel. When Augustus and Hazel first meet, Hazel says she becomes “conscious of [her] myriad insufficiencies” and immediately launches into a discussion of negative aspects of her physical appearance: “I had this pageboy haircut...Furthermore, I had ridiculously fat chipmunk cheeks, a side effect of treatment. I looked like a normally proportioned person with a balloon for a head” (Green 9). While Green describes Augustus as handsome and strong, he writes about Hazel in a much more negative physical light and as much weaker than Augustus. In addition, the description of Hazel as less attractive than Augustus follows “the judgment that the disabled woman's body is asexual and unfeminine” that Garland-

Thomson critiques in her work (Garland-Thomson 25). In all regards, Hazel performs the gender role of females as the weaker, less attractive, and sicker gender, specifically when they are ill.

In his essay “Disability and the Theory of Complex Embodiment,” Tobin Siebers explains that illness not only separates the ill from the healthy but also highlights a difference in status. Siebers asserts that societal “thinking is steeped in ideology” (Siebers 279). He calls this ideology *the ideology of ability* and defines it as “at its simplest the preference for able-bodiedness” (Siebers 279). In other words, society subconsciously desires to “perfect the body,” and this desire inherently denigrates those who have non-perfect bodies, especially if their bodies do not function in the way the average human body does (Siebers 278). Therefore, when non-disabled people view disabled bodies, they consciously or subconsciously identify them as the opposite of society’s goal of perfection, of able-bodiedness.

Rüdiger Kunow also addresses the ideology of ability in his book *Material Bodies: Biology and Culture in the United States*. In his section titled “Exception Incorporated: Disability as Inscription of Cultural Otherness,” he explains how disability inherently contradicts the ideals of society: health and able-bodiedness. Kunow explains that “‘Disability’ names a state of exception...from the usual shape and form of human embodiment, from the functional expectations or obligations associated with being a useful, namely able-bodied member of society” (Kunow 270). Moreover, because of the physicality of chronic illness, the resulting “disability—regardless of shape, form, or definition—is almost always also a highly visible difference” to those who are not disabled (Kunow 268). According to Kunow, this difference “tends to relegate other commonly used identifiers such as height, weight, clothing, etc. to secondary status,” causing the public to focus more on what is different about those with disability than innate characteristics of disabled people (Kunow 268).

Regardless of Green's intention, his novel highlights the physical distinction of illness and the resulting stigma and shame that ill people feel on a daily basis. In the beginning of the novel, Hazel spends time with her old friend from before her diagnosis, Kaitlyn. Kaitlyn is kind to Hazel. However, while shopping for shoes, she examines a pair of heels and says, "Is it even possible to walk in these? I mean, I would just *die*—" and then just stopped short, looking at [Hazel] as if to say *I'm sorry*, as if it were a crime to mention death to the dying" (Green 44). After leaving Kaitlyn, Hazel reflects on the fact that her friend feels as if she has to carefully choose her words around Hazel: "Any attempts to feign normal social interactions were just depressing because it was so glaringly obvious that everyone I spoke to for the rest of my life would feel awkward and self-conscious around me" (Green 47). Hazel feels as if her illness differentiates her from the healthy people around her, eliciting both their pity and their inability to relate to her as they could before. In her revered work *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, Rosemarie Garland-Thomson's assertions about visible disability can be applied here to Kaitlyn's response to Hazel in terms of the normate, or the person deemed 'normal' by society, compared to the disabled or ill person:

When one person has a visible disability, however, it almost always dominates and skews the normate's process of sorting out perceptions and forming a reaction. The interaction is usually strained because the nondisabled person may feel fear, pity, fascination, repulsion, or merely surprise, none of which is expressible according to social protocol. Besides the discomforting dissonance between experienced and expressed reaction, a nondisabled person often does not know how to act toward a disabled person: how or whether to offer assistance; whether to acknowledge the disability; what words, gestures, or expectations to use or avoid. (Garland-Thomson 12)

Kaitlyn clearly expresses the dissonance that Garland-Thomson describes, and as a result, she unintentionally separates herself from Hazel. Hazel's cancer results in her isolation from the healthy.

In addition, while Hazel, Augustus, and Hazel's mother wait in the airport for their flight to Amsterdam to meet Hazel's favorite author, Hazel keenly acknowledges the physical indications of her illness—her oxygen tank and nasal cannula—as well as Augustus's prosthetic leg due to his own cancer:

I could feel everybody watching us, wondering what was wrong with us, and whether it would kill us, and how heroic my mom must be, and everything else. That was the worst part about having cancer, sometimes: the physical evidence of disease separates you from other people. We were irreconcilably other, and never was it more obvious than when the three of us walked through the empty plane, the stewardess nodding sympathetically and gesturing us toward our row in the distant back. (Green 144)

By emphasizing Hazel's physical differences from other people, Green confirms that society separates the ill from the 'normal.' This scene also parallels one in history, in which African American people were forced to sit in the back of buses during the era of American segregation. In both cases, those considered distinct from the rest of society are physically removed from the rest of the population. Professors David Mitchell and Sharon Snyder would call Green's decision to describe this separation a mode of "identifying people with disabilities as a disenfranchised cultural constituency" (Mitchell and Snyder 228). Moreover, Green's depiction of Hazel as "unlike" other people and characters in the novel obeys the disability stereotype that disabled

bodies differ from able bodies in their “breakdown and abnormality” (Mitchell and Snyder, 228, 230).

Similarly, Augustus’s portrayal in the beginning of the novel as healthy and strong emphasizes how the public treats visible illnesses and invisible illnesses differently. While in the airport and contemplating her physical state, Hazel contrasts herself with Augustus. The general population does not perceive Augustus in the same way they perceive Hazel because the physicality of his illness is less noticeable. Unless someone was to look at his leg, they would “never know he’d been sick” (Green 146). Even so, he still appears to be able-bodied, at least more so than Hazel, because he walks around with little difficulty due to the prosthetic. On the other hand, Hazel has clearly visible breathing tubes, an oxygen tank, and other physical symptoms of her cancer treatment such as her puffy cheeks and short hair that distinguish her as disabled to the public. Thus, Green demonstrates how the physicality of certain illnesses results in different treatment by society and even different treatment by other ill people. Hazel even says that she ““didn’t want to care about [Augustus’s prosthetic leg], but I did a little. He probably cared about my oxygen. Illness repulses”” (Green 36). Although those close to Hazel do not appear to be repulsed by her, strangers in public often stare at her and avoid her because she differs from them, from the healthy. Moreover, in Augustus’s case, he exemplifies the pressure to “pass for normal” due to his lack of many physical demonstrations of his illness (Wendell 164).

Susan Wendell explains the reasoning behind the social view of illness in her article “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities.” First, it is important to acknowledge that Wendell defines chronic illnesses as “patient-centered or illness-centered rather than based on diagnosis or disease classification” and as “illnesses that do not go away by

themselves within six months, that cannot be reliably cured" (Wendell 163). She also names them "unhealthy disabilities." This definition contrasts with her definition of the "healthy disabled" discussed in my introduction. In her article, Wendell explains that the "fear of disability contributes to the social stigma of being disabled" (Wendell 171). Because people often do not understand Hazel's condition without experiencing it themselves, they are afraid of what they do not know. As Siebers also elaborates, "The level of literacy about disability is so low as to be nonexistent, and the ideology of ability is so much a part of every action, thought, judgment, and intention that its hold on us is difficult to root out" (Siebers 280). Similarly, people fear unhealthy disability because of the implications of illness: suffering. Wendell asserts that "illness is not by definition an evil, but people fear and try to avoid illness because of the suffering it causes" (Wendell 171). Illness becomes associated with suffering, which becomes associated with a tendency to avoid suffering. This avoidance of illness combined with illness's conflation with identity leads to the avoidance of ill people.

While illness isolates the sick from the rest of society, it also brings those who are ill closer together. This closeness can lead to the metaphorization and romanticizing of illness through platonic, familial, and romantic relationships. Green romanticizes illness in this novel in the form of metaphors. Susan Sontag explains best in her book *Illness as Metaphor* that metaphorical thinking about illness is detrimental: "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 the one most purified of, most resistant to, metaphoric thinking" (Sontag 3). Describing illness with metaphors damages the mental state of ill people, yet Green constantly uses illness metaphors in *The Fault in Our Stars*.

Green adopts one of the most infuriating metaphors for chronically ill people: the war metaphor. Sontag asserts that “the controlling metaphors in descriptions of cancer, in fact, are drawn not from economics but from the language of warfare: every physician and every attentive patient is familiar with, if perhaps inured to, this military terminology” (Sontag 64). Therefore, not only does Green utilize metaphors for illness, he also uses the most common metaphor for cancer. The reason that this metaphor upsets those with cancer is that it labels cancer as “the enemy on which society wages war” (Sontag 66). Thus, those with cancer are pinned against those without cancer in society, on the side of the battle that society wants to destroy. Moreover, Sontag explains that with cancer and other “modern diseases, the scapegoat is not so easily separated from the patient” (Sontag 71). The public blames people with cancer for the disease’s existence and its effect on healthy society. The war metaphor ostracizes cancer patients and puts them in opposition to the society to which they belong. They are forced to “fight” a “battle” they may not want to fight.

