

The Romance of Sick-Lit: Girlhood, Illness and Adolescence in Contemporary YA Novels

MA Thesis

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This thesis is dedicated to all the young girls that fell in love with reading, and vowed to change the world, like a girl.

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Chapter 1: Introduction

In 2012, John Green published the novel *The Fault in Our Stars*. The novel was an instant hit, selling over a million copies in the first year. The story was adapted for the big screen in 2014, only propelling its popularity. Green wrote a book that would form a blueprint for the reformation of the Young Adult romance genre; star-crossed lovers and impossible odds. The novel tackled a heavy and complex issue head-on. The novel opens with a support group for people with cancer, seen through the eyes of 16 year-old Hazel. The reader is constantly reminded of, and confronted by, Hazel's status as a dying person.

John Green was one of the many authors who has enthralled teenage girl readers with stories of illness. Illness stories have always been told, no matter the form. Details about chronic conditions like consumption (Tuberculosis) from the Victorian era, to modern day books turned blockbusters like *The Fault in Our Stars* and *Me Before You* (2016), are all stories of illness. 'Teen sick-lit' as Elman (2012) calls it, is a subgenre of the Young Adult Problem novels which emerged after widespread disillusionment with governmental authority led to the idea that teens needed to be exposed to the 'real world'. As a teenager, these books, often called tearjerkers, are a world to get lost in.

1.2 Young Adult Novels and Sick-Lit

Books and stories aimed at teenagers have existed since at least the 1930s, but it was often not named as such until the 1970s. For years, librarians and educators have been trying to answer the question of how to get young people, especially teenagers, to read. Labelling books for teenagers as Young Adult (YA) legitimised books and reading for teenagers. This was also done through the creation of a YA canon of books, which highlighted certain classics in the YA category (Blakemore, 2015).

YA literature has a fluid definition, but it is generally agreed upon that the term refers to books aimed at children between the ages of 12 and 18-20, or literature with a teenage protagonist and a plot that is centrally focused on the lives of teenagers (Dunning, 1962). YA was meant to be about the lives of teenagers, and thus addressed many of the problems that teenagers faced, whether on a social or personal level. The YA category was dominated by the so-called problem

novel, literature that centres around a problem, and solves it through characters. Specifically, problem novels shed light on a problem by making a character go through it (Harmon et al., 1972, p. 417).

YA problem books were fairly focused on racism, sexism and homophobia in the 1970s, but in the ‘80s this pivoted towards conservative values, and heteronormative gender roles. This was because it was believed that these books ought to represent good citizenship, which was characterised by able-bodiedness, emotional maturity, as well as traditional gender and relationship norms. From the problem novel emerged sick-lit, which generally followed the same plot developments. At the onset in the 1980s, much of the genre’s focus was on cancer, in various forms, although this has since evolved much beyond. The central story was about “getting well and getting the guy” (Elman, 2012, p.179), which displayed girls maintaining their physical beauty in spite of their illness, and boys retaining their athleticism despite illness. Sick-lit is often also a subcategory of the romance genre, and thus a romantic storyline is more often than not present. Usually this entails a sick girl (again, typically some form of cancer), meeting and falling in love with a healthy boy. The romantic progression is synchronic with the health progression, where love interests get closer as the illness worsens, until they get together, and eventually, the sick girl is declared healthy again (Elman, 2012).

The genre has steadily been popular over the years, with its timeless problems. After all, people will always get ill, and people will always fall in love, regardless of the problems they are facing. The YA novel as a whole saw a massive boost in popularity when *Harry Potter* was first published in the 1990s and gained popularity. This opened the door to YA fantasy, instead of the problem novel. As waves of YA fantasy books start popping up, trends cycled through; *Harry Potter* (1997-2007) popularised the magic institution that teaches unknowing protagonists about a whole new magical world where they are special. *Twilight* (2005-2010) brought paranormal romance to the YA domain, and *The Hunger Games* (2008-2010) reshaped the problem novel into YA dystopia. This cycle would eventually spin back around to the YA sick-lit novel with John Green’s *The Fault in Our Stars*, set in our world, with characters that face extraordinary but ‘realistic’ problems like illness and falling in love.

Young Adult media is aimed at teenagers, and has seen much critique over the years, ranging from commentary on the contents, to the complexity of the writing. Teenagers inhabit a liminal space in the hierarchy of society. They are not quite children anymore, have distinct personalities and thoughts, and can to an extent care for themselves. However, by most laws and by most adults (who are above them in hierarchies) teenagers are still considered children who cannot make independent decisions, and still need the guidance and supervision of a guardian. “the only boundaries which define the teenage years are boundaries of exclusion which define what young people are not, cannot do or cannot be” (Valentine et al., 1998, p.5), exercising control based on the physical age of the body. As such, much of YA media exists in a similarly liminal space between adulthood and childhood[1].

Among the population of teenagers, teenage girls and their interests are regularly invalidated. *Twilight*, *The Fault in our Stars*, the fan appreciation of Taylor Swift, and an exhaustive list of other pieces of media, artists and fashion trends, have been ridiculed, because their audience is primarily teenage girls (or perceived to be so). The interests of teenage girls are valued as less then, yet still enjoy significant commercial success. Teen romcoms like *To All the Boys I Loved Before* (2018) are made fun of, yet this is a genre of media that has had extended commercial success, and outlasted many trend cycles. The interests of teenage girls are of lesser value in all but monetary regard (Brunsdon, 1997, pp.2-3). When the teenage girl is cast in a YA novel of love in times of hardship, her uncertain identity of not just adolescence, or illness, but her *girlhood* is cast. Sick-lit depicts in some sense, how a girl ought to act while sick, and how the rest of her life plays out around it. The role of media, specifically children’s media, in representation has been widely researched. Media shapes reality as much as it reflects it, and public opinion can be significantly influenced by a piece of media (Action for Children, 2023). Media informs us of the values of a society, and determines public opinion, whether the media is fiction and non-fiction. This research aims to shed light on representations of illness in contemporary media.

[1] Much of YA media can also be seen as crossover literature, and is read by older adults too.

In this thesis I will investigate how illness narratives are told in YA literature, through the investigation of a number of novels aimed at teenagers. This to answer the following research question: How do illness narratives about young girls in Young Adult literature inform readers about societal values of illness and the sick role, and reflect on the representation of young girls in YA fiction? To answer this central question, I will explore several further questions, such as what diseases are represented, how these diseases are discussed, and how the sick role is fulfilled.

Chapter 2: Theoretical Framework

Several concepts will be important in the scope of this research, and need to be conceptualised here to further explore the central question.

2.1 Illness, Disease or Sick - Ab/normality

While the terms are generally used interchangeably, there are marked differences in specific uses of illness, disease, and sickness, which mark the frame in which the experience of being ill is discussed. Disease is the ailment as seen through the physician's eyes; a physiological malfunction, with negative effects on the body and daily functions of a person. When we refer to a disease, we often mean a diagnosis that a doctor has pronounced. Illness is the ailment as experienced by the person themselves; an undesirable state of health that is subjective to the person experiencing it. Lastly, sickness is the societal experience of an ailment; society's perception of the negative impact on body and social functioning of the affected person (Schermer, 2013). Throughout this research, the term illness will be used with these definitions in mind.

Similarly, the concept of health carries a lot of weight. While we all may have an understanding of what health means, and what it means to be healthy, this concept is far more complex and individual than we often realise. Health can be seen as the absence of disease, or normal biological functioning, according to Christopher Boorse (1975). Boorse based this definition on the statistics and biology of the body. One of the issues of this definition lies in the 'normal biological functioning', a phrase that implies that there is a single baseline that *all* human bodies adhere to. Normal means that anything that does not follow this norm is automatically abnormal.

The World Health Organisation (WHO) defines health as "...a state of complete physical, mental and social well-being and not merely absence of disease or infirmity" (World Health Organisation, 2006, Para. 2). However, this definition brings up similar issues as Boorse's did, as it has implications about what the human body ought to be capable of. When being healthy means complete physical, mental, and social wellbeing, being even slightly below the norm is immediately considered unhealthy, and abnormal. The WHO's aim is to achieve the best possible health for everyone, and as such this definition does fit within their constitution.

Our idea of what it means to be normal is only measured in terms of what is *not*. Being healthy, like heterosexuality, is seen as the natural state of things, a distinct status of non-being. As such, being ill or homosexual is seen as unnatural, or abnormal. Robert McRuer writes in his essay on compulsory able-bodiedness "you either have an able body or you don't" (McRuer, 2017, p. 398). He argues that, like compulsory heterosexuality, people attempt to appear able-bodied ('normal') because societies consider this the state of normalcy, and deviation is seen as wrong and unnatural. The definitions of what it means to be able-bodied and healthy are founded in the capitalist values of the body, where the ability to perform labour is used as a metric for health (McRuer, 2017). When one becomes ill, they are encouraged to do everything within their power (and their doctor's abilities) to return to health, and resume their normal social functioning. One enters the *sick role*, and until they return from it, will be considered in a permanent state of abnormality.

2.2 The Sick Role

Sociologist Talcott Parsons first introduced the concept of the *sick role* in his 1951 book *The Social System*, although he would continue to ponder the concept throughout his works. He argued that being sick was a form of social deviance, albeit one with certain permissions or expectations. The role of the sick person goes beyond just the physical state of being sick, and is not limited to the condition the sick person has. A sick person is exempt from 'normal' social obligations, because they are not a productive member of society. This 'deviance', marked by persistent pain, needs to be policed, which falls upon medical professionals (Parsons, 1951).

The sick role comes with an "institutionalised expectation system" (Parsons, 1951, p. 294), consisting of two rights, and two obligations. The first right is the exemption from a sick person's normal social role, relative to the severity of the illness. For example, a person with a cold, in a post COVID-19-pandemic world, might be exempt from going to the office, but they still have to fulfil their daily tasks for their function. Their right to work from home, does not mean they are exempt from working. Institutions that require a sick note or noted absence for illness are seeking legitimation, and whether the sick person is 'sick enough' to be exempt.

The second right is that the sick person is not responsible for their illness. The sick person should not 'just pull themselves together', they are in a condition that must be 'taken care of'. It is closely linked to the first obligation: a sick person should try to get better. The sick role is abnormal, and a person in this role is expected to return to the normal state; healthy. Lastly, the second obligation is to seek "technically competent help", usually a physician, and then to cooperate with the process of curing, or returning to the normal role (Parsons, 1951, p. 294). Illness, in the sick role, is a liminal state of being, that is neither ideal nor permanent.

These rights and obligations are all relative to the severity of the disease. The sick role can occur in three versions; the conditional version, where both rights and duties apply (most often someone with a curable disease); the unconditionally legitimate, when obligations do not apply (the terminally ill have no obligation to get healthy anymore); and the illegitimate sick role, where the condition is stigmatised by others, and the sick person is considered at blame for their condition (think of addicts, who are often put at blame for getting to the point of addiction, or a person with lung cancer who is blamed because they smoked).The sick role in fiction will most often be assigned to the protagonist, rather than a secondary character. The further role the protagonist takes on is dependent on the type of narrative the story is.

2.3 Illness Narratives

Arthur Frank expands on the sick role in stories or narratives more extensively. In *The Wounded Storyteller* (1995), Frank identifies three types of illness narratives. Narratives are the most easily recognised elements of storylines; stories can be unique, but the way the stories are told is based on combined narrative types, as made available in a culture. One might be familiar with the common ways to structure stories and plot, and the graph that is often drawn up for this, as can be seen in figure 1.

