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Representation Matters: Disability and its Narratives

Cover Page Footnote

I want to thank Dr. Jocelyn Froese for seeing promise in my article, despite only being in first year, and encouraging me to seek publication.

Representation Matters: (Dis)ability and its Narratives¹

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Abstract: *The representation of disabilities is complex and its dissemination through media is prevalent in social construction. In this paper, I will be using identity-first language which places the disability before the person as the descriptor. Through analyzing *A Curse so Dark and Lonely* by Brigid Kemmerer, this paper investigates what kinds of representation are found in young adult literature and how that representation affects the influence and use of disabilities in the genre. This will be done using narrative frameworks and Julia Kristeva's social paradigm. Disabled characters frequently suffer from narratives that go against progress in disability discourse and lack the substance to create real change in the field (Goethals et al., 2020). The quality of representation in texts should be based on interactions between disabled characters and their society rather than simply good or bad (Prater, 2003). Conclusions suggest that *A Curse so Dark and Lonely* is a model for robust representation of disabilities; disability studies is a broad field and needs more attention by scholars.*

Keywords: Disability, Narratives, Ableism, Social Paradigm, Representation, Disabilities Studies, Cerebral Palsy, Fantasy, Young Adult

The representation of disability has had a complex history. From disabled individuals being viewed as demonic to something that can be fixed, there has never been a widely known version of inclusion for disability in society (Sweed, 2020). Often disabilities in texts are used as metaphors, like loss or evil (Schalk, 2017). Disabilities are frequently superficial; sometimes as magical portrayals; melancholically; or in a super crip narrative. There is not much in between and few depictions of normal life. I will be using Brigid Kemmerer's *A Curse so Dark and Lonely* to explore the current state of the field of disability. Schalk (2017) defines disability as a "socially constructed concept that deems certain bodyminds and behaviours acceptable and others pathologically nonnormative and deviant"

through different discourses (p. 149). Disability can affect the mind and body but does not always remain stagnant. Thus, social constructs are created by the ambiguous nature of disability, subsequently leading to the discussion of disability becoming a taboo topic (Haigh, 2012). Literature has recently begun to incorporate characters with disabilities. *A Curse so Dark and Lonely* is a recent publication in terms of disability released in 2019 and has had little attention in scholarship. Previous scholarship has not examined *A Curse so Dark and Lonely* or incorporated a hybrid analysis of narrative frames and paradigms to this text. Representation of disabilities is substantial, but not powerful enough to provoke a positive response in texts. Therefore, Brigid Kemmerer's novel *A Curse so Dark and*

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Lonely, can be used as a model of how disabilities should be written and how this can lead to more robust disabled characters. The book uses modern narratives and plot devices to describe the biases in the fictional society, and it is an example of a novel using disability to create a more personalized character.

Disability Studies

Since disability is not present in public discourse it is commonly neglected. Disability is often not discussed in public discourse like other subject areas: race, sexuality, and gender. Disability studies provides a broad lens to critique and analyze any text and can be used in public discourse about disability (Weinstock, 2022). There are different schools of thought for those scholars that do participate in these discussions. Hughes and Wheeler (2018) note that disability literature is progressing despite attempts to lessen the fears of able-bodied people by diminishing disability. They also highlight that critiques of good and bad representations of disability are still necessary for disability studies (Hughes and Wheeler, 2020). There is still a place for this indication, but it is not all that matters. A disabled individual's interactions with able-bodied people and the world designed for them depends heavily on exposure to disability in media and other texts. Society is deprived of awareness about disability because of the lack of representation in texts. People with disabilities routinely feel isolated in interactions with able-bodied individuals because disability is presented as taboo through narratives (Goethals et al., 2020).

Scholars avoiding the initiative to write about disability studies contributes to the lack of representation (Allan & Cheyne, 2020). Disability studies is a more recent

field of study that can be applied to literature, film, and media (Sweed, 2020). The hesitancy to participate in disability studies by scholars does not help to widen the perspective of the area (Allan & Cheyne, 2020). This hesitancy can be attributed to the obscure nature of the field and the slower nature of the academic conversation (Allan & Cheyne, 2020). Critical avoidance of disability and disability studies in academic work is also a reason for the absence of concentrated work in the field (Allan & Cheyne, 2020). Consequently, the lack of academic articles and representation in other texts contributes to the misinformation and poor portrayals of disabled characters (Allan & Cheyne, 2020). This can lead to inaccurate information about disabled individuals to audiences and can reinforce stigmas.