Green describes both Hazel and Augustus, along with other ill minor characters, as fighting a battle against their illness in the novel. Even other ill people in the novel use this metaphor. For example, in the Cancer Support Group, one of the members in remission, Lida, employs the metaphor twice. When a twelve-year-old boy passes away from leukemia, she says “he’d fought hard” (Green 129). The second time she uses it to talk about Hazel at Cancer Support Group: “She just keeps fighting the battle, waking up every morning and going to war without complaint” (Green 131). Augustus describes his own cancer as a battle: “I don’t even get a battle. I don’t get a fight...It is a civil war, Hazel Grace, with a predetermined winner” (Green 216). Hazel, who admits that she “hated when people tried to build [her] up to prepare for

battle,” contradictorily uses this metaphor. When trying to comfort Augustus, she says, ““You’ll keep fighting”” (Green 216).

Healthcare professionals and other characters throughout the novel employ this metaphor as well. After Hazel rates her pain level in the hospital, a nurse says to Hazel, ““You know how I know you’re a fighter? You called a ten a nine”” (Green 263). On Caroline Mathers’s Facebook page, someone posted, “It feels like we were all wounded in your battle, Caroline” (Green 97). Green depicts Caroline as a cancer patient with a negative personality and not as a fighter, a characterization that is completely opposite to that of Hazel. However, Hazel fears that her illness and eventual death may have the same effect as Caroline’s death: it will hurt other people.

Hazel creates her own personal war metaphor as well: the grenade, in which she essentially calls herself a bomb that is going to blow up everyone around her emotionally when she passes away from cancer. She reasons that she should push Augustus away because of her status as a grenade, although this attempt ultimately fails.

Similarly, Green’s choice to make Hazel’s lung cancer incurable parallels her description of herself as a grenade. She believes that she cannot love anyone or let anyone other than her parents love her due to her cancer. Her degradation of her worth due to her illness demonstrates how Green follows the socially constructed idea that “cure is thought to depend principally on the patient's already sorely tested or enfeebled capacity for self-love” (Sontag 47). Hazel believes she should not be loved except by her parents, and as a result she has low self-esteem due to her illness. Following Sontag’s assertion, the fact that her cancer is incurable matches this depiction.

The war metaphor connects to the metaphor of an ill person as a hero, or the victor of the battle against cancer. Green falls into this trope of an ill person considered as a hero of their illness. Green portrays Augustus as the hero of the novel. The first glimpse at Augustus’s desire

to be a hero appears when he plays video games at his friend Isaac's house. Augustus abandons the true mission of the video game and sacrifices his character in order to save the "fictional schoolchildren" (Green 58). The video game states that he failed the mission, but Augustus feels triumphant because he saved the virtual children. He tells Hazel that his "life bought them a minute" (Green 59). Hazel does not understand his motives at first, but then she realizes "he believed the game might be really real" (Green 59-60). Augustus aspires to do something large in the real world, to make a grand sacrifice, in order to become a hero.

Similarly, when Augustus flies to Amsterdam, he is "downright *joyful*" while watching the movie *300* on the plane, which is about the death of hundreds of Spartans in a battle against Persians (Green 151). This movie choice perpetuates the war metaphor previously discussed. In addition, Augustus explains to Hazel that he enjoys the movie because it is "awash in the nobility of sacrifice" (Green 151). Once again, Augustus believes that sacrifice results in heroism and that his role in the world is to be a hero. Augustus believes his life has meaning only if he becomes a hero, and his heroism will occur in the way in which he dies. When he becomes weaker after his relapse diagnosis, Augustus is upset about his lack of heroism in the form that he wants it to appear. He wants society to recognize him: "I always thought my obituary would be in all the newspapers, that I'd have a story worth telling. I always had this secret suspicion that I was special" (Green 240). Augustus always wants the public to deem him a hero and does not believe he has fulfilled this goal. Hazel confesses near the end of Augustus's life that she hopes to help him "rid himself of this fear that his life had been lived and lost for no greater good" (Green 237). She wants to help Augustus believe that he was a hero.

In disability studies, the idea of the hero is commonly critiqued because of its effect on those who are disabled. In "Overcoming the Overcoming Story: A case of "compulsory

heroism,” Beth DeVolder discusses how heroism supports “the construction of the ‘normal’” (DeVolder). In fiction novels, making the ill or disabled character a hero once again demonstrates that they are different from the non-disabled characters in the novel. It isolates the disabled from the “normal” members of society and “strips persons of their individuality” (DeVolder). In other words, the heroism of an ill character obscures their other positive characteristics and ostracizes them from the majority.

Green himself confirmed that he intended to portray Augustus as the hero Augustus wanted to be. In the FAQ portion of John Green’s website, Green writes, “Yes, I think Gus is a hero” (Green). Even Augustus’s name supports the war and hero metaphors surrounding his character. According to John Green himself in his FAQ, Green chose Augustus’s name to be that of the first Roman Emperor, known as Augustus or Octavian. Augustus the Emperor was known for his military successes as well as for bringing about an era of peace called Pax Romana (Britannica). In other words, he was skilled at both war and peace. It makes sense that Green would choose to have Augustus Waters’s name relate to a war hero; he is fighting his own metaphorical battle against cancer. However, it is interesting that Green chose his name to represent both war and peace. It may demonstrate how at the end of his cancer treatment, there is a resolution that results in a sort of peace or resolution, an ending of the battle against cancer.

No matter how much both Augustus (and Green) wished it, Augustus is not admired as a hero by all of society. Augustus has not actually done anything heroic except *fight* cancer. Although having cancer and going through rounds and rounds of difficult treatment is admirable and demonstrative of profound strength and resilience, it does not make someone a hero, and many cancer patients do not want society to view them as such. As Paul Longmore explains in his article "Disability, Life Narrative, and Representation," unlike Augustus, ill people often do

not want to have to live up to expectations of heroism and superior strength, “to conform to, and thus confirm, a cultural script” (Longmore 458). By insisting upon Augustus’s heroism in such a widely-read novel, Green perpetuates the cultural pressure of the heroism narrative for those with chronic illnesses.

Green attempts to surpass illness tropes in the conclusion to *The Fault in Our Stars* yet still follows a path of illness narrative that Susan Sontag identifies in *Illness as Metaphor*. Sontag claims that often in literature, “...the person dying of cancer is portrayed as robbed of all capacities of self-transcendence, humiliated by fear and agony” (Sontag 17). This description exactly parallels Green’s representation of Augustus near the end of his life. It can be contested that Green attempts to depict a more accurate representation of death, rather than a romantic one in this case; however, he still follows the societal assumptions of illness as a metaphor because of the extreme transition in Augustus’s personality. Just as with Caroline Mathers, Augustus becomes his illness and exemplifies the exact mode of dying of cancer that Sontag critiques. It is interesting that Augustus is in fact sicker than Hazel, even though he was originally portrayed as healthier and stronger. Green’s intention to represent the way people sometimes pass away from cancer counters his idea of Augustus’s physical and mental strength that perpetuates the rest of the novel. In other words, Green’s depiction of Augustus completely changes at the end of Augustus’s life to represent the more negative aspects of cancer experience although this change in depiction contradicts every previous description of Augustus as strong and healthy.

When Green first labels Augustus as “late-stage,” or in an advanced stage of his cancer, Hazel mentions that he “puked up breakfast” and is “no longer the muscular, gorgeous boy who stared at” Hazel when they first met (Green 234). His shoulder is now “bony” and he is in a wheelchair, unable to walk for long on his own (Green 237). However, this is not nearly as

“robbed of all capacities” and “humiliated” as Augustus becomes (Sontag 17). Hazel visits Augustus at home one day and discovers “he’d pissed the bed” (Green 239). After the cleanup, Augustus demonstrates what Sontag describes in her book. He says, ““With each passing minute, I’m developing a deeper appreciation of the word *mortified*”” (Green 240). Augustus is ashamed and completely humiliated by the physical effects of his illness.

The critical point of Augustus’s transformation from confident, suave hero to “humiliated by fear and agony” comes when he pulls out his own medical device, a gastrostomy tube that provides Augustus with nutrients directly into his stomach, after driving to a gas station (Sontag 17). When Hazel meets him there, she calls an ambulance immediately. In this moment, she realizes, “The Augustus Waters of the crooked smiles and unsmoked cigarettes was gone, replaced by this desperate humiliated creature sitting there beneath me” (Green 245). Hazel acknowledges that Augustus’s decline does not follow the standard illness trope. Rather, Green adopts the narrative Sontag identified. Near the end of the novel, Hazel describes Augustus’s decline:

According to the conventions of the genre, Augustus Waters kept his sense of humor till the end, did not for a moment waiver in his courage, and his spirit soared like an indomitable eagle until the world itself could not contain his joyous soul. But this was the truth, a pitiful boy who desperately wanted not to be pitiful, screaming and crying, poisoned by an infected G-tube that kept him alive, but not alive enough. (Green 245)

In this very moment, although Augustus does not follow the “conventions” that Hazel criticizes, he does adhere to the trope for cancer (Green 245). He morphs from the strong, healthy, romanticized hero into the weak, humiliated cancer victim Sontag described.