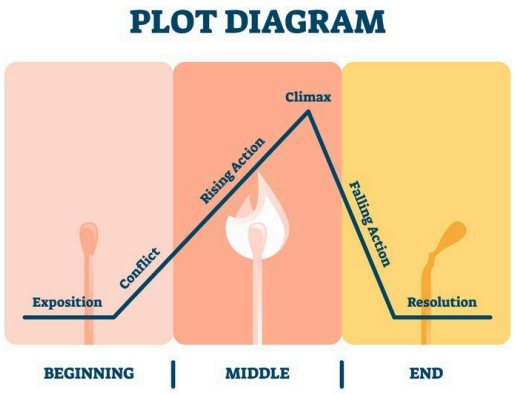


Figure 1: Common Plot Chart. Image by VectorMine.

No actual telling only fits into one of the three narratives posed by Frank, and the narrative type changes depending on the place in the story. The narrative types interrupt one another, and flow together to shape the story being told (Frank, 1995, p. 76).

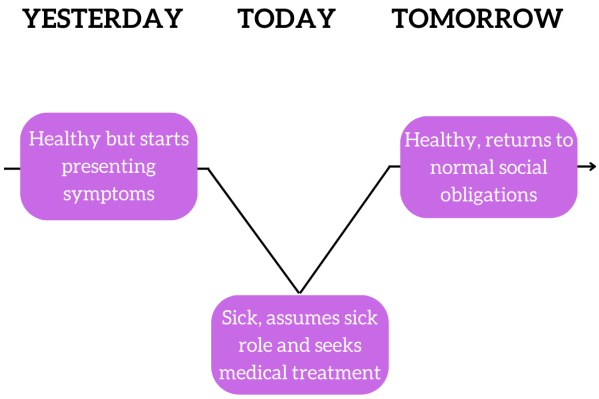
Frank's narrative identification is based on (auto)biographical stories, told either in writing or orally. Thus, his anecdotal examples are almost entirely non-fiction, but most do serve as adequate examples of the theory Frank composes, and can be used to apply to fiction stories.

2.3.1 The Restitution Narrative

The first of the three narratives Frank identifies, is the *restitution narrative*. Frank attributes this narrative to the stories most often told by newly sick people, and a less likely narrative for stories about chronic illness. The central theme for this narrative is that "Anyone who is sick wants to be healthy again" (Frank, 1995, p. 77), and thus the stories are told in that manner.

This narrative closely relates to the modern literature movement that centred their focus on the medical story. Health is seen as the normal condition, and the sick person ought to return to health, and desire to do so as well. This is where Parsons' sick role takes centre stage; the simultaneous right to not partake in your normal social functions, whilst also being required to seek a way to return to health. In modernism, the medical story reflects on the desire to understand science and our bodies. The gaze of stories is on the physician and their relationship to their patient.

The basic progression of the restitution narrative is that yesterday the protagonist was healthy, today they are sick, and tomorrow they will be healthy again. The narrative is filled out with talks of tests and the interpretation of their results, treatments and possible outcomes, physician's and their competence, as well as alternative treatments (Frank, 1995, p. 77). These stories are also often focused on the rearranging of the sick person's role in society, as their illness first worsens, and later improves once more, and thus their exemptions shift too.



Frank calls forth commercials for non-prescription drugs as a common and well-known version of the restitution narrative (pp.79-80). In these commercials, the protagonist starts in physical misery, often shown to be unable to fulfil their social obligations, such as partaking in physical activities, or having fun with family and friends; they are in social default. Then, the remedy being advertised is introduced, sometimes alongside an initial rejection of help, either the remedy or the person offering the remedy. Lastly, when the remedy is taken, physical comfort is restored, and as such, the protagonist leaves the sick role, and returns to their social obligations and engagements. This type of advertising for remedies is so well-known, that it can be reduced to a single image in a magazine or Instagram advertisement, and the audience is able to fill out the rest themselves.

This also serves as an example of the ways in which stories that use the restitution narrative can be told. They can be told retroactively, prospectively and institutionally. Commercials are institutionally told restitution narratives, where the story is told by an institution, such as a hospital or company that develops medicine, to reflect their effectiveness to a general public,

while educating people about the treatment but also "the story people ought to tell about their illnesses" (Frank, 1995, p. 79). When you follow the story arc as desired, and fulfil your sick role properly, you get being ill 'right'. The sick role, and successful fulfilment of it, is institutionalised further through things like sick leave, doctor's notes, and medical care.

The restitution narrative is also reinforced through popular culture, where the habit of thought is repeated over and over. It is as old as the bible, where God punishes the wealthy Job by taking away his family, wealth and physical health, to prove that Job's devotion to God goes beyond his earthly wealth. Job does not curse God for his misfortune, but rather the day he was born. In debate with his friends, who urge him to see the injustice of his illness, he refutes them, which God then rewards by restoring his wealth and making his condition even better than it was (Frank, 1995, p. 80).

Most people do fulfil their sick role as Parsons (1951) proposes it, but those who do not get better still believe their story will turn into a restitution, and they will get better. These are members of Frank's *remission society*. The remission society are the people who are half in the 'sick' world and half in the 'healthy' world. The members of the remission society have to accept a 'background level' of illness, where their life alternates between treatment and activity in their life (Frank, 2002, p. 139). The members of the remission society therefore have no use for the sick role.

The restitution narrative is obsessed with curing, just as the medical world is. The movements of curing, broken down into small sections, can even be therapeutic. Illness is a puzzle to be solved, and the act of piecing everything together is soothing. There is a solution, and a right way to achieve it. The sick role as developed by Parsons encompasses this modern approach to illness. Getting well is the only solution to the puzzle (Frank, 1995).

This goes beyond the acts of getting ill, and being ill. Philosopher Philippe Ariès proposed that in current western societies, death is seen as a failure of modern medicine. We, both individuals and medical professionals, exhaust every resource to find a cure or solution, and defeat is only seen in death. Life ought to be happy and healthy, and expressing sadness or suffering is bad manners

(Ariès, 1974). To pose this as a more personal anecdote, when my grandfather was hospitalised prior to his death, and they discovered he had tumours throughout most of his body, doctors had to decide not to treat anything, and instead make him 'comfortable'. His death most likely was preceded by a lot of pain and suffering, and thus, in my eyes, his death (despite devastating to my family and I), was a form of relief to his suffering. However, expressing this to others is difficult, as they expect that we had fought to keep him alive as long as possible. Other people impose the sick role on everyone, even until death; dying also counts as failing the sick role, whether that failing is on account of the physicians or the individual.

According to Frank's theory, the body needs to return to a state of predictability again. The remedy is a commodity, and the act of wanting to or attempting to shed the sick role, is productive in and of itself. The sick role is not an exemption from social obligations, rather a shift in social obligations. The restitution narrative juxtaposes the healthy body against the diseased one, either through a previous version of the self, or others around them (Frank, 1995, p. 85). Drawing on popular dynamics in sick-lit, the sick girl often has a healthy love interest, who serves the dual roles of juxtaposing their bodies, and being the opposite in their dynamic. The sick person's actions and capabilities are compared against those of the healthy person.

Whilst the hero in restitution narratives is often the sick person (and thus the sick person is often the protagonist), the stories bear witness to the expertise of self, not the struggle, as well as the expertise of medicine. The issue with the restitution narrative is that when it fails, there is nothing to fall back on. There is only the language of the survivor, no other language (Frank, 1995).

2.3.2 The Chaos Narrative

Chaos is the opposite of restitution; life will never get better in a chaos story. Events are told as the storyteller experiences life. The nature of chaotic stories lies in their lack of narrative order, which makes these stories hard to hear or read, as it lacks a 'proper' story. The life lived by the teller or protagonist is similarly seen as 'not proper', because the events do not follow one another in a logical order (Frank, 1995). Seemingly, this also means that the chaos storyteller is

unable to adequately fulfil the sick role, as their lack of getting better does not comply with what one ought to want or achieve.

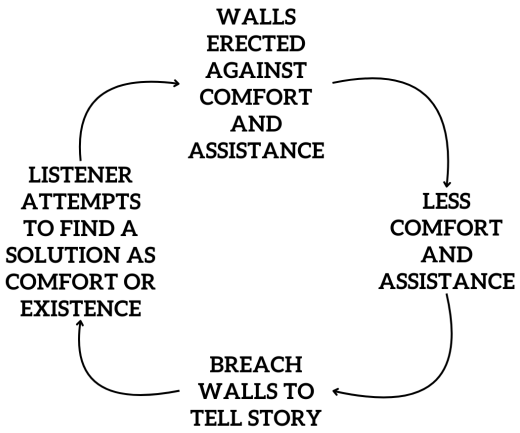
Chaos stories are anxiety provoking, because the listener expects a restitution story and prefers this narrative. In opposition to the restitution narrative, which tells the story of a triumphant return to health, the chaos narrative tells the story of how easily anyone can be sucked under. It competes with the modernist ideals of progress and remedy central in the restitution story, presenting instead vulnerability and futility. The lack of a happy ending in a chaos story makes it hard to accept as a narrative of illness (Frank, 1995). The ending is usually a more open ending than a straightforward happy, or sad one; there is no getting better, no point of returning to health, and no neat cut-off point to end the story on.

The story told is an attempt by the storyteller to reflect on their chaotic life, but unlike the listener, the teller is unable to step out and observe the chaos from a distance. Therefore, the attempt to verbalise the chaotic nature of life can only be an approximation of what is happening, or it "traces the edges of a wound that can only be told around" (Frank, 1995, p. 98). It is unclear whether this means that, according to Frank, chaos narratives told by an outsider are not chaos stories.

The chaos narrative is characterised by four things. 1) a non-narrative sequence, with no memorable past, or future that is worth anticipating, only the present; 2) it contains life possibilities that anyone fears, precisely because it could happen to almost anyone; 3) the overdetermination of the situation at hand, where troubles go far further and deeper than can ever be fully put into words; and 4) the staccato pacing of words, which eats away at the listener to reflect the way the situation of the teller eats away at them (Frank, 1995, pp.98-99).

Chaos contained within a narrative can be retroactively remediated, by filling the gaps where chaos reigned. The teller has missed bits and pieces of their own life, but through tools like videos, photos and other people's memories, they can still understand what happened. The story is told around the edges of the chaos, and by bringing the pieces around it together, the chaotic gap in the centre stands out in stark contrast (Frank, 1995).

There is also a distinct lack of control in the teller's life. There appears to be no controlling the outcome, nor can the teller control what exactly was going to happen. The chaotic nature is fueled by the fact that there is no one in control. Medicine, and modernist ideals, pretend to be in control, at the expense of denying suffering it cannot treat. The body in the chaos narrative is swept along without control by the fundamental contingencies of life; predicting anything has failed, at a cost. This contingency is seen as inevitable rather than really accepted. The desire to find an escape, solution, or remedy is expressed by the listener. A loop is created:



This loop encapsulates the inability to receive comfort, reflecting the body's lack of desire (Frank,1995, p.103). The desire it once had, has been too frequently disturbed, and desire is therefore pointless. Frank also addresses the embodiment of the situation: "Association with one's own body is also dangerous. The body is so degraded by an overdetermination of disease and social mistreatment that survival depends on the self's disassociation from the body, even while the body's suffering determines whatever life the person can lead" (Frank, 1995, p. 103). This sort of dissociation is expressed through phrases like 'it's hurting me' instead of 'I hurt'. Therefore, the body in chaos narratives is monadic,where it cannot find recognition or support for its pain and suffering. Additionally, the chaotic body is contingent, lacking desire and dissociated from the self. Chaotic bodies mirrored onto others show how easily the constructed image can be stripped; the chaotic body appears weak and unable to resist. All bodies suppress the possibility that they too can become chaotic (Frank, 1995).