Typically, the representation of disability in literature is little more than tokenism. Poor representation can consist of a minor character that helps an able-bodied character in their journey or does not move the plot forward (Prater, 2003). The contemporary take on the use of disability in literature is to promote awareness for either disability representation or the disability itself in some capacity; all aspects of disability should be explored not just a small glimpse (Rana, 2017). There are qualifications to determine whether a novel has good or bad representation; were they portrayed as a minor or major character and did they play an active part in the story; is the point of view from a character with a disability; how much did disability play a role in the story (Prater, 2017)? Applying this framework to *A Curse so Dark and Lonely*, Harper is one of the main characters who plays an active role in the story, the plot does not revolve around her disability, and she moves the plot along. Although

disability is not the main story, the author's intention is to bring more representation into the young adult genre; disability plays a significant role in Harper's journey, which ultimately drives the plot forward. The book promotes awareness of cerebral palsy (CP) through Harper's personal struggle. Although it discusses CP, it is through a single mild instance, and thus it fails to discuss the scope of cerebral palsy.

Another approach to understanding representation in novels is the social paradigm which is a major influence on the marginalization of disability. The social paradigm is a social model of societal norms. Often the social model includes systemic issues of race, gender, and sexuality, but this can also include disability. The social paradigm can be used to analyze how a book is placed within it; does the novel conform to the current paradigm or does it resist and challenge current norms? Changing the social paradigm to include normalizing disabilities is the goal. This type of thinking can be seen in *A Curse so Dark and Lonely* with the intention to bring awareness to a disability while also humanizing Harper. The novel does not conform to traditional ideas about how disabilities should be seen and instead presents a story that challenges how disabilities should be written. She is not a helpless victim and shows courage when she fights off an assailant drugging another girl because "[she] can[not] do *nothing*" (Kemmerer, 2020, p. 8). Harper's disability does not diminish or overwhelm her but enhances her natural qualities. This action reveals that Harper's character and CP are used to demonstrate that people with disabilities are like everybody else. Harper simply has to live with CP and is not defined by it. She notes that in order to save an unconscious girl she has to "slip out of

[her] sneakers so [her] stupid left foot [would not] make a dragging noise against the pavement" (Kemmerer, 2020, p. 8) to notify the assailant. Harper eventually changes the social paradigm in her own world by discussing her disability.

The social paradigm occurs all over the world, but in France, philosopher Julia Kristeva is trying to make a social model where disability is included (Haigh, 2012). Historically, first-world countries have established disability regulations, but France has often slowed to catch up despite their ideals of "liberty, equality, and fraternity" (Haigh, 2012, p. 308). The value of disability inclusion reveals itself to be everywhere and so it is a major problem that it gets neglected. Samantha Haigh utilizes French contemporary novels with disability to show how the social paradigm can be altered to include disability. Often commercial texts push boundaries that can lead to greater societal change. In these novels, authors push boundaries of sex, self-worth, and changing the gaze of disability (Haigh, 2012). These authors are aware of the ever-changing political and cultural context of disability, because of this they write stories that represent the change they want to see and the problems to get to that future (Haigh, 2012).

Ableism

The social paradigm needs to be reconstructed but that is not all that needs to be changed. Ableism is the discrimination against disabled people and is often presented through microaggressions. Not thinking about the needs of people with disabilities is conditioned ableism and this can be seen through the exclusion of disability in sports, schools, and literature. When a child at the supermarket points out that a person has a prosthetic limb, the mother shushes them and says that is

impolite to highlight differences. In this instance, ableism is being reinforced by the mother, implying that pointing out differences is bad and should be ignored. This is not the message that should be shared as this further implies difference itself is bad. That moment in the supermarket could have been a teachable moment. Ableism is conditioned at an early age and requires active change.

Forms of ableism can be found in literature. Disability is often used as literary symbolism in an able-bodied character's moral development (Prater, 2003). Neglecting to view the negative effects of writing about disability this way perpetuates ableism. Microaggression theory and the idea of disability hierarchy are used to promote ableism (Hughes, 2018). Microaggression theory refers to intentional everyday communication that fosters negative behaviour toward a marginalized group (Hughes, 2018). Disability hierarchy: research states that certain disabilities are preferable over others (Hughes, 2018). These theories lead to an understanding of ableism because as Hughes notes, the messages from the novels she analyzes often get obstructed by societal ignorance and intolerance towards disabled individuals (Hughes, 2018). Ableism is a systemic problem; the social paradigm is the system. To begin to overcome ableism more interaction between able and disabled people is needed (Hughes, 2018). If society's mindset towards disability changes, the biases constructed will start to fade (Hughes, 2018).