John Green decided to write *The Fault in Our Stars* after meeting a young girl with metastatic thyroid cancer. Her name was Esther Earl. Esther passed away from her illness, and Green wrote *The Fault in Our Stars* in her honor, to recognize her memory and to teach the world about her experience as a teenager with cancer. Green's motivations for writing this novel are admirable and touching, and he does his best to represent as many aspects of illness experience as he can. Nonetheless, *The Fault in Our Stars* inadvertently contains illness stereotypes that can influence young readers to perceive illness in a damaging light. Moreover, the novel's popularity proves that chronic illness narratives can have a major impact on the way the public views chronic illness. Although Green's purpose was noble, *The Fault in Our Stars* thus requires the above critical examination in order to bring awareness to the detrimental illness stereotypes and internalizations that our society needs to overcome. There are additional young adult novels that perpetuate these same stereotypes. However, these representations are not just in the realm of young adult fiction; they are present in children's literature as well. There are a few children's novels that center on children with chronic illnesses, and one in particular is as popular for children as *The Fault in Our Stars* is for young adults: *House of Robots*, by James Patterson and Chris Grabenstein.

Chapter 2: *House of Robots*, illness identity, and a child's suppression of illness experience

Unlike *The Fault in Our Stars*, *House of Robots* immediately aligns itself with standard illness stereotypes through its narration: the main character is not the ill character. The healthy, male brother—Sammy Hayes-Rodriguez—narrates the story. However, the condition of his ill sister, Maddie, drives the plot. She has Severe Combined Immunodeficiency (SCID), an autoimmune disorder that prevents her from leaving her house for fear of catching an illness. Because her immune system is so weak, if she catches even a cold, she could die. The story centers on her mother's creation of a robot that acts as a proxy for Maddie to attend school. She speaks through the robot's mouth, watches class through the robot's eyes, and essentially experiences as much of school as she can from her own room. Nevertheless, the authors James Patterson and Chris Grabenstein hardly write about Maddie's feelings about her situation and focus instead on Sammy's interactions with the robot, who goes to school for Maddie by attending with Sammy.

There may be an implicit, gendered reason why the main healthy character is male and the ill secondary character is female. Judith Lorber and Lisa Jean Moore discuss gender disparities of illness in their book, *Gendered Bodies: Feminist Perspectives*. They address the fact that in American society, "Men's physical capabilities are, for the most part, considered superior to women's" (Lorber and Moore 3). *House of Robots*' authors reinforce this social stereotype by selecting the female sibling as the ill character and portraying the male sibling as healthy and full of life. Children reading this novel, therefore, may believe that illness and weakness are gendered and apply this incorrect belief in their daily lives, outside of fiction. For example, children may think that female children are more likely to become sick than males and treat other female children differently, even negatively, as a result.

Moreover, the specific choice of SCID as Maddie's disease is interesting in regard to gender. The authors included no citations for research on SCID in the novel, so it is unclear if they knew the modes of inheritance of the disease. The most common form of SCID follows an X-linked mode of inheritance (SCID Net). It is rarely inherited through an enzyme deficiency or an autosomal inheritance mechanism. X-linked inheritance occurs when a disease is passed down from parents to children through the X-chromosome; in other words, it is a sex-linked inheritable disease. It is much easier for an X-linked disease to be passed down to a male because males only need to inherit the gene once, as they possess only one X chromosome. A female must inherit the gene on both of her X chromosomes. For this to happen, both her mother and father must carry the gene on an X chromosome, as she inherits one chromosome from each parent. A male only has one X chromosome, so if he carries the gene, he develops the disease. Therefore, in *House of Robots*, Maddie's father must have the disease in order for Maddie to inherit it in this manner. However, he does not have the disease. One can conclude that Maddie's SCID either must result from an enzyme deficiency or is autosomal recessively inherited. If it is autosomal recessively inherited, both her father and mother must possess one copy of the SCID gene for Maddie to get the disease, which is unlikely. Thus, Maddie's inheritance of the disease has occurred in very rare circumstances. The authors may have selected this form of SCID in their novel so the female character, rather than the male character, could have the disease. In addition, if the SCID gene is autosomal recessive, both children had an equal chance of inheriting it, yet Maddie did and Sammy did not. Although I do not know the authorial intent regarding SCID, the authors still depict an ill female character and a healthy male character. This representation supports the societally imposed female inferiority and male superiority, demonstrated through an illness narrative.

Additionally, the female character cannot leave her room as a result of her illness, and the male character and male robot both possess the physical freedom to leave their home, to attend school, and to participate in outdoor activities. This difference respects a societal concept in which women stereotypically stay in the home while men freely walk throughout the world.

Lorber and Moore discuss the choice to gender illness in their book *Gendered Bodies: Feminist Perspectives*. They explain how "in Western societies, most people are persuaded to accept gender inequalities by a belief that they emerge from the body" (Lorber and Moore 2). Illnesses have a bodily component, and the body is associated biologically with sex and socially with gender. If gender relates to the body, and the body connects to illness, then people associate gender with illness. Linking gender with illness further increases the subconscious or conscious emotional toll that chronic illness takes on people, especially the young. Moreover, this association subconsciously influences young people who read gendered illness novels. They internalize the gendering of illness and act accordingly with this belief in reality. Depiction of the stereotype of the female as ill and the male as healthy can lead to negative actions and behaviors from young people toward both male and female ill people. Females will be treated as the weaker gender even more so than before, and males will also experience the effects of this categorization.

According to Lorber and Moore, it is important to know that "as bodies prone to illness and early death, as well as higher infant mortality rates and lower pain thresholds, men's [bodies] are actually more fragile than women's" (Lorber and Moore 3-4). Contrary to popular belief, males are just as likely or even more likely to fall ill than females. Therefore, due to social stereotypes of gender, if males develop an illness, they may be considered to be weak just like their supposedly weak female counterparts. This consequence maintains another negative

standard that having feminine traits is shameful for males. The connection between gender and illness damages males just as it damages females.

In addition, the robot that Maddie's mother builds to go to school for her is male, not female. Maddie's mother is very innovative, intelligent, and serves as the breadwinner in her family, all of which oppose some stereotypes of women as supposedly inferior to men. The authors aptly promote female empowerment with this change in standard roles. However, the robot's gender contradicts that message. Although Maddie is female, the healthy version of herself that can attend school—the robot—is male. Maddie's mother invented many other robots that stay in their home, and they are not all male, so it is not an issue of ability to create female robots. Maddie's mother invented a female teenage robot and a female "child-care contraption" called Nanny Nano (Patterson and Grabenstein 104). She possesses the capability to make female robots, but ultimately elects to make the robot that represents Maddie in school male. This choice to label the robot as male also perpetuates the societal standard of males as stronger and healthier than sicker, weaker females. There is no indication in the novel that Maddie chose the gender of the robot or that her mother even considered making the robot female. The robot is simply male, and no character questions this choice or discussion of it at all. If there were gender equality of illness in this novel, Sammy would be female, Maddie would be male, or the robot would be female.

Just like *House of Robots*, *The Fault in Our Stars* presents illness as a gendered condition. Augustus, although still suffering from cancer just like Hazel, appears stronger and healthier than Hazel. Similarly, Sammy is a healthier, more vibrant character than his ill sister Maddie. Similarly to what Saad determined in his critical analysis of children's fiction, both female characters in these novels embody the stereotype of the female ill character as

subordinate to the healthier male. However, unlike Maddie in *House of Robots*, Hazel narrates *The Fault in Our Stars*, and her illness is not the only one guiding the plot. In *House of Robots*, there would be no storyline without the presence of Maddie's illness. Both Hazel's and Augustus's cancer experiences drive *The Fault in Our Stars*. Hazel has the ability to express her feelings about her illness because she narrates the story. Maddie does not narrate at all. Green proves he appreciates ill characters for their inherent worth by allowing the characters to express their thoughts, emotions about their experiences, and their general lives, along with their illnesses propelling the plot. On the contrary, Patterson and Grabenstein depict Maddie solely for her illness and ignore all opportunities to bestow the female ill character with any power of narration about her experience. Although both sets of authors follow the gender stereotypes of the ill female character as weaker and sicker than the male character, Green still provides his female character with much more voice and autonomy than Patterson and Grabenstein.

Maddie's gender is not the only aspect of her illness experience in this novel that critics should call into question. As discussed above, her illness itself—or unhealthy disability—propels a plot rather than stands on its own. In their essay “Narrative Prosthesis,” David Mitchell and Sharon Snyder discuss how many stories have a “discursive dependency upon disability” (Mitchell and Snyder 225). Without disability, these stories would have no purpose for their disabled characters. In *House of Robots*, if Maddie did not have SCID, she would not be in the novel. Moreover, the novel would not even have a plot; there would be no novel. In other words, her character exists solely for her illness's purpose for the story rather than for her value as a character. This narrative prosthesis reveals not only a deficiency of characterization of Maddie but also a plot that relies heavily on illness rather than the personalities of its characters.