In chaos narratives the struggle for sovereignty over one's own experience has been lost. When the struggle is told, there is distance from the chaos, and the teller has already somewhat emerged from the chaos spiral. The fear of recurrence at the end of a treatment turns the story once more into a restitution narrative. Chaos stories show the fragility of what props up other stories (Frank, 1995).

In short, chaos narratives are the spiral of one's situation into overdetermination to the point that words can only describe an approximation of what living amidst the chaos is like. For this research it is likely that chaos narratives will only occur within a larger narrative that takes on the shape of one of Frank's other illness narratives, or a different one altogether.

2.3.3 The Quest Narrative

The quest narrative is "meeting the suffering head on" (Frank, 1995, p. 115), using illness to gain something. It affords the teller a voice, because it is the only narrative where the teller has a story to tell. Unlike the restitution narrative, where the remedy (or doctor) is the active player, or the chaos narrative where the suffering is the active player, the quest narrative has the teller as the active player (Frank, 1995).

Frank therefore posits that most of the published illness stories today are quest stories. Illness is framed as a journey, renaming the illness to establish a new relationship between illness and the reader. Quest narratives look for alternative ways of being ill; illness is a journey to discover a sense of purpose.

The structure of the quest narrative consists of three stages:

1) Departure: Starts with a call (symptom), often refused because the hero knows the suffering that will come. This lasts until the call can no longer be denied, and thus the first threshold is crossed (hospitalisation, determination of the severity of the condition).
2) Initiation: The road of trials, where the various sufferings of the illness are told. Undergoing transformation is a lengthy process, and a significant dimension of the storyteller's responsibility.

3) Return: Return as no longer ill, but marked by illness, whether physically or mentally. The teller returns to a world that they have travelled beyond; they have access to different (new) experiences and knowledge (Frank, 1995).

The person's role is that of the hero, conquering the illness and obstacles. A hero's moral status is derived from initiation by means of agony. Suffering is integral to myths and the hero's journey. Learning the integrity of suffering leads to an insight being gained at the end of the transformation. This is the boon at the end of the journey (Frank, 1995).

There are three common facets of the quest narrative, according to Frank, which categorise the wide range of quest stories: the memoir, the manifesto, and the automythology. In this research, only one is relevant. The **Manifesto** is the least gentle of the quest narratives. The truth learnt in manifesto stories is prophetic, whilst the story also carries the call for social action. Society is suppressing a truth about suffering, and this must be revealed. Tellers of manifesto quests emphasise the responsibility that one carries when attempting to return from illness because of this. The previous state of health is a naive illusion the teller does not wish to return to. Disability stories often combine aspects of memoirs and manifestos, as the hero is often stripped of their worldly possessions (health, aids) as they enter the journey. Memoirs reflect on a life interrupted by illness, while the manifesto calls for social change, and *how* the ill person is considered an ill person in society. For a disabled person, telling the story of how the gradual loss of health came with a parallel loss of independence and dismissal as an emotionally capable person. Manifestos assert "that illness is a social issue, not simply a personal affliction" (Frank, 1995, p. 122). It emphasises how disease and suffering is increased by society, and calls for change.

A risk of quest narratives, according to Frank, is that it can present too cleanly and complete, and therefore lack nuance about trauma in favour of telling a neat return from illness (Frank, 1995). Despite Frank's copious rebuttal of Parsons theory of the sick role, this narrative remains focused on curable diseases that one can 'return' from. He does not address the possibility of someone never returning from the journey, nor does he posit that the quest might then take on a different shape. The quest narrative as Frank theories it, also does not address recurrence: when despite a transformation or boon, illness remains or recurs, and the process steps back into the quest.

While this narrative more specifically addresses the written story, Frank still mainly refers to biographical non-fiction stories that discuss illness, and therefore still does not reflect on how his theories on illness narratives can be applied to fiction stories.

While this theory will more than adequately serve as a framework for this research, there are some issues with it. Frank is inevitably influenced by both his personal experience, as well as his basis for his narrative theories. He draws mainly upon orally told stories, and only occasionally refers to written narratives. His theory therefore mainly reflects on how one tells a story of illness, and does not consider how writing down the story affects the narrative. Lastly, Frank does not consider that the writer of an illness narrative may not be the ill person the story is about. He only considers autobiographical tellings, and thus his theory is lacking about the outside perspective. This can especially be seen in the chaos narrative theory, which talks about only being able to talk around the edges of the chaos, and the retrospective remediation. The position of the teller of the story as outsider cannot be applied to this theory.

Besides Frank, illness narratives have mainly been the topic of discussion in regards to how non-fiction stories of illness ((auto)pathographies) can contribute to our understanding of the patient experience. Mike Bury (2001) proposes the contingent, moral and core narrative, which are mostly a tool for the analysis of illness stories through discussed elements, unlike Frank's narratives, which are a categorisation of the intent of the teller, enshrined in *the way a story is told*, rather than the topics discussed in the stories (Bury, 2001). Hall-Clifford (2015) theorised why autopathographies have captured the attention of the public, but only non-fictitious accounts often written by and about celebrities. As such, she does not define any categories of narratives, and merely theorised on the impact of illness narratives.

2.4 Girlhood

As I briefly brought up in the introduction, one of the themes in this thesis is girlhood, and its fragile existence in society. Being a girl is beyond being a physically immature/young woman, and the construction of girlhood is culturally and societally dependent, argues Catherine Driscoll in *Girls: Feminine Adolescence in Popular Culture and Cultural Theory* (2002). Childhood is a concept stemming from the 18th century, when previously there were babies and people, and no

transitional phase between the two. Childhood involved new educational processes to shape an adult. Driscoll reflects on the importance of girls in the 20th century, and how they are products of late modernity. She argues that feminine adolescence, despite being popular in discourse across disciplines, have been excluded from theories, instead choosing to focus on adult femininity. Adolescent femininity is only used to construct girls as a contrast to the mature, adult woman, to equate womanhood to independence, agency and originality (Driscoll, 2002, p.9).

According to Driscoll, youth is vital to cultural analysis "because it presents a crucial point of cultural reproduction and cultural change" (Driscoll, 2002, p.10). The construction of youth culture heavily relies on the popular culture that surrounds it. Rebellion is expected, but also seen as temporary and transitional. The feelings of alienation, and desire for rebellion became intrinsic to the representation of youths as a group, fostering a liminal space between childhood and adulthood. However, the liminal narratives are overwhelmingly about young men, and not girls. Not every subculture is recognised as a valid subculture. Teenage girls form cultural groups that are rarely recognised as subcultures, instead their status is derived from their involvement in school, and relative to the boys they hang out with. 'Girls' is used as an overarching subculture, yet is simultaneously not specific enough and too homogenous (Driscoll, 2002, p.210).

"Late modern adolescence has been publicly and popularly figured as expressing a tension, a disjunction, between (physiological) maturity and (social) majority" (Driscoll, 2002, p.48), but this does not reflect in equal amounts on boys and girls. The bildungsroman (coming of age novel) is often focused on boys, and how they become men, whereas a girl's coming of age is almost always intertwined in romance fiction. Girls in adolescence are malleable, and changeable, and a culturally defined category, rather than merely biological. Boys, in cultural theory, are seen to be more likely to resist social expectations, especially publicly. Girls are not represented as defiant, rather they are considered to be chasing conformity and fitting in. The teenage world around school and home is mainstream and conformist, where conventional happy endings are expected (Driscoll, 2002).

Girl media focuses on a (heterosexual) romance plot (which defines it as 'girl media'), with subplots about appearance transformations, education, and parental relationship resolutions.

Notably, this resolution often takes place despite the marginal role of parents in the media. The girls of teen media may appear varied, but all fall into “an accepted range of behaviors and expectations” (Driscoll, 2002, p.220).

Girlhood, presented in popular culture, is constructed as malleability and a desire for conformity, opposite the rebellion and alienation of boyhood. Reflective of the political and social attitude towards teenage girls, this dissection of girlhood is important to understanding the role of girl protagonists that feature in the corpus of this thesis.

Chapter 3: Methodology

The aim of this research is to gain insight into how the sick role is presented to teenage girls in fiction literature, and what illness narratives are used to convey this. The research method best suited to this question is narratology, the analysis of how the story is told. A narrative text can be broadly defined as any cultural artefact that tells a story. Narratology combines a multitude of narrative theories (Bal, 2017, p.4). For the purpose of this research, several theories stand central, all that can be applied specifically to novels.

Firstly, the matter of plot. 'Plot' can be defined as "the ways in which the events and characters' actions in a story are arranged and how this arrangement in turn facilitates identification of their motivations and consequences" (Kukkonen, 2014, para. 1). Broadly, plot is the organisation of events in a story, and how the events are connected. It can inform readers about motivations and consequences to progress the story, and provides a structure for the author to achieve particular effects. Plot creates coherency in a story, allowing a distinct start, middle and end to a story (Kukkonen, 2014).

In regards to the corpus of this research, 'plot' was seen as the particular events that progress the story, and how they are organised to create coherency and authorial effect. Important matters of plot, those that inform readers about the motivations of characters, or the further development of the characters, were marked for commentary.

This brings up the second narrative element, 'character'. 'Character' refers to a participant in the storyworld that is human or human-like. The status in narratological analysis of a character is widely debated in different schools of thought, and how they can be treated in analysis. Characters are a part of the narrative and progression of the story, but by virtue of being named entities in the story, become a distinct element. A character is ascribed properties that construct their characterisation. There are categories of characters, most famously Forster's 'flat' and 'round' characters, where flat characters are constructed around a single idea or quality, and a round character is more organised and diverse. The way a character is presented in a story dictates the way in which the reader relates to them. A character can be a narrative agent, focaliser, narrator or narratee (Margolin, 2010, pp. 52-57).

In this research, characters were the named participants in a story. The attention was primarily on the traits ascribed to a character, and how they inform their motivations for certain actions and lines of thinking. Additionally, how characters change throughout the story was important. This attention was mainly for the protagonists of the stories, as those were the characters with an illness that constructed an illness narrative.

This leads to the third narrative element, 'focalisation', which is "the perspectival restriction and orientation of narrative information relative to somebody's (usually, a character's) perception" (Jahn, 2010, p.173). Focalisation was introduced to reformulate perspective and point of view. It breaks down in two three degrees of restriction. 'Zero focalisation' means that the narrator knows more, or more precisely, says more than any of the characters know. This is often coined the *omniscient narrator*. 'Internal focalisation' refers to a narrator that is equal to the character; the point of view and perceptions are limited to those of a focal character. This focal character can be fixed throughout the novel, or shift between different characters. Lastly, in 'external focalisation' the narrator says less than a character knows, acting as a fly on the wall that has no insight to a character's thoughts and motivations unless expressed (Jahn, 2010, pp.173-177).

Focalisation was the main narrative tool to determine the distinctions between different illness narratives in this research. It shaped the interpretations of Frank's illness narratives (1995), as will be discussed below. These three narrative elements were used as identifiers to answer the posed research question.

3.1 Illness Narratives for Analysis

As previously discussed, Arthur Frank's illness narratives (1995) are primarily focused on spoken stories, and therefore do not always translate adequately to written narratives, and particularly fiction narratives. In order to utilise them in this research, the main elements of each narrative were used to construct a category.

The restitution narrative is characterised by the journey to recovery, and the yesterday-today-tomorrow element. This narrative was identified when the plot centred around

(successful) treatments, timelines of illness and recovery. Character's motivations had to be centred around recovery and restitution of the healthy state to qualify as narrating a restitution.