Young Adult Literature & Cerebral Palsy

The genre of literature that has the most potential to make a change in disability studies is young adult fiction

(YA). This is because young readers are more open-minded to the possibility of variation in the social paradigm. There has also been a boom in young adult fiction, specifically in YA fantasy; as seen on YouTube and TikTok with a heavy focus on book subcultures on the platforms (Hughes & Wheeler, 2018). The rise of teen interest in fantasy leaves the opportunity to illustrate diversity and intersectionality in literature for popular audiences. *A Curse so Dark and Lonely* creates intersectionality with the inclusion of disability, gender, and class through the main character Harper. Harper is female, lower class, and has cerebral palsy. The medieval period she goes to highlights how different she is as she stands out not only because of her CP, but also her socioeconomic status. Heroines and heroes, like Katniss Everdeen in *The Hunger Games*, often struggle in only one area of their life; Katniss lives in a poor district (Collins). But that is not real life, and there is never just one problem, there are multiple. Kemmerer shows that a teenager with CP in a strange place must deal with many complex issues. Using fantasy as a mechanism to deliver important messages in an entertaining and meaningful way can lead to bigger and broader implications in disability discourse.

Cerebral palsy is caused by abnormal development in the brain that triggers weakness in the muscles early in life; there are different degrees of CP, some people cannot talk or are wheelchair-dependent, and some have a milder form of CP (Kemmerer, 2020). The text does a good job of integrating Harper's disability naturally into the story without trying to make a point of incorporating diversity. Harper is a high school dropout helping her brother gain cash for their dying mother, and when Harper spots an intoxicated girl

getting kidnapped by a man, she rushes to defend the girl and ends up being kidnapped herself to another time and place (Kemmerer, 2020). Harper must adapt to medieval times and continue to work with her disability. Harper overcomes physical obstacles like knife throwing and sword-fighting; she comments that “[she] just [cannot] move quickly enough. [Her] balance is lacking [...] and] more of a struggle than it should be” (Kemmerer, 2020, p. 335). If Harper, with mild CP, struggles with these activities, then the typical person with CP would struggle more than her. When Harper goes to a different reality, her CP is viewed as a physical injury that gets pointed out by other characters (Kemmerer, 2020). The little commentary towards her CP from this society is alluded to in the dialogue about how “[she is] clearly injured in some way” (Kemmerer, 2002, p. 29). But her disability is never viewed as one by other characters; disability is invisible in this society and is not widely known by any character in this world (due to the social paradigm in this society). This coming-of-age story serves as a model to better represent disability in literature; there are still flaws regarding authenticity, but the intent to write something that people can relate to is present. If more novels represent disability in this capacity, there would be an overall improvement in the field of disability. Disability stereotypes still persist in new book releases, but are instead used to debunk myths and taboos, like *A Curse so Dark and Lonely*. The representation of disabilities in this novel is substantial enough to create a positive response. Therefore, using this novel as a model for how disabilities should be written can lead to more relatable characters.

Frames and Tropes

In a recent study, scholars found that the majority of people find information about disabilities in the media and that different models for disabilities exist (Goethals et al., 2020). Disabled individuals are represented through narrative frames and counter-frames; these frames are different angles of how these people are portrayed in media stories and can be combined to build multiple frames into one story (Goethals et al., 2020). This is done using multiple media texts to find common characteristics that represent disabled people and confirm that these frames are very influential (Goethals et al., 2020). The daily lives of disabled individuals are affected by socially constructed frames that are also seen in literature (Goethals et al., 2020). Novels including *Graceling* and *A Splintered Spindle* use common disability tropes as convenient plot devices or simply to have a disabled character. In similar novels or more broadly, the social paradigm, there is an archetypal human: male, able-bodied, white, handsome, and European (Goethals et al., 2020). This archetypal human can be seen frequently in films, especially in the superhero genre. This contributes to a lack of representation of disability since the outline for the ideal human is so restricted. A transhuman is someone that looks human, but has abilities beyond that; this idea can be applied to both able and disabled people, yet contributes to the archetypal human. For instance, an archetypal human and transhuman in *A Curse so Dark and Lonely* is Rhen, a prince who is able-bodied, handsome, and European, but has supernatural powers from a curse. Rhen and Harper can be contrasted in this way. Rhen is able-bodied while Harper has a disability, and yet they are defined as main characters because of

transhuman and disability discourses. Harper's CP is viewed as something that will be with her forever that becomes part of her identity. For example, when Harper is offered a chance to cure her "broken body" with magic she refuses because her "body is not broken" (Kemmerer, 2020). In opposition to Rhen, whose curse is viewed as something to get rid of; the curse is supposed to be with him for eternity and he refuses to accept that his curse is part of his identity. For instance, part of Rhen's curse is that he turns into a monster when he fails to fall in love each season (Kemmerer, 2020). He views the monster as separate from himself because the monster kills people, and he has "a chance at stopping" it (Kemmerer, 2020, p. 186). Harper observes that she is lucky for only having a limp after many surgeries and Rhen disagrees with her definition of luck. She reminds him that he is "someone who lives in a castle [...] but calls himself cursed" (Kemmerer, 2020, p. 73). The dichotomy that transhumanism and disability bring to the novel reveals that although disability can often be viewed as a curse, it can also make people stronger and more resilient. While in opposition the transhuman narrative tells audiences that being the archetypal and perfect human does not always mean being a better person.