Readers also lack information about Maddie other than about her illness. There are no concrete details about Maddie's personality or any characteristics except that "Maddie has *the* best smile of all time," is in third grade, and has blue eyes (Patterson and Grabenstein 109). In contrast, Patterson and Grabenstein portray her family members with details unique to their personalities. Her mother, Elizabeth Hayes, is an engineering professor at Notre Dame University who invents robots. She often slips into "The Zone. Whenever she stares off into space like that, I know her high-powered brain is hard at work, running off to infinity and beyond" (Patterson and Grabenstein 42). Her father is a successful cartoonist. Both of her parents are members of Mensa. The authors even describe the parents' relationship. They play in a band together, and Sammy discusses how "they laugh a lot. I mean *all the time*. They're unbelievably silly. Mom and Dad also hug a lot, too. Like they're still dating" (Patterson and Grabenstein 52). These are just some of the many details about Maddie's parents included in the novel.

Maddie's brother Sammy narrates the novel, so readers receive direct insight into his mind and personality. Conversely, because Maddie does not narrate, readers do not know about her feelings about her illness, her inner personality, or how her mind works. Instead, Maddie's brother tells her story rather than Maddie herself. Although this choice enables readers to see how illness affects relatives, it prevents readers from understanding how Maddie copes with her illness from her own perspective.

In addition, Patterson and Grabenstein describe the robot for Maddie, Error (nicknamed E), even more than Maddie. He speaks often in the novel and has a unique tone that is expectedly robotic. However, he adopts the voice of Sammy and other students as he learns from them. He even possesses emotions. Sammy says he believes E is "kind of choking up" when he asks Sammy for more emotional support at school (Patterson and Grabenstein 23). He jokes and

laughs. E also admits to feeling left out at school because he is so different from the other students (because he is a robot). He participates in class, and he defends Sammy from bullies. Sammy discusses at one point how emotional E is: “But sometimes—like when he sighs or wiggles his eyebrows or bops out a beat with a pair of pencils—I forget that E is a robot, that his brain is just a bunch of circuit boards and wires. I even forget that he doesn’t really have a heart. Or feelings. Then again, maybe he does” (Patterson and Grabenstein 213). At the end of the novel, Sammy even refers to E as his brother.

On the other hand, Patterson and Grabenstein barely describe Maddie, and she has very little voice in the novel. The authors give Maddie even less personality and emotion than the non-human character. Thus, it is clear from the dearth of description of Maddie and the plethora of that of her family, along with the fact that Sammy is the true focus of the story, that the ill character is identified as her illness rather than appreciated for her innate personality. Rosemarie Garland-Thomson discusses in *Extraordinary Bodies* that this representation of an ill character in fiction is not uncommon. She explains that there is a “frequent assumption that a disability cancels out other qualities, reducing the complex person to a single attribute” (Garland-Thomson 12). Moreover, Maddie’s lack of narration also follows the standard “representation [that] tends to objectify disabled characters by denying them any opportunity for subjectivity or agency” (Garland-Thomson 11). Thus, Maddie’s character is a demonstration of the common depiction of ill characters in a novel.

The only details about Maddie the reader receives are those from her relatives praising her for her heroic response to her illness. Moreover, all of this praise revolves around how she comforts others rather than how she copes with her illness for herself. For example, when Maddie goes to the hospital because she is having difficulty breathing and has a high fever, she

comforts Sammy and assures him that she will be fine. He narrates, “We’re waiting for the ambulance, and I guess I look as freaked out as I feel, because Maddie just smiles and says, ‘No biggie, Sam. Don’t get your panties in a twist’” (Patterson and Grabenstein 99). Later in the novel, Sammy reflects, “Maddie always acts like her situation is no big whoop” (Patterson and Grabenstein 115). Sammy constantly emphasizes Maddie’s relaxed reaction to her SCID.

Maddie’s family admires her nonchalance. It can be inferred that she prefers to act casual about her illness to reassure her family. However, there is no indication in the novel of how she truly feels about her SCID and how she copes with it. She is never angry, sad, or remotely scared or nervous during the novel, not even during her severe illness episodes. Her family praises her only for her positive reactions to her illness. The authors ignore an opportunity to help children perceive all sides of how young people experience chronic illnesses. Instead, they (perhaps without realizing) encourage conflation of illness with identity and promote a potentially harmful perception of children with chronic illnesses.

The end of the novel is the only time when we get a glimpse into Maddie’s psyche, when Sammy’s mother explains the purpose of E:

‘E is going to school for *Maddie*. And she didn’t want to be the center of attention. You [Sammy] know Maddie...She didn’t want you to worry about E’s success or failure, because she knew you’d care too much. That’s why I couldn’t tell you what I was really trying to do.’ (Patterson and Grabenstein 307)

Rather than ask her family to support her regarding her illness, Maddie sacrifices her own desire to cope in exchange for mitigating the worries of her family, especially for her older brother. Because of the immense amount of praise surrounding Maddie, her family clearly approves of this approach to coping with illness (and so, apparently, do the novel’s authors).

The tendency of Maddie to focus on her illness's impact on others rather than on herself illustrates another common stereotype of women. In American society, historically and presently, it is common for the public to praise women for their deferral to others and their disregard of their own needs. Society labels women as maternal figures who care for others over themselves. Maddie represents this view of women by choosing to appease her family's worries rather than coping with her illness's detrimental effects.

Lorber and Moore examine an interesting dichotomy of illness experience in novels that Maddie also embodies: "The stories of people with disabilities convey mixed messages. One is that body limitations can be overcome through one's efforts and the help of other people. The other message is that body limitations become part of one's status because of the way other people see you" (Lorber and Moore 188). Maddie's mother tries to help Maddie in the former way by building the school robot; she is the only character in the novel that seems to place more importance on Maddie's illness experience than her own response to the illness. However, Maddie also attempts to surpass her "limitations"—an inability to leave the house and constant hospitalizations—by reassuring others that she is unconcerned and unbothered by her situation. Her family thus identifies her simultaneously as her illness and as a praiseworthy hero for her method of coping (which is to essentially not cope). It is damaging to ill people and to healthy people's perception of ill people to adopt the view that ignoring illness's emotional effects for the sake of family members is a good idea. This viewpoint encourages ill people to wrongly overlook their mental and emotional health and reinforces the idea that healthy people's needs and worries are a societal priority over the ill person's experiences.

In his book *Disease and Representation: Images of Illness from Madness to AIDS*, Sander Gilman addresses how ill people have become subordinate in our society: "The understanding of

the patient as a vessel holding disease and, therefore, an extension of the disease, is determined by the norms of the society in which the observer and the observed are present. The basic structure is that of all stereotyping" (Gilman 4). This stereotyping in *House of Robots* conflates Maddie's identity with her illness and supports the idea that her emotional needs are less important than those of her healthy family. *Their* ability to cope with her illness is more important than *her* ability to cope with *her* illness. Moreover, it seems that Maddie internalizes this view of herself, subconsciously agreeing that she should act as if her SCID is "no biggie" for the sake of her family (Patterson and Grabenstein 307). Gilman explains how this internalization occurs:

...whenever an image of difference projected onto a group within society has sufficient salience for an individual in the stereotyped group as to be completely internalized, the individual acts as if the image is a pattern for self-definition whatever the validity or implications of the charge of difference or the image imposed. This sense of difference is triggered by any deep-seated sense of ontological insecurity, such as that created by a double-bind situation in which one must rationalize one's sense of self with the image of the Other projected upon a group with which one is identified. We thus actively seek to accept society's sense of our own difference in order to recreate our sense of oneness with the world. (Gilman 5)

Based on Gilman's argument, one can conclude that Maddie adopts the stereotype that society imposes upon her in order to feel as if she belongs to said society. She is already physically separated from society due to her autoimmune disorder, and she most likely wants to minimize the emotional and mental separation that she can control. Her mother's invention of a robot through which Maddie can attend school supports this reasoning. The robot helps her feel that

she belongs to society, that she can experience a ‘normal’ childhood. Having the robot enables Maddie to feel closer to the other—healthier—children. Therefore, Maddie internalizes the idea that her family’s emotional health takes precedence over her own, as it is another societal-based phenomenon. Maddie dismisses her own health to feel that she has a place in a society that prefers the healthy over the ill.

Patterson and Grabenstein describe how many chronically ill people process their illnesses in American society. However, they could have concluded with a scene, description, or representation of Maddie that would improve the narrative of chronic illness in our society rather than a perpetuation of the current perception. I want readers to know that at present, chronically ill people in literature often internalize societal norms. By addressing these norms, I raise awareness of their presence and promote a desire for social inclusivity for the ill in literature.