The chaos narrative was hardest to quantify into a category, as Frank mainly discusses the *in*ability to express the chaos that one lives in. As such, narratives qualified as chaotic when dissociation from the body was focal, as well as the spiralling out of control that Frank describes. Additionally, the form of the writing helped shape this category, with the staccato 'and then.. And then' reshaped into various narrative features like fade-to-blacks, interruptions and a general lack of structure. One last qualifier consisted of Frank's juxtaposition of the restitution and chaos narrative. If restitution was the need to return to health as quickly and correctly as possible, the distinct lack of this expressed a chaos narrative.

The quest narrative is already well-suited to written illness narratives, as are the memoir, manifesto and automythology within this narrative type. As such, this category was taken as is, mainly identified through the character development and motivations in the story.

Using these categories, five YA sick lit books were analysed, to answer questions in regards to the presentation of illness and the sick role for teenage girls.

3.2 Parameters of Research

The books selected for this research had several criteria attached to them. First, the selected novels needed to have a target audience between the ages of 15 and 17, and thus firmly fall into the category of Young Adult fiction. Books had to be written/published after 2010, to account for changing trends in publishing, reading, and storytelling, as well as updated understanding of treatments and disease. One of the protagonists of the book had to be a teenage girl. This is to account for the target audience of the book. In storytelling, protagonists often have characteristics in common with the intended audience, in terms of age and gender, to relate the character to the reader. As such, it can be assumed that a book about a 15-17 year old girl is aimed at girls of the same age range.

The selected books had to have a central storyline about illness. I did not aim for certain

particular illnesses to be included, but I wanted to include a range of books. This included chronic and treatable physical illnesses, as well as mental illnesses. Eating disorders, a popular topic in teen media, fall under the category mental disorder, as per the DSM-5 (American Psychiatric Association, 2022, p. 372). Lastly, whilst not a requirement, most books that meet the above parameters are likely to have a storyline about romance. Therefore, I made no distinction in the degree of romantic storyline across the selected books.

3.3 Corpus

To select the books that made up my dataset, I first noted down books I remembered that fall into the sick-lit category. Additionally, I looked at book review website *Goodreads*, where users can add books to lists (called shelves on the website) based on a chosen categorisation, and leave community driven-reviews of novels. The list *Sick Lit Books*, particularly, provided much of my reference list of potential books. Using the synopsis on *Goodreads*, I determined if the book centred on illness. I cross-referenced this list with my notes, and then checked the books against the above listed parameters. This led to the following list of selected novels:

- *The Fault in our Stars* by John Green (2012)
- *Five Feet Apart* by Rachael Lippincott, Mikki Daughtry & Tobias Iaconis (2018)
- *Everything, Everything* by Nicola Yoon (2015)
- *Finding Balance* by Kati Gardner (2020)
- *What I Lost* by Alexandra Ballard (2017)

Books that were part of a larger series were excluded, as these are harder to analyse in isolation. Additionally, books set in fantasy universes, or books that featured magic elements were excluded. This is because these books are often set in alternate societies that have different values around illness, or the illnesses featured in the books are used as a magic ability, which changes the so-called sick role as Parsons defined it.

Out of the five books selected, three were turned into major motion pictures. This was not a prerequisite for selecting a novel, but like the romance element, movie adaptations were inevitable. The adaptations were not included in the analysis, but they do serve as an indication

of the success sick-lit has enjoyed over the last 15 years.

The Fault in Our Stars follows 16-year-old Hazel, who has stage IV thyroid cancer, diagnosed at 13. She is depressed, and awaits the inevitable death that comes with the terminal diagnosis, despite an experimental drug that bought her a few years. She attends a support group for children with cancer, where she meets 17-year-old Augustus. He's in remission from osteosarcoma at the onset of the novel, and an amputee (Green, 2012). Despite both of them having cancer, their types of cancer, and subsequent treatments and prospects are very different. Osteosarcoma is bone cancer that typically forms on the femur, fibula, or tibia. Whilst often treatable with chemotherapy and an operation to remove the tumour, amputations to prevent metastasis are not uncommon (Radboud UMC, n.d.). Thyroid cancer is mainly treated using chemotherapy, and sometimes surgery (National Cancer Institute, 2023). The novel focuses on their "plot twist" romance, and their respective feelings about death and oblivion. This novel is about a terminal physical illness, but does discuss the treatments Hazel and Augustus have undergone (Green, 2012).

The two protagonists of *Five Feet Apart* are Stella and Will (Lippincott et al., 2018). Both have Cystic Fibrosis (CF), a chronic physical illness where the mucus and other secreted fluids become thick and sticky, rather than thin and slippery. This causes fluid to build up, particularly in the lungs and pancreas (Chalmer, 2021). Will and Stella meet in the hospital, when Stella needs treatment for what appears as a simple infection. Will, on the other hand, is undergoing experimental treatment for the antibiotic resistant *B.cepacia* bacterial infection. Stella is at the top of the lung-transplant list, as long as she doesn't catch any major infections in the meantime. A lung-transplant can extend her life by a few years.

People with CF are extremely vulnerable to infections, and therefore two CF patients cannot come in close contact with each other. Will wants to defy the rules of his condition, whereas Stella seeks to control as many of the variables as possible. The novel focuses on their love story, and how they develop a relationship despite the mandatory six-foot distance. CF is a chronic physical illness that can only be treated to extend life expectancy and patient comfort, not cured (Lippincott et al., 2018).

Everything, Everything follows Maddy and Olly. Maddy has Severe Combined Immunodeficiency (also known as bubble baby disease). In the words of the novel she is "allergic to the world" (Yoon, 2015, p.3), and cannot leave her house without endangering her life. Her house is equipped with air filtration systems, an airlock and decontamination equipment. Her mother is a doctor, and she has a nurse who visits daily to monitor her vital signs. Olly moves into the house next to Maddy's. He is healthy, but has a very dysfunctional homelife. Their relationship develops through instant messages and emails, until they start meeting in person in the carefully monitored home. Maddy, desiring to live instead of just being alive, starts defying the confinement of her condition. Of the 5 novels selected, this is one of two with a healthy male love interest. She meets with Olly in the confines of her carefully monitored home numerous times, but this is eventually brought to a halt when her mother finds out (pp.136-138). Maddy is put in (further) house arrest, not allowed to have any visitors, and her nurse, Carla, is fired for allowing the visits.

Maddy runs away, owing to her growing resentment towards her mother. She wants to live beyond her impossible life in her small world (p.169), and goes to Hawaii, her deceased dad's favourite place, with Olly. There, they explore the islands, whilst Olly is under the false impression that Maddy is using medication to mitigate the symptoms of SCID. She eventually nearly dies, going into cardiac arrest. At the ER, it is determined she suffered from myocarditis, an infection of the heart muscle. Upon her release from hospital, she once again becomes confined to her house, until a follow-up email from the ER doctor in Hawaii raises her suspicions that she does not have SCID.

Finding Balance follows Mari and Jase, both survivors of childhood cancer, in remission. Mari had Osteogenic Sarcoma, and had her leg amputated, with very little residual limb. She cannot at any point ignore or hide her cancer survivorship because of this. Jase had Lymphocytic Leukaemia at three years old, and has no memory of this. Beyond his yearly check-ups and one week Camp Chemo, he does not acknowledge that he had cancer. No one at his high school knows that he had cancer, nor that he attends camp for children who have (had) cancer with Mari. When Mari transfers to his school, his anonymity as a cancer survivor is jeopardised.

While both are in remission from their respective types of cancer, their relationship to the status that survivorship grants them differs greatly, and both have to cope with how their role in society is affected by it. Whilst this is the second novel that features cancer as the central illness, the story far more focuses on the long term consequences of cancer (Gardner, 2020).

Lastly, *What I Lost* is about Elizabeth, who is admitted to a treatment centre for girls with eating disorders, to be treated for anorexia (Ballard, 2017). Anorexia Nervosa, as previously noted, is categorised in the DSM-5 as a feeding and eating disorder, subgrouped into restrictive type and bingeing/purging type(American Psychiatric Association, 2022, p. 382). Elizabeth, whilst not explicitly stated, has restrictive anorexia, as she recalls extreme dieting and limiting her food intake. Repeatedly the story reiterates her fear of gaining weight. The story focuses on her time spent at the treatment centre, and her struggle with her recovery.

Of the five novels selected, *What I Lost* has the most limited romance storyline, and is primarily focused on Elizabeth's recovery. It deals extensively with the consequences of anorexia, as well as the societal stigma that surrounds the mental illness (Ballard, 2017).

Chapter 4: Analysis

As discussed in the methodology, Frank's illness narratives have been adjusted to fit written narratives that were then used to identify the narratives in the selected novels. Based on these categorizations, I gathered the following observations.

4.1 I Diagnose You With…

Classic sick lit as Elman (2012) discussed it, most often had cancer as the illness of choice. Anna Leahy, in her review of pathographies between mother and daughter, proposed that cancer-lit puts into words the heaviness that cancer introduces to the lives of the ill person, as well as those around them (Leahy, 2019).

The Fault in Our Stars followed the classic sick-lit template in terms of what illness took the centre stage. Early on in the story Hazel lays out her diagnosis, and the treatments that followed. She starts with her official initial diagnosis "Stage IV thyroid cancer when I was thirteen" (Green, 2012, p.24), and in the following paragraph explains how metastasis tumours spread to her lungs. At age fourteen she experienced pulmonary oedema, which left her in a state she describes to Augustus as drowning, and nearly died in the ICU (intensive care unit) from pneumonia. She describes how her "Cancer Doctor" managed to remove fluid from her lungs, and that due to an experimental drug, her lung tumours shrunk, and stayed that way, something she refers to as her "Cancer Miracle". This miracle only resulted in extra time, and she remains reliant on supplemental oxygen; her cancer has not grown or shrunk, and she remains terminal (pp. 24-26).

Where the book deviates from Elman's description of sick lit, is the role of the love interest. Whilst an ill love interest was not uncommon during the initial rise of sick lit, the image of the healthy boy that falls in love with the sickly girl is far from rare. Middle grade book *Achtste-groepers huilen niet* (Eighth Graders/Cool Kids Don't Cry) by Jacques Vriens (1999), and *Hoe overleef ik mezelf?* (How Do I Survive Myself) by Francine Oomen (2002) are examples of this exact imagery, where the healthy male love interest serves as an inspiration, because they fall in love with the sickly girl during the hardships of illness.

Augustus, when the reader is introduced to him through Hazel's focalisation, is in remission from osteosarcoma. ""My name is Augustus Waters," he said. "I'm seventeen. I had a little touch of osteosarcoma a year and a half ago…"" (Green, 2012, p.11). This is all that the reader learns of Augustus's illness initially. As part of his treatment he had an amputation, and now walks with a prosthetic leg. His status of being in remission is only brought up once explicitly, when discussing eligibility for a Make-a-Wish wish: "I was surprised that Augustus was Wish-eligible, what with being still in school and a year into remission" (p.89). Only when he once again assumes the sick role, does his diagnosis come up briefly again. He talks about going in for a scan, and reveals to Hazel that he has metastatic osteosarcomas all over his body, although this is not stated explicitly. Rather, he says "I lit up like a Christmas tree, Hazel Grace. The lining of my chest, my left hip, my liver, everywhere." (Green, 2012, p.214).

Within the limits of this conservation, he goes from being cancer-free, to an end-of-life diagnosis. From then until the end of the novel, Augustus's illness takes the centre-stage over Hazel's. Despite this, the characters' discussions do not go beyond the topic of pain relief, when Augustus expresses being in pain, and takes unspecified medicine to relieve it (p.221). The novel ends with Augustus's passing, another deviation from sick lit tradition. Whilst Hazel, as the protagonist, is alive by the end of the novel she is not cured, and she does not get her happy romantic ending. This was the first indication of the transformation sick-lit has undergone from its initial introduction in young adult literature, to the current prevailing popularity.