Like Maddie, Hazel in *The Fault in Our Stars* internalizes social norms of illness, but she internalizes them on a different scale and through a different mode of expression. While Maddie plays down her illness and avoids coping to take care of her family, Hazel tries to push away those she loves in order to take care of them. As previously stated, Hazel believes that she is a metaphorical grenade, and her death will be so horrible to cope with that she should not allow anyone to get close to her. Because of the progress of her cancer, she is in a different state of mind than Maddie, and she attempts to protect those she loves by asking them to stay away from her. Maddie, in contrast, has a severe illness that could be fatal, but if she stays home and avoids contact with germs, she has a higher and more controllable chance of survival than Hazel. Therefore, the two girls view their illness’s impact on others similarly but on different scales. Maddie believes that pretending she is fine will help her family cope with her illness, while Hazel believes that forcing people to consider her illness’s impact on them will help them protect

themselves from her future death. Both Maddie and Hazel choose to ignore their own needs, for expression and for love, respectively, to ensure the happiness of those around them. They thus blame themselves for the fact that their families and loved ones have to deal with their illnesses.

Moreover, both girls internalize the idea that their illnesses harm others more than they harm themselves, and that others' need for coping with their illnesses surpass their own needs. It is important to acknowledge the presence of this internalization in the two novels and recognize that it most likely will impact the way readers view chronic illness. In other words, these depictions of coping with chronic illness may lead readers to believe that the best way for people to cope with chronic illnesses is to put their loved ones first and ignore their own mental and emotional health.

In *House of Robots*, Patterson and Grabenstein employ the trope of the ill child as only possessing positive characteristics that are solely related to her illness and not intrinsic. When the authors introduce readers to Maddie's illness, Sammy states, "By the way, about one in every two hundred thousand kids is born with SCID. I wonder if they're all as amazing as Maddie" (Patterson and Grabenstein 67). There are two things to note in this quotation. One is that Sammy states that Maddie is amazing and has SCID. Because of the wording of this quotation, it seems as if Maddie is amazing *because* she has SCID. Along with equating Maddie's character with her SCID diagnosis, Sammy may believe that anyone who has SCID is also probably amazing. Conversely, he may also believe that Maddie is the only person with SCID who is amazing, and no one else with SCID could ever be amazing. No matter which is the correct implication from his statement, by combining Maddie's character with her illness, Sammy conflates people's identities with their SCID diagnoses. Sammy is the clear voice of the novel, as

he speaks directly to the readers through his narration. Therefore, the novel itself perpetuates the idea of illness as identity.

Similarly, Augustus Waters considers his cancer as his identity at the end of his life, as do the other characters in *The Fault in Our Stars*. As discussed previously, Augustus says that his “cancer is me. The tumors are made of me” (Green 216). Hazel also repeats this sentiment of Augustus, stating that his cancer “was made of him” (Green 261). Hazel describes how Augustus’s entire personality changes due to the intensification of his cancer, and she does not make an effort to see Augustus as the same person as before his cancer worsened. In her mind, Augustus’s cancer changed his core being, his inner personality, and there is no separation between his illness and his identity. In addition, Caroline Mathers’s entire personality derives from her illness, and Augustus does not acknowledge a difference between her behavior before and after her illness.

In both of these novels, illness defines personality and identity. In reality, illness does impact behavior, thoughts, and actions. However, illness does not solely cause identity and personality formation. Rather, people have individual characteristics that they possessed both before and after their illness diagnoses. The authors of illness novels depict illness through their art, yet they still need to be aware that readers may interpret illness as completely identifying.

In this same vein, Patterson and Grabenstein maintain a stance on illness coping mechanisms that demonstrates how internalization of societal norms damage ill people. Reflecting on how Maddie tries to play off the seriousness of her illness and focuses on Sammy instead, Sammy thinks, “She always makes sure everybody else feels great—even when she doesn’t. Like I said, my little sister is pretty incredible” (Patterson and Grabenstein 71). In this case, Sammy praises Maddie again. There are no cases in the novel in which the authors portray

Maddie in a negative light. However, there are also no points in the novel at which the authors characterize Maddie in a manner unrelated to her illness. In fact, there are very few details about Maddie in the novel that are unrelated to her illness. Her positive characteristics derive from her illness behavior. It can be concluded that the praise surrounding Maddie is solely due to the existence of her illness. In this novel, the depiction of Maddie is fictional, yet it fails to artistically describe illness in a way that would best represent it to readers. An ill person, even in a story, should be lauded for their unique character traits and not only for their behavior regarding their illness.

House of Robots eventually became a trilogy. In the subsequent two novels, Maddie still drives the plot yet is not the main focus of the narration. In fact, Maddie remains alive through all three novels, and Sammy even creates a robot that destroys all the germs around Maddie and enables her to leave the house. This is a very unexpected result for someone with SCID. Although Sammy's cure for SCID is clearly fictional, it promotes a false hope of a cure for children with SCID in reality when no such cure of this sort exists. New techniques such as bone marrow transplants and gene therapy can help improve the immune systems of those with SCID, yet these are not mentioned in the novel. In addition, although it is important not to equate the ideas in novels with the opinions of authors, I would like to address James Patterson and Chris Grabenstein specifically because of the lack of citations for this novel. I understand that it is a work of fiction. Nonetheless, Patterson and Grabenstein chose a real disease in their depiction of fictional characters. If Patterson and Grabenstein did not identify the disease by name or created their own fictional autoimmune disorder, they would have more creative license with its symptoms and experience. However, they name SCID directly. Therefore, their writing will have an impact on the way children perceive those with SCID, and there is a chance that someone

with SCID could read the novel. Neither Chris Grabenstein nor James Patterson reveals any personal experience with SCID or chronic illness on their websites, and other online sources and interviews do not describe either of them as having any illness experience. An article *The Daily Beast* only briefly mentions Patterson undergoing prostate surgery, and Patterson co-authored a non-fiction book titled *Against Medical Advice* about a child's experience with Tourette's syndrome, obsessive compulsive disorder, and anxiety. However, neither author has publicly acknowledged experience with SCID or chronic illnesses other than those Patterson wrote about with Hal Friedman—that he learned about secondhand—in *Against Medical Advice*. In particular, there is no evidence of them learning about physical chronic illnesses like SCID. The authors do not discuss the illness in *House of Robots* in any interviews. Moreover, the book does not contain any citations or resources about SCID or illness experience; there is no indication that the authors conducted any research on SCID. A reader could safely assume that all of the information about the illness and a child's illness experience in this novel originates from the author's self-knowledge or was researched, and neither of these seem to be the case. There is a disclaimer in the beginning of the novel that is present in many novels that explains that the work is purely fictional. However, regardless of the intent for the book and its potentially fictitious details, fictional stories about real illnesses have real-world consequences. It is important to address the way that the illness stereotypes in this novel impact the children reading about them, especially if the stereotypes are used without background research.

To elaborate, children are usually unaware of the authors' research behind their stories. They do not know if the authors researched the disease they depict and often do not even realize that it needs to be researched for accurate representation. Therefore, everything the authors say will appear truthful, even in a novel. Even if they know the story is fictional, the details and

information provided—such as information about an illness—will appear to them as factual. It appears that Patterson and Grabenstein described the symptoms of SCID correctly. However, they do not provide readers with the knowledge of how they can appreciate SCID illness experience, understand identity's separation from illness, and separate gender and illness. Therefore, more work needs to be done with regard to illness representation in this realm of children's fiction.

Once again, I would like to clarify that although fiction writing is art, it still will influence readers. My goal is to raise awareness of when art is positively and negatively impacting its readers. From my work, I hope authors become more cognizant of the subtle effects that their writing about chronic illness can have on young readers, and readers can increase their understanding of how art impacts their perceptions and actions toward chronic illness.

Chapter 3: Bibliotherapy and Fiction's Social Influence

Reading and writing about illness have therapeutic and socially influential consequences. Fiction about illness helps others understand the experiences of those with chronic illnesses, especially when it becomes as wildly popular as *The Fault in Our Stars* and *House of Robots*. Narrative medicine establishes a baseline for discussing how novels can represent illness and illness experience in a positive, healing way. Rita Charon pioneered the field of narrative medicine with her book *Narrative Medicine: Honoring the Stories of Illness*. She defines the field as “medicine practiced with these narrative skills of recognizing, absorbing, interpreting, and being moved by the stories of illness” (Charon 4). Narrative medicine emphasizes the impact of telling one’s story on understanding illness experience and coping with illness in a therapeutic manner. Narratives provide a reader “with a rich, resonant grasp of another person’s situation as it unfolds in time” (Charon 9). By reading about someone’s situation from the perspective of an ill person, readers better comprehend how that person believes they are perceived and how they handle their illness. Thus, doctors reading an illness narrative can create effective therapeutic plans for ill patients, and healthy people can learn how to best understand and empathize with the viewpoint of an ill person.

Narrative medicine specifies that both doctors and ill people write about their personal experiences. There are benefits from writing and reading these reflections, and narrative medicine’s techniques apply to fictional readings as well as first-person memoirs. Specifically, reading fiction is not only a therapeutic way for ill people to view representations of their own illnesses but also enables healthy people to better comprehend the experiences of their chronically ill peers. I will use the term *bibliotherapy* for reading for therapy and empathy cultivation in the rest of my discussion.

Bibliotherapy can be as effective as narrative medicine because many of narrative medicine's benefits and purposes match those of bibliotherapy. In her piece "Fiction-reading for good or ill: eating disorders, interpretation and the case for creative bibliotherapy research," Emily Troscianko asserts for bibliotherapy what Charon does for writing about illness. She states that a fictional book "speaks directly to the cognitive significance of storytelling: the parallelism between the structures of narrative and of experience itself. Experience is intimately bound up with the narrative spin we put on it" (Troscianko 201). To extend this insight, fictional depictions of illness correspond to the way readers and writers interpret real-world experiences. Readers learn about how illness affects people in reality from these fictional stories and thus better understand how to interact with those who suffer from illnesses. However, as I will address later on, some portrayals of illness in literature may also differ from the way ill people want others to understand their realities and perpetuate damaging tropes of illness experience.

In addition, Charon's arguments for narrative medicine transfer to those for bibliotherapy. Charon states that "many of us have been struck by the parallels between acts of reading and acts of healing" (Charon 108). Reading's healing effect derives from learning about the experiences of others through words. David Comer Kidd and Emanuele Castano provided evidence in a psychological analysis, titled "Reading Literary Fiction Improves Theory of Mind," that this argument applies to fiction reading. To perform this analysis, Kidd and Castano conducted five experiments in which they tested for differences in theory of mind development using a standardized examination technique for scenarios of reading fiction versus reading non-fiction, reading versus not reading, and reading what they call "literary" fiction versus "popular" fiction (Kidd and Castano 1). As a clarification, Kidd and Castano define theory of mind in this study as the ability to comprehend the feelings of others without needing to experience them

oneself. For Kidd and Castano, the distinction between “literary” fiction and “popular” fiction is that literary fiction is “writerly” while popular fiction is “readerly” (Kidd and Castano 1). These definitions derive from the ideas of Roland Barthes. Kidd and Castano assert that “although readerly texts, such as most popular genre fiction, are intended to entertain their mostly passive readers, writerly, or literary, texts engage their readers creatively as writers” (Kidd and Castano 1). The researchers assume that popular fiction does not provide as much cognitive stimulation as literary fiction. I disagree with Kidd and Castano’s division between types of fiction and their resulting distinction in theory of mind cultivation for those categories.

To explain why Kidd and Castano did not need to separate types of fiction in this manner, I will draw upon Lindsey Grubbs’s critique of their study. Grubbs explains that Kidd and Castano took Barthes’s ideas of writerly texts and readerly texts out of context. She explains that “Barthes once asserted that ‘literature is what gets taught’; he and his peers found no meaningful distinction between literary and nonliterary fiction, and would have recognized the division as a frankly ideological one” (Grubbs 4). Therefore, Barthes would have disagreed with Kidd and Castano’s choice to separate fiction into two categories. Moreover, Kidd and Castano told research participants that “prize jurors” awarded some of the works in the study for providing more intellectual stimulation than others, and this influence from the supposedly distinguished jurors’ opinions could have altered how the participants read the “literary” texts as opposed to how they read the “popular” fiction texts (Kidd and Castano 3). Grubbs details my concern in her question, “what would happen with the theory of mind measures if participants thought they were reading ‘literary fiction’ while they were actually really reading ‘popular fiction?’” (Grubbs 5). Without prior knowledge of the category of fiction they were reading, participants might have read the two types of fiction equally and might not have developed differences in theory of mind

cultivation. Due to these discrepancies in fiction categorizations, I will continue my argument accepting that Kidd and Castano found an increase in theory of mind development from reading fiction, but I will not focus on the differences they determined between literary and popular fiction's effects on theory of mind. The two novels I analyze additionally disprove Kidd and Castano's distinction between literary and popular fiction because of their large influence. Although the novels are popular, they still profoundly affect the way their readers view and understand the ill. Thus, reading both literary and popular fiction may cultivate theory of mind, and I will continue my argument with this underlying assertion.

Kidd and Castano determined that reading fiction can parallel healing just as reading first-person narratives can: "Fiction seems also to expand our knowledge of others' lives, helping us recognize our similarity to them" (Kidd and Castano 1). In other words, people learn how to empathize with others (using theory of mind in this case) through reading fiction, and this empathizing has a healing effect. Moreover, fiction-reading offers a mode of therapy similar to the one that narrative medicine provides for the chronically ill. Charon explains that first-person narratives allow patients to cope with their illnesses and overcome them:

The powerful narratives of illness that have recently been published by patients reveal how illness comes to one's body, one's loved ones, and one's self. These narratives, or pathographies as they are sometimes called, demonstrate how critical is the telling of pain and suffering, enabling patients to give voice to what they endure and to frame the illness so as to escape dominion by it. (Charon 65-66)

Thus, illness narratives help patients cope with their chronic illnesses by expressing their feelings about their situations in words. Charon also proves this contention with a negation, stating that "without narrative acts, the patient cannot convey to anyone else what he or she is going

through” (Charon 13). Writing about illness not only allows patients to express their emotions through words but also enables readers, who may be physicians, to tailor their support for optimal care. Similarly, Troscianko asserts that fiction reading proffers a therapeutic effect for readers:

Fiction may ‘provid[e] readers with models to help them handle situations,’ or convey new facts or alternative ways of approaching problems. However, it can also allow readers to ‘escape into new roles and identities and sample lifestyles vicariously’, and help them overcome fear, guilt or shame by imparting a sense that their problems are normal and so can be talked about freely, so also helping them to build up trust with a therapist. (Troscianko 205)

Like narrative medicine, fiction reading enables readers to understand and cope with their life situations, such as a chronic illness, and deal with them in a healthy manner.

Charon also contends that “as an instrument for self-knowledge and communion, narrative is an irreplaceable...partner to human beings as they make and mark meaning, coping with the contingencies of moral and mortal life” (Charon 40). Reading and writing first-person narratives allows people to express their feelings in words, giving tangible meaning to their emotional experiences. Kidd and Castano emphasize how multiple literary theorists, such as “Bruner (20), like Barthes and Bakhtin, [have] proposed that literature engages readers in a discourse that forces them to fill in gaps and search ‘for meanings among a spectrum of possible meanings’ (p. 25)” (Kidd and Castano 1). Therefore, the same meaning-making of narrative medicine exists for fiction reading.

There are additional reasons why theorists argue that fiction reading can be therapeutically beneficial for readers. Kidd and Castano explain that theory of mind and empathy

develop from fiction reading because fiction “uniquely engages the psychological processes needed to gain access to characters’ subjective experiences” (Kidd and Castano 1). Through understanding the perspectives of fictional characters, readers grasp subjective experience in the real world and in their own lives. Moreover, fiction reading enables readers to contemplate situations in a protected environment: “The worlds of fiction, though, pose fewer risks than the real world, and they present opportunities to consider the experiences of others without facing the potentially threatening consequences of that engagement” (Kidd and Castano 1). Fiction provides a safe space in which people can determine the best ways for them to cope with their own illnesses as well as how to behave toward others with chronic illnesses.

There are many similarities between the benefits of narrative medicine and fiction reading. Thus, fiction reading can be used as bibliotherapy for people with chronic illnesses as well as a way for the healthy to learn how to understand and act appropriately toward those with chronic illnesses.

People’s illness experiences differ greatly, and stories may risk criticism and have potentially damaging effects if chronically ill people disagree with the representations of their illness in fiction. If novels do not depict all chronic illness experiences, they can alienate those with chronic illnesses who feel their specific situation is not included. This occurs especially with novels such as *House of Robots* and *The Fault in Our Stars* due to their success and large reach. These popular novels demonstrate some illness experiences and stereotypes, as discussed in the previous chapters, but many illness experiences remain unacknowledged in these texts. Therefore, authors and readers must know that fiction reading increases awareness of different illness experiences yet is not all-encompassing. Nonetheless, reading these stories provides a

benefit similar to that of narrative medicine: it can be a form of therapy for both patients and doctors.

Currently in the field of medicine, there is a push for an increase in fiction reading to understand illness because of the above benefits and risks; the present lack of healthy doctors' comprehension of ill people's experiences; and an inability to reconcile disability theory, narrative medicine, and standard medical practices. Rebecca Garden details the reasons behind this lack and misunderstanding in her article "Disability and narrative: new directions for medicine and the medical humanities." She argues that the reason it appears that medical professionals do not understand the chronically ill, or those with unhealthy disabilities as Wendell determined, is that "those who are non-disabled have relatively few conscious encounters with the difference of disability" (Garden 1). Physicians often do not realize the large disparity that their disabled patients perceive between them due to their differences in health. Patients feel that their (assumed to be) healthy doctors occupy a position of both authority and superiority due to differences in occupational *and* physical status. Doctors do not often notice this outlook in their patients. Garden argues people can resolve this issue of ignorance through reading: "through disability studies and critical examinations of narrative informed by disability studies, practitioners can provide better care for patients with disabilities and work as allies towards more equitable relations in the clinic" (Garden 1). By acknowledging and attempting to understand the perspective of disabled patients, doctors can offer more tailored and equalizing modes of care.