In Kati Gardner's *Finding Balance*, both protagonists Mari and Jase had cancer prior to the novel's events. Unlike *The Fault in Our Stars*, however, both Mari and Jase are cancer free when the story starts, and are in remission from their respective types of cancer throughout the novel. Like Augustus, Mari had osteosarcoma (referred to in this novel as osteogenic sarcoma), and had an amputation to remove the cancer. Whereas *The Fault in Our Stars* glossed over the diagnosis, treatment and amputation, Mari's amputation and the residual limb she was left with is a major topic of discussion. Early on, the reader learns that "no one was really amputated like Mari. She had one of the highest levels of amputation, and even at camp, where there were other amputees, most had at least *some* residual limb" (Gardner, 2020, p.61). The central focus of the story is

Mari's struggle with her amputation and the public perception of this. Her state of remission is not explored.

Jase had lymphocytic leukaemia at age three, and has no memory of this. He is only reminded of his cancer survivorship when he goes to the hospital for a yearly check-up, and when he goes to Camp Cancer, a summer camp for children who survived cancer, which both he and Mari attend. Whilst he has been cancer-free since early life, he is diagnosed with cardiomyopathy towards the end of the novel (p.469). This is a result of the chemotherapy he received to treat his leukaemia. Whilst a manageable condition, it revokes his status as healthy. Due to his age and lack of physical marks from leukaemia he has been able to hide his cancer survivorship from others. When he is diagnosed with cardiomyopathy he has to halt his normal activities like swimming for the school team, and adjust his life around this new chronic condition.

Because the focus of this story is more around survivorship, remission and social issues, treatments and diagnosis are only briefly discussed. In a presentation to her class Mari discusses the treatment she received after being diagnosed with osteogenic sarcoma at 10 years old: "I spent the next year in and out of hospital, receiving life-saving chemotherapy, radiation treatments, and several surgeries" (p. 223). Besides this instance, her amputation is the only treatment that is referenced, because this cannot be separated from her status as an amputee, or her attempt to find a prosthetic limb that works for her. Jase received chemotherapy, which causes his cardiomyopathy (p. 421). His cardiomyopathy is to be managed with "daily medication and monitoring" (p. 520), but this is not referenced again in the novel. This is likely also because this diagnosis is formalised only shortly before the novel ends, thus leaving little room to explore this topic.

What I Lost very loosely discusses an actual formal diagnosis. In brief intervals Elizabeth brings up that her family doctor had expressed concern about her weight (Ballard, 2017, p. 49), and that an incident at school led her to be admitted into in-patient treatment (p.163). Through the discussions about how she purged food, and restricted her food intake, it becomes clear to the reader that she has anorexia, but naming her eating disorder is rare. Frank (1995) argued that all illness stories are naming stories, but *What I Lost* seemingly explicitly avoids naming the illness

that befalls Elizabeth. She does state that “All the women in my family seemed to have a touch of anorexia” (p.149).

This novel has extensive discussions of the treatment for EDs, as it is set almost entirely in an in-patient treatment centre for girls with eating disorders. Elizabeth is taught the rules of her treatment: during meal times, they have a set amount of time to eat their food, and they need to finish their portions. If they do not do this, they are given a calorie shake (pp. 22-23). The girls in treatment are not allowed to discuss weight, their restricted eating habits, or ways to exercise covertly despite being under constant supervision. Through Elizabeth’s eyes the reader meets with a nutritionist to set a meal plan during and after treatment (p.115), as well as several forms of therapy where Elizabeth’s mental state and feelings are discussed (p.15).

Unlike *The Fault in Our Stars,* and more extensively than *Finding Balance*, this novel goes into detail about the long term physical repercussions of anorexia. Elizabeth has to get a bone density test to determine if she is at risk of osteoporosis, as part of the standard medical check-ups she received as an in-patient (p.143). Another patient at the clinic has mitral valve prolapse because of anorexia (p.98).

Similarly, how Elizabeth developed an eating disorder is an important aspect of the novel. During her therapy sessions as well short passages throughout the novel, Elizabeth talks about how she started dieting to lose weight, encouraged by her mother, and how she kept wanting to lose more weight; “I cut out carbs and ate things like cauliflower mashed potatoes and noodles made from seaweed. I told Mom I was dieting and she said: “Let me know what I can do to help. I think you’d look great if you lost a few pounds”” (pp. 34-35). The novel ends shortly after Elizabeth leaves in-patient treatment, and therefore does not reflect on the long-term mental effects of eating disorders, nor does it discuss lesser known types of eating disorders. Thus, Elizabeth's status as a member of the remission society is not discussed.

Cystic Fibrosis, as the central illness in *Five Feet Apart*, is by far a much lesser known and rarer illness than both the various forms of cancer the other novels discuss, and anorexia. The setting of the novel is in a hospital, and as such the reader is made actually aware of the rules and

treatment of cystic fibrosis (cf). Stella, as the girl protagonist, does not discuss when she got diagnosed with CF, most likely because it is diagnosed in infancy. She is in hospital for a sore throat and fever (Lippincott et al, 2018, p.4) but it is later discovered that her gastronomy tube, through which nutrition is transported directly to the stomach, is infected. She is awaiting a lung transplant, and needs to do everything she can to remain as healthy as possible so that she is ready for a transplant at any time. A lung transplant would grant her more time, as her lungs are steadily failing. At the end of the novel she receives the lung transplant she has been waiting for. The novel ends with Stella going on a holiday to make up for the class trip she missed at the start of the novel, and Will going on the world trip that he desired to embark on, as long as he gets frequent checkups. The novel does not end with an outright happy ending, but does have a distinctly positive tone about Stella's health.

Will, the boy protagonist, also has CF. Unlike Stella, however, he has an antibiotic resistant infection B.cepacia. This infection cannot be cured, and he is partaking in experimental drug trials to see if there is a way to treat it, spearheaded by his mother. He is in hospital for one of these trials, against his will. He has to be extremely careful with other CF patients because he can spread the infection to them. Like Stella, his initial diagnosis is not discussed, only why he is currently in hospital.

The rules of CF patients are a central device in the novel to develop the romance between the protagonists. Cystic Fibrosis patients are to keep six feet apart at all times, because the fluid that builds up in their systems carries more infections, and CF'ers can easily infect each other. Stella, Will, and other characters with CF have to wear masks and gloves when outside their hospital room due to the high chance of infection. This is not in an effort to educate the reader who is unfamiliar with CF treatment, but to construct a compelling love story. I likened it to the forbidden love trope, where two lovers fall in love, but are forced apart, by culture, family, or circumstance. The most famous forbidden love is Romeo and Juliet, where the two lovers must find a way to be together despite their families' feud. To draw the parallel with Stella and Will, the obstacles that forbid their love are the cultures of their lungs, rather than the clashes of culture. Their mandated distance becomes a challenge to concur, and their inability to touch each other is made into a sensual tease (pp.185-186).

Different treatments for CF are discussed in the novel, again in the name of telling a compelling love story. Stella and Will have sessions where they wear vibrating vests that loosens the mucus in the chest, getting nebuliser treatments, or IV courses, although it is not clarified what this IV is infusing (p.92). Several types of medication that help with different side effects are brought up repeatedly, because Stella has created an app to help keep track of her scheduled treatments. The reader is kept acutely aware that CF has no cure, and that both Will and Stella have a short life expectancy. Stella's lung transplant is only ever contextualised as buying her time, not as a solution. The chronic nature of cystic fibrosis is therefore highlighted in the story.

Lastly, *Everything, Everything* features the least known illness of the corpus. Protagonist Maddy has Severe Combined Immunodeficiency (SCID), which means she cannot leave her house. Her house is carefully maintained so that no outside air can enter, and everything in her life is managed so that she cannot be exposed to one of her "triggers" which can cause severe allergic reactions (Yoon, 2015, p.3). Her diagnosis trajectory is explained at the end of the novel, when it is revealed that she does not have SCID. As an infant she had Respiratory Syncytial Virus (RSV), which meant she was a very sickly baby. Her father and brother had died in a car accident around the same time. Her mother, in her grief, researched that RSV can be caused by a compromised immune system (pp.272-273).

However, Maddy finds out that she in fact does not have SCID, "I find a printout about RSV from the web. She circled a section that explains that RSV is more severe in people with compromised immune systems. I find a photocopy of the first page of an article on SCID from a medical journal. Her scrawls in the margins are illegible. After that there's a single visit to an allergist and then visits to three different immunologists. Each concludes that no illness was found." (Yoon, 2015, pp.272-273)

The discovery that Maddy does not have SCID follows after she runs away from the safety of her home and goes to Hawaii with Olly. She falls ill with a viral infection that leads to myocarditis (infection of the heart muscle), and her heart stops briefly. A doctor that treated her at the hospital reaches out to share that while Maddy has a very weak immune system, she does not

appear to have SCID. Her lowered immune system is because her environment was so carefully monitored and maintained.

Everything, Everything is the only novel which features a prominent love interest whois healthy. Olly is Maddy's next door neighbour, and has a dysfunctional family, but does not have any illness. Maddy's family is also dysfunctional, but is not presented as such, most likely because the book is written through Maddy's limited focalisation, and the reader only becomes aware of the level of dysfunction as Maddy discovers her mother's lies. Despite taking on a different story direction, it is in this regard that *Everything, Everything* takes on the most classic composition of the teenage sick lit novel from the 1980's (Elman, 2012).

The five novels of this corpus discussed the details of illness in varying degrees. Where *Five Feet Apart* references the exact details of the disease, as well as the treatment, *Finding Balance* focused more on the social aspects of illness. Cancer remained the most 'popular' illness for protagonists, but the novels repeatedly and explicitly discuss remission, terminality and long-term effects.

4.2 Let's Talk about Death, Baby

Due to the wide variety of illnesses, the illness narratives that emerge take on various shapes. The restitution narrative most clearly emerged in *What I Lost*. Whilst it appears to be a chaos narrative at the onset, this is only because Elizabeth initially does not want to be cured; undergoing treatment means gaining weight and no longer being a size zero. Her express desire to keep the benefits of the illness, being thin, and therefore her refusal of treatment is at odds with what a restitution narrative conveys. The absence of restitution invokes the chaos narratives. Elizabeth, as well as other girls at the treatment centre, let their eating disorders engulf them, because their desire lies at the centre of the illness (Ballard, 2017, p.39). Rather than, as Frank (1995) described it, life never getting better in spite of what the ill person wants, *What I Lost* initially presented intended chaos.

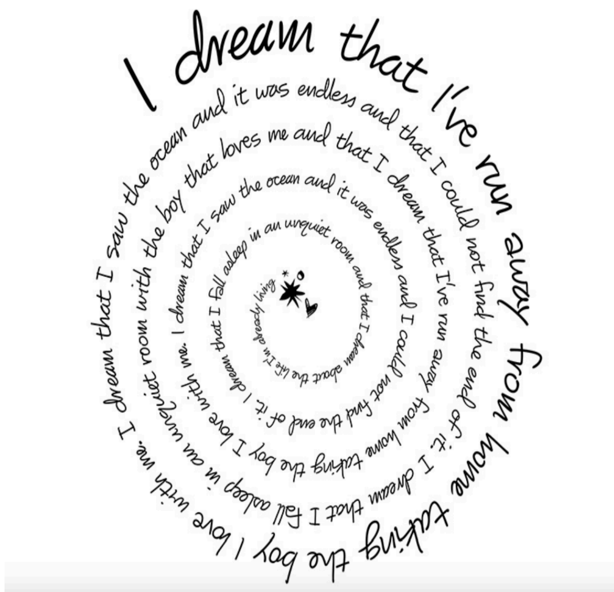
However, the narrative shifts as Elizabeth is in treatment for longer, and as she reflects on how she got as ill as she did. As the title of the novel suggests, Elizabeth reflects extensively on

everything she lost to become a size zero. She reconstructs the social obligations she had, and how she lost them because of her illness. Her boyfriend broke up with her because he could not handle how thin she was, how little she ate, and how she felt like a skeleton (pp.211-214).

As she stays longer at the treatment facility, and is confronted with what might happen if she continues to get more ill, Elizabeth starts wanting to get better, and starts complying with the treatments. “And when I thought about it I did have things to be happy about. I’d finished my lunch. In fact, I was proud to report that I'd finished every meal and snack in the past week” (p.231). The fact that she is already at the treatment centre means that she is already in the process of healing. At the end of the novel, Elizabeth is back home, and starts attending school again. Her friends and parents are functioning as her support system, and she tentatively starts fulfilling her social obligations again. The novel does not outright claim that she is ‘cured’, but the narrative resolves neatly. There is only one explicit mention of the chance of recurrence, or that Elizabeth will have to cope with her eating disorder for longer than the end of the novel: “Tristan, thousands of miles won’t stop me from counting calories in my head” (Ballard, 2017, p.412).

Like *What I Lost*, *Everything, Everything* has a fairly straightforward narrative present. The chaos narrative is present in the fluid structure of the book. Chapters vary from pages to single paragraphs (Yoon, 2015, p.34); at times, images fulfil the narrative role (p.17). When Maddy’s heart stops, the page is entirely black, with the words “My. Heart. Stops.” (p.237), and on the next page, when her heart starts beating again, the same black page now says: “And starts again” (p.238). Right before her heart stops the chaos spiral is even visualised, as Maddy dreams of

home and the words on the page are shaped like a spiral (p. 233), as pictured below.



Maddy's dream spiral. Yoon, 2015, p.233.

The chaos narrative is also present in the progression of the story. SCID is a chronic illness, which can be treated in infancy with a bone marrow transplant, which serves as the only possible permanent cure (Boston Children's Hospital, n.d.). There is no further cure, and for Maddy this means that there is no getting better. She experiences her life as events happen, and sees no change in her ill state. As such, there is no chance of restitution. Then, when she learns that she was never ill, there is no longer a need for restitution, as she is (mostly) healthy. This absence of restitution, but also the absence of the disease, reflects the chaos' narrative's lack of control. Another element of the chaos narrative, as Frank (1995) discussed it, is the non-narrative sequence of the story. Maddy's discovery of her mothers lies is the only time in the novel where events prior to the events of the story are discussed, and the reader learns little else about the past. Similarly, the final chapters of the book only reveal the direct aftermath of Maddy's freedom (pp.300-305).

The consequences of Maddy's long-term confinement are only briefly discussed. In the email she receives from the doctor that treated her cardiomyositis, the doctor expresses that she believes that "your immune system is especially fragile given what I could surmise about the nature of your upbringing" (p.262-263). This is not brought up again in the novel, neither by Maddy or

other figures. Thus, unlike *What I Lost*, there is no resolution, or return to normal, because the normal that was known cannot exist anymore (Yoon, 2015).

The quest narrative that is present in *Finding Balance* is first identified by the title. The novel's central focus is on navigating life with a disability, as well as living in the remission society. Mari is kicked out of her high school because she loses her balance in the school cafeteria, slipping on a grape with her crutches. "The administration thinks that it would be best for everyone, to make school as successful as possible for you, that you either use a wheelchair during school hours or pursue using a prosthetic limb" (Gardner, 2020, p.24).

She starts attending the same high school as her friend Jase, which is her call to action for her quest narrative. Whereas she cannot escape her status as a member of the remission society, Jase has carefully made it so that at school, no one knows that he had cancer. Both have to learn how to live with the consequences of having been ill, and that they will never be able to assimilate back into healthy society entirely again.

For Jase, the call to action that starts the quest, is Mari's arrival at school, and the potential that his status as a member of the remission society will be revealed. Frank (1995) identified the departure of the quest narrative as a symptom, but as the central theme of this novel is not the suffering of the disease itself, but rather the suffering of the consequences, the departure is set when both protagonists are confronted with these consequences.

Their respective struggle with reconciling their 'cancer selfs' and teenagehood is the initiation, where they are met with obstacles. When their desires for the outcome of the quests are at odds, their relationship becomes the obstacle. Mari wants to be accepted as a normal teenager at the school, in spite of her amputation and crutches. She wants to be open about her experiences with cancer, and how it has and has not affected her life. Jase, on the other hand, wants his cancer not to be acknowledged. This becomes impossible when it becomes clear that his cardiomyopathy is going to halt his normal activities (o.a. swimming).

The return from the quest is mainly prompted by Jase revealing his past cancer diagnosis. Mari's quest ends with her telling her story to share a message. *Finding Balance* is a 'manifesto' quest, using the terminology of Frank, that seeks to share a message about what it means to have cancer, and what the remission society looks like for teenagers[2].

In *The Fault in Our Stars* there are two illness narratives that emerge, which trade places throughout the story. At the onset of the novel Hazel's story is a chaos narrative. She is dying, there is no denying that, and she is depressed. She attends a support group, and lives her life with no betterment in sight. Her terminal condition means there is no hope for restitution. She refers to herself as "...a grenade, and at some point I'm going to blow up and I would like to minimize the casualties, okay" (Green, 2012, p.99).

Hazel almost craves the oblivion of death, and finds Augustus's quest strange because of it (p.168). Augustus's narrative is initially a quest narrative. He is in remission, and wants to die in service of a greater good, and be remembered (p.168). Because the focalisation is limited to Hazel's perspective, the reader does not get insight into the departure or initiation of the quest. Augustus is writing an ending to the story both are obsessed with, because the author left it intentionally unfinished, which is what Augustus wants to be his mark on the world.

When Augustus's metastasis is revealed, his narrative abruptly shifts into a chaos narrative. There is no hope of restitution, and his quest to die for a greater good becomes impossible. His quest has failed, as he cannot return having gone beyond the world of the healthy. Hazel describes his quest in a post-mortem message on his Facebook:" He died after a lengthy battle with human consciousness, a victim—as you will be—of the universe's need to make and unmake all that is possible" (p.266). Frank (1995) identifies the chaos narrative as anxiety inducing for the listeners of a story, something that is reflected in Augustus' rather abrupt health regression. The reader expects a happy ending for Hazel and Augustus, but this becomes starkly impossible when Augustus' health declines and his eventual passing.

[2] The manifestation of this narrative likely has to do with the author's position. Kati Gardner is a survivor of childhood cancer herself, and an amputee. She is the only author who appears to have had the illness that is central in the novel. Authorial influence is outside this research scope, but warrants investigation.

Hazel's narrative cannot shift much. She still does not have restitution, nor does she have a real quest. She takes over Augustus's quest, and ensures that his impact on the world is known, if only to his loved ones. She establishes a memoir of his life, but has long established that her life will end as abruptly as Augustus's (Green, 2012).

Like *The Fault in our Stars*, in *Five Feet Apart*, the two protagonists represent two illness narratives. Stella is the restitution narrative. She reflects at the start of the novel that she can live her life "pretty normal", and that it is only occasionally that her Cystic Fibrosis interrupts (Lippincott et al., 2018, p.4). Her restitution, and return to her idea of normal, is a lung transplant.

Will establishes the chaos narrative. He has no cure, no restitution to look forward to, and as such is spiralling through chaos. He wants to refuse treatment, and is waiting to do so as soon as he turns 18 (p.33). His past hospital visits are a blur, just "mountains and mountains of snow that fell while I was there" (p.53). Within Stella's restitution narrative, she is constructing a manifesto. She has a YouTube channel where she documents her journey with CF, and wants to raise awareness for the illness (p.12). This quest however, does not take a prominent narrative role in the story.

The illness narratives, both Will's and Stella's, are not at all obvious. The middle of the novel is primarily a love story, where the reader experiences the two getting to know each other and falling in love despite their illness. It is only when they are starkly reminded of the fact that they cannot be together because of the dangers of CF, that the illness narratives come to the forefront again.

Stella refocuses on her desire to get new lungs, and her desire to stay in optimal health (by her standards), whereas Will resumes his effort to no longer have to undergo treatment. When Stella falls through the ice at the end of the novel, right before she receives her new lungs, the height of the restitution illness is reached, as she almost dies. Then, restitution finally arrives, when her heart is restarted by Will, and immediately after, when she goes in for transplant surgery (p.239-254).The end of the novel shows Stella getting to live her life in this new cured state. Will

gets to travel, but his narrative is still that of chaos, because he still has no chance of restitution (p.273-276).

The restitution narrative is much broader in the novels than how Frank (1995) described it. Because a majority of the illnesses in the stories are chronic, there cannot be a return to health. However, unlike what Frank posed, this does not negate the restitution entirely. For Stella, in *Five Feet Apart*, restitution is her new lungs, and resuming her normal life. Similarly, chaos narratives manifest in the absence of *any* restitution, such as Augustus' end-of-life diagnosis, or Will's untreatable infection; this same chaos took on a different shape in *Everything, Everything*, where the stylistic makeup of the book, and Maddy's vocalisation facilitate the lack of clear forward movement. Despite Frank's posed theory that quest narratives are most common in published illness narratives, this did not prove true in this research, where only one book featured a prominent quest narrative.

4.3 How to be a Sick Girl 101

Whilst analysing the narratives present in the corpus of this research, the sick role that was imposed on different characters sketched a distinct pattern, which can be reliably traced across most of the corpus. The girl protagonists are organised, love reading, and comply with their illness' rules and treatment. Stella (*Five Feet Apart*) makes lists of as many things as possible, Maddy references a lot of novels throughout *Everything, Everything*, and Mari (*Finding Balance*) also expresses a love for reading.[3] The boy protagonists stand in contrast to their love interest, being more outgoing and adventurous. Will wants to travel the world and see everything, Augustus (*The Fault in our Stars*) makes daring moves such as emailing the author of Hazel's favourite book, and Jase is the popular jock that wants nothing to do with being a cancer survivor. As Driscoll (2002) discusses, girls and boys are often depicted in contrast to one another in girl media, with the rebellious boy and the conformist girl. This depiction is notably present in the corpus of this thesis.

[3] The love for reading is possibly an appeal to the target demographic, so that the girl protagonist is most appealing to the reader, who is a teenage girl that presumably loves reading as well.

In *Five Feet Apart*, the way Will and Stella perform the sick role initially are very opposite. Stella attempts to have perfect control over every aspect of her illness that she can. She complies perfectly with her sick role, mentioning that "I don't even flinch" (Lippincott et al., 2018, p.15) when her blood is drawn and IV's are inserted. She also has her own medicine cart in her room, that she organises for optimal use (p.11). Lastly, she is designing an app for people with chronic illnesses where they can track their medication schedules and dosage information, as well as medical charts. The app sends notification when Stella needs to take her medication (p.41).

Will on the other hand, wants nothing more than to defy the doctors, and stop all treatments. He cannot wait to turn 18, and be able to make his own medical decisions (p.33). He does not wear a mask when walking around the hospital, and his rebellion irks Stella (p.38). He wants to be alive, and a 'normal' teenager as he is dying. He wants to return to his social obligations, and not do his best to become better. Stella encourages Will to start following his regime, and he encourages her to start living a little bit more. She is "stealing something back" by only keeping five feet away from Will, instead of the typical six feet. Defying the rules of CF, and consequently, breaking with the rules of the sick role, where one must listen to what the doctor says, is seen as a romantic gesture between them.