I also counter the historical notion that disability studies of literature and medical practice are irreconcilable. Rather, they can work in conjunction to improve physicians' care of those with chronic illnesses and other unhealthy disabilities. Disability theorists believe that doctors

reject illness experience's value and instead want to cure all forms of disability, eradicating it and the connected experiences from society. The theorists claim that medicine dismiss the presence of disability experience in society by treating illnesses as purely biological and ignoring their emotional impact. On the other hand, medical theorists argue that disability studies theorists rebuff the importance of medicine and biological treatment. Garden explains that "one significant challenge for clinicians who enter a dialogue about disability in others is to sustain that dialogue despite an apparent rejection of medicine or the medical perspective" (Garden 2). This statement embodies the main conflict between disability theorists and medical practitioners. The two groups cannot reconcile their positions because they believe their tenets are inherently contradictory. However, I do not believe this to be the case.

The medical perspective does not have to be only biological: "rejecting the medicalisation of disability and needing medical care are not mutually exclusive" (Garden 4). While medicine focuses mainly on treating disease, the current method of education in medicine welcomes the idea that not all diseases are curable. In some cases, doctors can only treat the symptoms of an illness and not completely cure the patient. Curing the patient also may be possible but will not occur for many years. These are the types of illness that I focused on in my previous chapters: chronic illnesses. Disability theory can inform medical care by teaching doctors how to treat their patients with chronic illnesses both biologically and emotionally. Rita Charon's claims support this idea and indicate that it can be accomplished through the practice of narrative medicine. Charon asserts that "to know what patients endure at the hands of illness and therefore to be of clinical help requires that doctors enter the worlds of their patients, if only imaginatively, and to see and interpret these worlds from the patients' point of view" (Charon 9). Namely, narratives provide doctors with an empathetic understanding of their patients'

perspective. Because the benefits of fiction reading parallel those of narrative medicine, fiction reading can also educate doctors on how to understand their patients and thus enhance their medical practice. Bibliotherapy is important in regard to the understanding, empathizing, and treatment of people with chronic illnesses.

Moreover, the fields of medicine, specifically that of narrative medicine, and disability studies have the same goal: they both aim to improve the well-being of ill people. Although the disability studies' focus is on emotional health, narrative medicine emphasizes physical as well as emotional health. Along with supporting the emotional health of patients, they also both promote the same way to achieve that health: through reading and writing. Reading and writing *fiction* is the missing piece that can help these two fields reconcile and no longer completely oppose each other.

Doctors can improve their quality of care by combining disability theory and medical theory, practicing bibliotherapy, and reading fiction about illness; in other words, the humanities can improve the practice of medicine. In her analysis of Kidd and Castano's study, Grubbs argues that "incorporating humanities approaches could improve the practice of science as it approaches topics typically in the purview of the humanities or social sciences, asking how the goals of scientific advancement could be shaped by work across the discipline" (Grubbs 1). Grubbs believes that literary scholars can work with researchers to promote more humanistic forms of scientific practice.

Joseph S. Alpert, Helle Mathiasen, and other healthcare theorists and professionals similarly discuss the benefits of humanities in medicine in *A Clinician's Companion: A Study Guide for Effective and Humane Patient Care*. In their introductory essay "Literature and Medicine: The Human Perspective," Alpert and Mathiasen argue that medicine is not a purely

scientific field. Rather, medicine intimately connects with the humanities; it is “the shoreline where the sea of science meets the land mass of the humanities” (Alpert and Mathiasen 164). Moreover, many doctors partake in humanities activities in order to reflect upon their experiences in the medical world. For example, poet William Carlos Williams was a physician by training who expressed his emotions about his experiences in healthcare through poetry and prose. Alpert and Mathiasen also assert that physicians can learn how to practice medicine empathetically by reading fiction because “a number of questions and issues relating to the study of medicine...are portrayed in various works of literature” (Alpert and Mathiasen 166). By reading and writing fiction, physicians can, like other readers, observe situations about chronic illness in a safe environment and learn there how to act empathetically toward the chronically ill in reality.

Although many may argue that this empathy in medical care is an innate characteristic that not everyone possesses, I believe physicians can cultivate empathy through the practice of medicine *coupled with* fiction reading. The increase in empathy from fiction reading is well-documented. David Dodell-Feder and Diana I. Tamir compiled fourteen studies of empathy and fiction reading and concluded that “fiction reading leads to a small, statistically significant improvement in social-cognitive performance” (Doddell-Feder and Tamir). Therefore, reading about illness will increase doctors’ empathy and their care for chronically ill patients. In his book *Empathy and the Practice of Medicine: Beyond Pills and the Scalpel*, Howard Spiro supports this argument by explaining that it is possible to enhance empathetic care of medical professionals. Increasing empathy “requires the consideration of human life and experience; the reading of stories and novels” provides that consideration (Spiro 11). In addition, Spiro counters the argument that empathy is only fostered through practice: ““If empathy depends on experience,

then that is the area in which novels, fiction, stories, and paintings can enlarge empathy,” especially through reading "clinical tales" about illness (Spiro 11). He asserts instead that reading novels provides the experience that empathy cultivation requires. Therefore, empathy can improve through the practice of medicine and the practice of reading fiction.

Fiction reading both improves ill people’s emotional health and informs proper medical care of those with chronic illnesses. Specifically, reading is important for children and young adults. Children and young adults (which I define as people in their teens to their early twenties), are very impressionable at their young age. Fiction reading and other forms of popular media especially affect the viewpoints and actions of young people. Reading fiction about chronic illnesses can and will change the way children view those with chronic illnesses and how children with chronic illnesses will view themselves. The impact of chronic illness fiction reading can be both positive and negative. If fiction books inform children’s perspectives, inadvertently or not, it is important to increase awareness of the way the books represent the experiences of those with chronic illnesses illness stereotypes. However, it is also essential to remember that there are a multitude of ways people experience illness in reality, and representation for all of these experiences cannot happen in one or two novels alone.

Children with chronic illnesses can use fiction reading that represents chronic illness in a beneficial light as bibliotherapy. They can learn how to separate their illness from their identity, alleviate personal guilt for their illness, and focus on their emotional and mental health. Moreover, children without chronic illnesses can learn about these illnesses through a mode in which the situations are real but they can practice how to best behave, understand, and include those with chronic illness in a fictional world. Children can apply the lessons and representations of illness from fiction reading in reality. If what they learn results in regarding other children

with chronic illnesses in a positive and welcoming manner, then I believe that fiction reading will greatly change the way that society treats chronically ill people.

House of Robots and *The Fault in Our Stars* are examples of young adult fiction and children's books that depict chronic illness in both helpful and damaging ways. Both describe real illnesses that children suffer from in our society, both physically and emotionally. The authors portray families, friends, and the ill children's reactions to the illnesses. They explain how chronic illnesses can be isolating, identifying, and also result in guilt and shame for those who are ill. However, they also demonstrate how people can positively perceive chronic illness and not separate people with chronic illnesses from the rest of society. I believe that these two novels do not always properly represent chronic illness, but they are a starting point for addressing chronic illness in children's and young adult fiction. Moreover, it is important for authors and readers to be aware that these books are influencing children.

Although these novels raise awareness of the experiences of chronically ill children, they cannot describe every single experience. Additionally, if more novels become as popular as *The Fault in Our Stars* and *House of Robots* while still depicting the same amount of illness experience in the same manner, many children with chronic illnesses reading the novels may feel excluded from the societal narrative. They may believe that their ways of experiencing their illnesses are incorrect or wrong because they are not represented. Moreover, healthy readers may believe that ways of experiencing illness that do not exist in novels are misguided or illegitimate.

This is another point in which disability studies and narrative medicine can inform and improve each other with the help of fiction reading. Narrative medicine advocates reading and thinking about chronic illness narratives critically. Disability studies asserts that the public should not presume that one example of a chronic illness experience encompasses all chronic

illness experiences and that believing this to be true damage those who are not represented. These two theoretical fields can collaborate in order to create a mode of representing illness without exclusions. This collaboration would promote reading fiction as a way to understand and empathize with chronic illness experiences and apply the knowledge gained from the novels to real-life experiences. People reading about the chronic illnesses can then learn that these descriptions are not all-inclusive. Rather, they can appreciate these depictions—appreciate the awareness of the experiences demonstrated by the fiction writers—while also comprehending that the depictions include emotions and mental states that reach across many illness experiences. The tangible experience may be different, but the intangible knowledge obtained establishes a basis for understanding other experiences. For example, Maddie’s nonchalance about her illness in *House of Robots* provides the reader with a greater understanding of how people with chronic illnesses internalize blame for their situations. This blame is most likely common across multiple illness experiences, not just one of SCID. Similarly, Hazel often feels separated from the rest of society due to the physical effects of her metastatic thyroid cancer in *The Fault in Our Stars*. Hazel’s feelings of otherness occur for people with many different types of chronic illnesses. By learning about Maddie and Hazel’s fictional emotions, readers can better comprehend the emotions of chronically ill people in the real world. However, readers must retain an understanding that every individual has a unique experience with illness. Fiction reading can be therapeutic, but readers must understand that it does not indicate every illness experience.