Stella also repeatedly expresses the need to appear fine to her parents, because her parents' happiness is of the utmost importance to her: "I don't want to worry my parents. I *can't*" (p.39). This contrasts with Will's defiance of his mother, who is the reason he is undergoing experimental treatments, something he does not agree with (p.55). Stella's parents eventually reconcile, and Will and his mother come to agreements about his treatment by the end of the novel. The resolution of parental relationships looks very different for both of them, and despite the relatively limited role of the parents, is important enough to be mentioned in the final chapters as part of the overarching resolution.

This trend continued in *The Fault in our Stars*. Hazel is going through the motions of sickness, attending a cancer support group because her mother and doctor recommended it (Green, 2012, p.6). She even explicitly mentions the role of the sick person, although she renames it Professional Sick Person, and how that role comes with requirements, specifically sleeping a lot

(p.38). Hazel does not accept her current situation as normal, and comments that she cannot remember what normal lung function felt like (p.114).

Her illness is at odds with her ability to be a teenager, as Hazel's mother expresses to her: "of course your father and I are excited to see you become a young woman, making friends, going on dates" (p.99). Augustus encourages her to do more than go through the motions of her life, when he invites her to go to Amsterdam together (p.89-90).

Hazel, like Stella in *Five Feet Apart*, also has an express desire to make her parents happy (p.8). She is concerned about what her mother will do when Hazel is no longer around to care of, and upon learning that her mother is studying to become a social worker, Hazel is very happy to know that her mother has found another purpose (p.297-298).

What I Lost toiled with the invalid sick role. An eating disorder is still often considered to be a self-imposed problem. Elizabeth refuses to acknowledge that she is sick: "I wasn't that sick. I was just a little bit anorexic" (Ballard, 2017, p.17). She has an express desire to return to her normal social role, where she gets to spend time with her friends, and study for the SATs, among others (p.52).

Elizabeth wants her sick role to be caused by something "I wanted it to be simple. I wanted to say, *I got anorexia because of this,* or *because of that,* or *because of the other thing*. I wanted to be able to blame something - or someone" (p.149). Her mother's pride that she has lost weight validates her reasons to remain ill, and she, like Stella and Hazel, wants to keep her mother proud (p.87). Her relationship with her mother becomes strained when Elizabeth starts reflecting on her mother's attitude and how it fostered her eating disorder. Her mother feels like she is being blamed, and Elizabeth wants her to acknowledge that she is not healthy either, nor are her habits. At the end of the story, it is revealed that her mother has also started treatment for her disordered eating, and is attempting to break through her habits. This is presented as the reconciliation of the relationship between mother and daughter.

Tristan, the eventual love interest, imposes the self-inflicted aspect of the illness on Elizabeth. He mentions that his sister, who also has an eating disorder, chooses to throw up, and that not being ill is as easy as just not doing it (p.177) He also does not grasp that Elizabeth is unable to just turn off counting calories, and that if they just leave their hometown, she can leave behind her role as "the anorexic girl" (p.412).

Maddy shares some aspects of her sick role with the others in *Everything, Everything*. She initially complies with all the rules of her conditions, willingly undergoing the regular check-ups, and staying inside as her mother requires. Keeping her mother happy and complying with doctors orders are rolled into one for Maddy, because her mother functions as her doctor, and she does not see other medical professionals besides her mother and care nurse.

Maddy longs for a normal life, and acknowledges what she cannot do because of her condition. She lists out the "normal teenagery things" that she cannot experience "learner's permit, first kiss, prom, first heartbreak, first fender bender" (p.10). When she runs away from home, prior to finding out that she is not ill, her having defied the sick role is unimaginable. When Maddy visits her nurse Carla at her home, Carla accuses her of being a ghost (p.182). Olly cannot comprehend that Maddy has left the house, has defied the rules laid upon her (p.172).

Once it is revealed that she does not have SCID, she mentions that not being ill means that she is a normal teenager (p.264), inferring that her confinement made her fundamentally abnormal. Her mother is exempt from any blame and responsibilities because she is ill, and imposed her fears on Maddy. When asked if she is willing to forgive her mother, Maddy calls her actions unforgivable, but is informed that her mother was ill and still is ill, and should therefore be forgiven regardless (p.294)

The end of the novel grants Maddy escape from the sick role, because she is no longer perceived as sick. She is able to leave for New York and fulfil her social obligations, albeit for the first time instead of once more.

Finding Balance is the only book in this study to subvert the sick role trend that I observed. Mari actively resents the sick role that is imposed upon her. She has certain exemptions her fellow students do not have, such as being allowed to carry a backpack (Gardner, 2020, p.14), which underlines her status as someone who can never quite be out of the sick role. Her teachers want to go out of their way to help her, and Mari finds their comments and attempts annoying (p.16). Mari, per the suggestion of her school principal, starts looking into a prosthetic leg again, after previous attempts had been unsuccessful and uncomfortable; after all, if she gets a prosthetic "you could look like everyone else" (p.25). She feels inadequate because she uses her crutches instead of choosing to get a prosthetic (p.51).

For Jase, any sign of illness is automatically attributed to a potential recurrence of leukaemia. His mother pushes for tests when he forgot something, because it could be a side-effect of the chemo. Jase himself mentions that "[his mother] thought a cough was a sign of his leukaemia coming back" (p.31). After being teased for having had cancer in middle school, he has kept his cancer survivorship private from his high school friends. This effectively split him into two separate entities, Jase, who had leukaemia, attends Camp Cancer, who knows Mari, and Jason, who is one of the most popular people in his high school, swimmer on the swim team, and does not know Mari, nor anything about being an amputee or having cancer (p.42).

Jase not being public about his past cancer is unimaginable to Mari, because she cannot hide the physical signs of her amputation (p.59). She wants to be able to not tell her story "in the first thirty minutes of meeting [people]" (p.206) because that is easier than letting them guess at what happened. Mari is angry that her status as a member of the remission society is permanent, because her amputation will always prevent her from being perceived as healthy. Jase, like Augustus, Will, and Maddy, wants to live separate from his identity as a sick person. He is technically healthy and appears a part of healthy society, but his membership of the remission society means that any day his status as healthy can be revoked, nor can he ever entirely reassimilate into healthy society.

In *Finding Balance*, the themes of wanting to be a 'normal' teenager take on a very different shape than in the other novels. Rather than striving to change or get better, Mari wants others to

accept that she is normal, and that her disability does not make her abnormal. As mentioned, she expresses her discomfort with being offered accommodations, but also dislikes presenting cancer recovery stories as great heroic feats. “I hate inspiration porn” (p.129), is what Mari proclaims after a promotional video about life with disabilities shows people performing “extraordinary-for-anyone” feats (p.127). For her, the normal she wishes for is a change in the way society perceives her, rather than changing to fit in this perception.

Jase is clinging onto the normal/healthy appearing character he constructed, and throughout the novel, is forced to confront that his sense of normal cannot be maintained. He is abruptly faced with the consequences of his illness, and needs to re-learn his normal, and how this affects his social life. He craves conformity, where Mari craves societal change. This effectively switches the roles traditionally assigned to girlhood in media, where the girl wants to fit in, and the boy wants to rebel (Driscoll, 2002). Jase’s fear of alienation is in opposition to Mari embracing her status as an outsider.

The theme of parental happiness, and how it plays into how the girl protagonists perform their sick role, is notably absent. Jase does experience the typical friction with his mother, where she wants him to acknowledge his former sick role more widely, and continue to attend his check-ups. Partially, this results in his disregard for the symptoms that start to appear in his life during the story, as his desire to disprove his mother fuels the dismissal of his symptoms. Mari’s parental relationship is very different, where Mari’s parents defer to her over the medical decisions, and Mari does not make decisions to appease her parents. Their parental relationships are not fractured, and thus do not need to be reconciled within the confines of the story.

Chapter 5: Discussion and Conclusion

The aim of this research was to answer the question: *how do illness narratives about young girls in Young Adult literature inform readers about societal values of illness and the sick role, and reflect on the representation of young girls in YA fiction*? Using Arthur Frank's (1995) illness narratives as a frame for the stories told, I analysed 5 YA literature books with girl protagonists between the ages of 15 and 18, to establish the societal value of the sick role assigned to these young girls.

Whilst Frank's illness narratives served as a good theoretical frame, it needed some adjustments in order to properly apply the theory to the corpus of this research. Frank established his theory mainly relying on orally shared illness stories. This meant that his theory was uniquely suited for non-pathological use (as opposed to other research into illness narratives, which is focused on the use of them in medical settings). However, this meant that Frank's narratives are weak for application to written narratives. The quest narrative that is the only one acknowledged as a written narrative possibility. The chaos narrative, for the purposes of this research, was the distinct absence of restitution, because Frank only described it as a narrator's inability to touch the centre of the chaos taking place in their life. A restitution narrative consisted of those narrative elements that were focused on returning to a prior degree of health. Rather than 'healthy' being the return to full health, the interpretation that was used for this research was the state of health the characters in the narrative considered desirable.

Whilst Arthur Frank's illness narratives (1995) formed a good basis for the type of stories told, there were several shortcomings. Some were already previously addressed, and amended for application in this research, but other aspects limited the conduction of the analysis. Because Frank based his theory on non-fiction accounts told by 'the wounded storyteller', and as such expects the author of the story to also be the ill protagonist. Due to this, some of the main attributes of the three narratives are rooted in the first-person focalisation limitations, and had to be taken liberally in order to apply to the corpus of this research.

5.1 All Around Me Are Familiar Cases

YA sicklit has undergone a degree of transformation since its initial rise in popularity. Elman (2012) observed that cancer was by far the most popular choice of disease in the '80s. Two of the five novels I analysed had main characters that suffered from cancer, of which *Finding Balance*, was about protagonists that survived cancer, rather than the disease itself. Cancer is an easy to apply illness, familiar enough to many people that the details need not be discussed. Likewise, the main treatments for cancer, as well as their side effects are well known enough that no part of the story needs to be dedicated to the nitty gritty details. Cancer, in sick-lit, functions as the easy out to not have to go into medical details, and write a story where illness functions as just one of the many obstacles in the protagonists' love story. *The Fault in our Stars* focuses very little on the medical side of the story until it becomes inevitable; Augustus' metastatic tumours and eventual death are a stark reminder to the reader that Hazel is also dying, as much as the book does not touch upon this fact much.

Finding Balance displays the social perceptions cancer survivors deal with. As such, beyond a cursory mention of what treatments Mari and Jase had undergone when they were ill, the main focus is not on the medical element. Where in *The Fault in our Stars*, Augustus' amputation is only mentioned as a character trait, for Mari her life has been profoundly impacted by being an amputee. The book reflects more on the long-term social and medical consequences of having cancer. This is highlighted when Jase is diagnosed with cardiomyopathy, and how his self-perception is affected by the need to not be a cancer-survivor in the eyes of others. Cancer does not serve as a backdrop for romance here, but as a social factor in the protagonists' lives.

In *Five Feet Apart*, I observed why cancer serves as the easy out. Cystic Fibrosis is a much more unknown disease, and the causes, treatments, and impacts are similarly unfamiliar to the average reader. Stella and Will undergo treatments together, and the reader learns about the treatments there. The rules of behaviour that are assigned to people with CF, are used in this novel as the main obstacle in their romance. The protagonists are in a forbidden love story at the hands of a disease that neither of them can be cured from. Stella is awaiting a lung transplant, and any upsets to her health can set back her progress on the donor list. Will's untreatable bacterial

infection raises the stakes of their romance, because if he passes it to her, she will become ineligible.