Another way this issue could be resolved would be to increase the number of novels about illness experience. By increasing the quantity of stories, it most likely will increase the diversity of the stories as well. One of the reasons I wanted to research this topic was the current dearth of fiction involving chronic illness for children and young adults. This lack promotes what

disability studies stresses as an issue: unequal representation of illness experience and consequent social isolation of people who feel unrepresented. There is a need to increase the number of young adult and children's chronic illness fiction popularly available in order to promote more inclusivity for the chronically ill. A way to inspire more authors to write these genres of fiction about illness is to increase the awareness of the need for them. I aim to do so through writing this analysis. However, there is a want of other critical analysis of young adult fiction and children's fiction about physical chronic illness. Literary critics could analyze these novels more to augment the awareness of this type of writing in popular media as well as the scholarly sphere of literature. If children and young adults with chronic illnesses believe that their stories are being heard and being told, as narrative medicine encourages, they will then feel less alienated from society, and the societal norm of health as superior to illness and disability may diminish.

Along with increasing the literary criticism of these novels, another method is to increase the awareness of these issues in writers themselves. Writers can consider the representation of illness during their writing process in order to weigh the influence of their work about chronic illness on readers. Writers need to be aware that their words will be influencing readers in ways that they may not realize. There is a significant difference between not knowing one's influence, which I would like to call unconscious influence, and being aware of one's influence, which I call conscious influence. When a writer is conscious of his or her ability to shape the opinions of his or her readers, then that writer has the freedom to choose how he or she wants to influence those readers in whatever manner they prefer. Rather than inadvertently spreading messages that the writer may not want to spread, the writer can write their work with their ideas for influence in mind.

Literary critics also can play their own part in the process of fiction reading influencing readers. There is a need for more literary analysis of children's books because children are highly susceptible to outer influence. A study led by L. Folkes found that "there are significant age effects on susceptibility to social influence, typically a decline from childhood to adulthood" (L. Folkes et al). This effect can be either positive or negative. Therefore, it is the responsibility of literary critics to raise awareness of how novels could be influencing children, and they can achieve this task by critiquing young adult and children's fiction. It is generally uncommon for literary critics to analyze children's and young adult books because those books historically have not been looked upon highly in terms of literary value. This bias toward certain kinds of literature and away from others is visible when Kidd and Castano attempted to classify different types of fiction by their levels of "readerly" or "writerly" ability (Kidd and Castano 1). There is an inherent assumption that some types of fiction are more "literary" than others (Kidd and Castano 1). Children's books are not often considered to be literary. I counter this argument because of their major societal influence. If a book influences people so greatly that it may change the way they view the world, there is a need for critical examination of it. Therefore, I consider these books to be "literary" as well and to require analysis by literary critics (Kidd and Castano 1). If critics increase awareness of the potential ways a book could influence a child or young adult, then writers and readers will be better equipped to manage how they write novels and how they read novels, respectively. In addition, critiquing a chronic illness novel can also help increase the understanding that these novels do not demonstrate every representation of chronic illness experience. Rather, critics can focus on specific illness experience descriptions as individual ones and emphasize themes over the illness experiences themselves. This specific analysis will help readers—especially chronically ill readers—realize the wide variety of illness

experience and become more inclusive in their interpretations in literature and behavior in society.

My first two chapters demonstrate how literary critics can raise this awareness and why it is necessary to do so. As discussed in my introduction, I chose to analyze *House of Robots* and *The Fault in Our Stars* because they are two very popular novels for children and young adults that lack critical analysis in both the literary and medical fields. By discussing both the positive and negative representations and stereotypes of illness present in these novels, I have raised awareness of their presence to both readers and to the writers of books about chronic illness. My goal is to help readers understand how these novels could influence their view of the world. Therefore, with the awareness of this potential influence, readers can determine for themselves how they interpret these works and choose how they will be influenced. If literary critics continue this path of analyzing chronic illness fiction for children and young adults, it will further the impact of my work on a much larger scale.

Readers can also increase their awareness of the potential influence of a novel on their view of society. As explained above, awareness provides readers with more liberty to understand and choose how a novel affects them. However, this awareness is more difficult to cultivate in children. Due to their lack of experience in the world and greater susceptibility to influence, it is more challenging for children to understand how the book could influence them than adults. This impressionability indicates why both fiction writers and literary critics have a greater responsibility in the fields of young adult and children's fiction than in adult fiction to bring greater awareness to the public of the influence of the works on readers. When young readers of chronic illness fiction are able to acknowledge the influence the books may have on them, it will help them decide how the books affect their view of the world. Once again, the influence will

change from unconscious to conscious. Moreover, this change in influence will help children with chronic illnesses who read chronic illness fiction. Rather than feel excluded by stories that do not represent their exact illness experience, it may help them to understand that they are reading simply about one illness experience that is not all-inclusive. Instead, they can appreciate a story for its representation of any illness experience and use the story as a way to learn how to cope with their illness experience in real-life society.

Doctors also can become readers of chronic illness fiction, and their awareness of differences in chronic illness experiences and illness stereotypes can inform the way they treat their patients. It is important for doctors to read critically so they can learn from the way fiction authors represent chronic illness. With the knowledge gained from understanding fictional experiences of illness, doctors can improve the way they empathetically treat their chronically ill patients. This skill is especially important in the case of chronically ill children and young adults. Once again, young people are more impressionable than adults, and the way their doctors treat them may affect them on a deeper level than older people (although this is not universally true). Therefore, doctors and their patients can mutually benefit if doctors read chronic illness fiction with the awareness of how the books may influence them. Doctors can improve their performance at work and their overarching treatment of their patients, and patients will feel more comfortable and understood by their doctors.

My purpose throughout this project has not been to tell John Green, James Patterson, and Chris Grabenstein to change *The Fault in Our Stars* and *House of Robots* in order to make them more suitable for bibliotherapy and chronic illness education. Rather, my goal is to increase *awareness* of how their use of chronic illness and chronic illness experience in their novels demonstrates illness stereotypes and can potentially affect the way readers view ill people in

society. If authors, critics, and readers all understand how literature can change the way society views illness, they can make the influence a positive one and truly promote change in the behavior and treatment of chronic illnesses for doctors, non-chronically ill people, and the chronically ill themselves.

Conclusion

Narrative medicine initiates the path for novels about chronic illness to aid in the cultivation of empathy in doctors. Bibliotherapy can unite medical practice with disability theory through the shared desire to improve the treatment—physically, mentally, and socially—of chronically ill people, specifically children and young adults. Moreover, novels can help non-chronically ill people understand chronic illness experience. Chronically ill people themselves benefit from reading about illness experiences in fiction; awareness of the presence of the experience in popular media can promote their feelings of inclusion and decrease the belief of their differences from other people in society. It foments feelings of shared experiences, of empathy, and of understanding.

House of Robots and *The Fault in Our Stars* often depict representations of chronic illness that either do not comprehensively describe illness experience or that follow illness experience stereotypes. Nonetheless, they both increase chronic illness representation in young adult and children's fiction. By even writing about chronic illness in fiction, these authors have started a movement to promote inclusion of chronic illness experience in society. Literary criticism of these novels and of other chronic illness fiction can help authors understand how their works influence readers in reality. Thus, it is important that we increase the critical analysis of chronic illness fiction to promote awareness of how experiences can vary, how stereotypes can be either detrimental or beneficial, and how the fiction may affect the way chronic illness representation appears to the general public. My analysis of these two novels is my initial contribution to promoting this goal.

By critiquing the way writers depict chronic illnesses in novels, I am not aiming to condone limiting what authors write about through censorship. Rather than endorsing censorship,

I am endorsing research of illnesses in young adult and children's literature. If an illness is fictional in a novel, as in it does not exist in reality, or if the illness is not named, authors have more creative license in how they depict that illness and its consequent experience. However, if an illness is named and is real, authors have a greater responsibility to research it and represent its symptoms and experiences the way they exist in reality.

My hope for this work is that by critically analyzing chronic illness representation in fiction, I am promoting an increase an awareness of how this representation can affect the writers, readers, and theorists of chronic illness. I also hope that the amount of chronic illness in young adult and children's fiction will continue to increase, augmenting the inclusion and acceptance of children with these illnesses in reality. Subsequently, it is my wish that more critical examination will follow this increase. These forms of literature are often considered to be of lower critical value, but I want to change the scholarly beliefs about these novels. Young adult and children's literature significantly impacts readers and the way society will view chronic illness not just now, but well into the future, when the readers grow up. The influence of these books now must be recognized and examined. With an increase in awareness of the influence will come an ability to determine how authors will write about chronic illness, how critics will analyze chronic illness fiction, and how readers will choose to understand chronic illness and use their knowledge in the real world.

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