The forbidden romance fueled by the rules of an unfamiliar illness was also in *Everything, Everything*. Maddy's confinement acts as a really good obstacle to any development of her relationship with Olly. Her isolation, and the careful monitoring of her environment and health are shown as the only treatment options for SCID, and the severity of the illness is emphasised to Maddy and Olly repeatedly. In part, the lack of discussions about treatments are because Maddy does not actually have SCID.

What I Lost dedicates the most attention to treatment. Despite the fact that Elizabeth's anorexia is rarely named, the story's central focus is on her recovery. Anorexia nervosa is decently well-known, but unlike cancer, its treatments, causes, and consequences, are much less widely known. Anorexia does not function as a device for a love story, and the treatment Elizabeth undergoes is the centre of the plot.

What illnesses are selected in these stories, was more about the story being told, than the representation of a certain disease. Cancer is the familiar disease that allows explorations of the characters beyond their diagnoses. Lesser known illnesses like CF or SCID can still serve as obstacles in a romance story, but require more exploration of the particulars of the illnesses. Thus, the obstacles in the romance are the illnesses themselves, rather than the social elements around it.

5.2 Frankly, These Narratives are Getting out of Hand

What I Lost is most clearly a restitution narrative. Elizabeth's journey as a character is about regaining the health she lost, but also about coming to accept that she was not healthy for a long time. She wants to return to her normal healthy state, and achieves this through treatment. Frank named the restitution narrative as the narrative every teller wants to tell, but only one of the five books is mainly about restitution. Similarly, Frank names the quest narrative as the popular narrative for published illness stories, but only *Finding Balance* is a quest narrative and manifesto that confronts the reader with societal shortcomings.

The chaos narrative was most recurring in my research, because it manifested as the absence of restitution. All the books dealt with chronic or terminal diseases, which meant there was no clear point of return to health. *What I Lost* and *Five Feet Apart* had the most elements of a restitution, but even so acknowledge that the illnesses are not cured by the end of the story and will not be. Stella does not want to return to a state of health as Boorse (1975) or the WHO (2006) would define it, but to a level of functioning that is healthy for her. The restitution that takes place has to be viewed through different definitions of healthy, where the ill protagonist is healthier than they were at the start or in the middle of the novel.

When there is no possibility to return to health, like Augustus and Will in their respective stories, chaos dominates the narrative. The spiral towards the end is only downwards, even if the author can name the chaos through the eyes of various characters.

5.3 I'm So Sick of it not being about Bread Rolls

Parson's (1951) sick role has particular rights and responsibilities. The sick person is exempt from social obligations, is not responsible for their condition, but must do everything in their power to return to health, and seek out the appropriate care from physicians. This role became gendered in the analysed novels, where certain obligations were more emphasised for the girl protagonists than for the boy protagonists.

The ill girl protagonist is the perfect patient that follows all the treatments that the doctor prescribes, and does so with a smile, and a desire to keep her parents happy. This role is most explicit in Stella's characterisation: she is very preoccupied with being a good ill person, in part because of the awaited lung transplant, and repeatedly mentions that she wants her parents to be happy again. Hazel does what her mother and doctor tell her (like attending the support group), because she is concerned about who her mother will be when she passes away, and Maddy expresses similar motivations. The role assigned to the girl protagonist is beyond that of a sick person. The girlhood role that is displayed, is in line with Driscoll's (2002) discussion on adolescent femininity. Girls are malleable and desire to conform to fellow girls. The express desire of the girl protagonists to be normal, is an expression of their need for conformity, and

their compliance in the sick role is reflective of girls as malleable, and unlike the rebellious teenage boy. Lastly, the girl protagonists' almost struggle with their parents' happiness, and feel responsible for their emotional states. Girl media often pays particular attention to reconciling parental relationships, despite the limited role of parents in the narrative (Driscoll, 2002), and within the corpus of this thesis it is no different.

The boy protagonists are the defiant sick characters, who above all want to live their teenage life as normal. Once again this role is made most explicit in *Five Feet Apart*, when Will refuses to do his treatments, and wants nothing more than to turn 18 so his mother can no longer make medical decisions for him. Only through Stella's coaching does he start actually taking treatment seriously. In turn, he teaches Stella more about being a defiant teenager. Augustus, and Olly, take their respective love interests on 'normal' teenager adventures, and incentivise them to be more free. The boys' relationship with their parents was also notably different. Rather than wanting to keep them happy, the boy protagonist experienced repeated friction with their parents. Jase, in *Finding Balance*, is annoyed by his mother's constant reminder that he had cancer, and her concerns around his health. For the most part, this role as motivator for choices, is the only role parents play in the novels, fulfilling a superficial role in the narrative. Boys are presented as (righteously) rebellious, exercising friction against the societal confines (the sick role) they are presented with (Driscoll, 2002). Their struggle with alienation is expressed through this friction, rather than any expressed desire to be a 'normal' teenager.

The obligation of returning to health is also underscored greatly. Most protagonists, like Stella, want to be as healthy as possible, to be normal and fit in with their peers. This can be going on school trips, travelling the world, leaving the house, or a number of 'teenagery things'. Mari and Jase are exceptions to this trend. Mari wants the rest of the world to accept her current state of being (perfectly healthy, an amputee) as the normal, and plights for societal changes to how people perceive her, rather than try to fit into the normal others have set for her. Jase attempts to cling to the normal he knows, where he can hide his membership of the remission society, even as health problems occur and he is forced to deal with them. Most protagonists cope with the compulsory able-bodiedness as McRuer (2017) defined it, where they feel a compulsive need to be normal in the eyes of society.

5.4 Implications

These YA books set a precedent of what a sick girl ought to act like, and how a sick boy ought to act in response. The illness narratives as Frank (1995) presented them, are overwhelmingly chaotic. Elman, in her 2012 exploration of teenage sick-lit, argued the compulsory able-bodiedness and heterosexuality present in the 1980s emergence of the genre, and how this reflected on the broader political landscape at the time. The recent resurgence of the genre, has brought changes to the foundation of the genre, broadening the spectrum of illnesses, as well as changing the outcome of the stories. Cancer is still the familiar, almost easy illness, that can be understood with little elaboration, but it is no longer presentable as only curable. Because of this, an overwhelming element of the restitution narrative falls away.

The popularisation of the genre in the 2010s also came after significant strides in medical research, and more (public) attention to lesser known diseases, which allowed for illnesses other than cancer to be explored. Illnesses like cystic fibrosis and SCID presented interesting narrative devices that could drive a love story, whilst also being able to explore the complexities of being chronically ill. As a subgenre of the romance genre, sick-lit in this research took on elements of a forbidden romance, with medical obstacles instead of cultural and societal.

The quest narrative is uncommon among the stories, whereas elements of the restitution narrative are present in all books. Despite this, restitution, or return to (complete) health, is not the outcome for these stories. Protagonists die, or their role in society changes so drastically that they cannot deny their role anymore. This caused the chaos narrative to be so recurrent. Connected to the romance element, the chaos narratives provide obstacles and complications for the teenage love stories, and the lives the protagonists wanted to live.

What has not changed from the 1980s, is the compulsory able-bodiedness that characters express. Only one of the novels actively rebelled against the compulsory need to be normal, and is thus the expectation to the trend. Partly due to this compulsory able-bodiedness, most of this corpus does not present as a manifesto or commentary on society.

There are three main broader political and societal implications put forth in this research. First, we have a better understanding of diseases, and the terminal or chronic nature of them, as well as the long term consequences that can arise. Secondly, there is still a compulsory need to conform to society's standards of what is normal or healthy, and do everything within your power to achieve this. The sick role is gendered, presenting differently for boys and girls. Lastly, teenagers are considered capable of dealing with complex emotional matters, like death. They need to learn about real world problems, and novels serve as a teaching tool.

Girlhood is a role beyond the physical state of the body, that is reflective of societal and political attitudes towards girls. Sick girls are depicted as wanting a normal teenage life, which involves romance, sexual exploration, looking like their peers, shopping, and going on the trips their peers go on. Their desire to conform and fit in reflects on a large cultural trend, which dismisses teenage girls as valid subculture groups, rather seeing girls as being, deep down, all the same, and wanting the same things, even if their behaviour is slightly varied.

5.5 Study Limitations

This research presented several limitations, both methodological and practical. Firstly, due to time restraints and the size of this research, the selection of books was limited. The scope was narrowed to adjust for these constraints, but inevitably this also narrows the implications of the research. I exclusively focused on young adult books with girl protagonists between the ages of 15 and 18. Therefore, whilst there are patterns in the behaviour of boy protagonists within that scope, I have not established if this pattern is similarly present in books with primarily boy protagonists. This also applied to the age factor.

Secondly, this research was limited to English language books, also because of time constraints. The corpus was hand-selected, and I relied on personal knowledge of the books to determine if they were suited to the research. In my effort to represent a variety of illnesses, I occasionally excluded titles from my short-list, because they featured an illness that was already represented, or I deliberately searched for books that featured a specific condition. As such, the corpus of this research is not an accurate/representative sample of the wider range of sick-lit.

Thirdly, in this research I exclusively focused on the role that is presented in the books, and did not investigate how this might impact readers. The implications of this research can therefore not be used to draw conclusions about the effect of the presented sick role on readers. Despite these limitations, this research still presents a number of interesting implications that can be used for further research.

5.6 Recommendations

Based on the implications of this research, as well as the limitations, there are several aspects that warrant further research. The variety of illnesses that are presented, and why they are selected, needs investigations. This thesis focused on the presented sick role in teenage girl protagonists in sick-lit, and in order to expand upon this, further research is needed about the impact and interpretation of this sick role.

Additionally, whilst this research did address the romantic elements of the novels to some extent, more research into the specific elements of relationship dynamics could expand upon the presented sick role. Heterosexual couples seem to be the main relationship that feature in teenage sick-lit, and this possibly impacts the presentation of the sick role as investigated in the scope of this research. Further expansion of the scope could include adding non-English books to the corpus, and investigating a different age range and genre. Perspectives on mental disabilities, and neurodivergent disorders are also a potential investigation angle. Finally, in this research I could not adequately investigate the author's motivations for writing the stories, which provides space for more investigations.

5.7 Conclusion

YA sick-lit, headed by novels like *The Fault in Our Stars*, are a part of the cycling trends of youth literature. The reflections on the societal roles of boys and girls in these books have changed alongside the cultural and political landscape, and continue to be a reflection of what we want teenagers to read about. Emphasis on accurate and diverse representation has been expressed, both in society and in research. Media exists as a reflection of society, whilst also shaping society. Thus, the role present in teenage sick-lit is both reflective and shaping.

My study has concluded that illness narratives in teenage sick-lit are typically chaos narratives, lacking the chance for restitution, in part due to the terminal or chronic conditions that are selected to be featured in the stories. The societal value of being sick, or the social sick role, is distinctly gendered, where girl protagonists are compliant in their sick role, and boy protagonists are defiant in their sick role. The involvement of the parents is largely superficial, and they mainly serve as a motivator for the behaviour of the teenage protagonists. Girls desire for the parent to be happy, and thus comply with doctors to get better as swiftly as possible, whereas boys defy the sick role to defy their parents. Young girls exist in the liminal space between adulthood and adolescence, and as a dismissed and devalued target demographic. Their role as a sick girl, as presented in YA sick-lit is romantic, chaotic, and compliant.

Chapter 6: Bibliography

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