In *A Curse so Dark and Lonely* multiple frames are used to empower the main character instead of capitalizing on her disability. The human enhancement frame is used when Harper finally tells her captor about her cerebral palsy (Goethals et al. 2020; Kemmerer, 2020). Harper describes how she developed CP at birth, how it affects her and others, and the surgeries she has had (Kemmerer, 2020). Harper is most affected in her left leg, she describes tingling, coldness in her leg and the difficulty she has with coordination and

movement: all common symptoms of CP (Kemmerer, 2020). The use of human enhancement in literature is most often applied in science fiction where technology cures disabilities. Despite having surgeries, Harper's CP is not cured nor invisible, but she has fewer symptoms than before (Kemmerer, 2020). The hero frame is used, yet she is heroic not because of her disability but because of her courage and her determination to work with her CP (Kemmerer, 2020). Normally characters are framed with 'the hero' because overcoming their disability is the reason for them being a hero; in the fantasy/sci-fi genre this frame can be applied to superheroes with super-abilities because of their disability (Goethals et al., 2020). This is not the case for Harper, she does not let her CP define who she is, instead it is something she works with. The last frame used is the helpless victim. Harper was forced into this frame by her family who saw her as powerless and needing assistance because of her CP (Goethals et al., 2020; Kemmerer, 2020). Kemmerer flips the helpless victim frame as Harper comes to realize her power through her journey in an unfamiliar land as she learns to defend herself. This frame is most used to manipulate audiences into feeling sympathy for the disabled character (Goethals et al., 2020). The combination of frames that are used to break down social conventions helps to make Harper an active character in her own story; it is not often that disabled characters get their own story. The use of frames in the novel allows for more powerful portrayals of disabled characters and overall better representation that disabled individuals can relate to or be inspired by.

Science Fiction

Narrative frames are commonly used in literature, but so are tropes and

narrative devices that relate to disability. The most apparent one is ‘the cure’ (Allan & Cheyne, 2020, p. 390). This trope can be found in the science fiction (SF) genre due to the genre’s use of a distant future, where human suffering is nonexistent through scientific advancement. The absence of disability can be attributed to this element. The Science Fiction Research Association (SFRA) collected academic articles for a 2015 conference on marginalized topics in science fiction such as people of colour, women, class, and the LGBTQIA+ community (Allan & Cheyne, 2020). Disability was not mentioned during the conference or in any of the articles and was later added as a footnote in response to Kathryn Allan and Ria Chenye contacting the SFRA about the error (Allan & Cheyne, 2020). During the conference, it was ironic when one of the articles used the lens of gender in SF but ignored implied traits of a disability (Allan & Cheyne, 2020). The whole point of the conference was to bring awareness to marginalized topics but ended up excluding disability. Allan and Chenye (2020) encourage scholars to approach disability studies and be part of the change; social media discourse discusses disability and its representation as academic circles have a tendency to fall behind on new topics like disability. The exclusion of disability is often an unintentional misstep but is part of a long history of neglect (Allan & Cheyne, 2020). Science fiction helps people escape and learn, as well as start difficult conversations like disability (Allan & Cheyne, 2020).

Fantasy and science fiction are similar in how disabilities are represented. Either frames or tropes can be used in high fantasy or a far future. The helpless victim narrative in fantasy looks very similar to SF: someone who resents their disease and

feels vulnerable, but with SF there is a possibility for a cure. This idea of ‘fixing’ disabilities comes from 18th and 19th-century doctors who believed that they could fix disabled people, which can be seen in literature from that period (Sweed, 2020). Previously, disability was thought to be something demonic or inhuman (Sweed, 2020). In science fiction, disability comes full circle as ‘the cure’ could be considered inhuman due to the lack of human struggle. This can almost be perceived as taking humanity away and in *A Curse so Dark and Lonely*, Harper’s relationship with her CP enhances her humanity. Science fiction is a rich genre to explore through disability because there is an option to remain human instead of the transhuman ideal. SF lacks humanity thus lacking accurate disability representation.

Most science fiction uses extrapolation to show their world is futuristic, and it is difficult to find science fiction without a variation of disability (Allan & Cheyne, 2020). Extrapolation is applied to disabilities with the plot device of ‘a cure’ (Goethals et al., 2020). What if in the future there was no illness or human weakness? This can be seen through impossible surgeries, prosthetics, or the use of superpowers (Goethals et al., 2020). This type of narrative is arranged to be upfront and apparent that disability representation is in the text; not the type of representation that should be seen (Sweed, 2020). In the novel, Harper has had previous surgeries, but her cerebral palsy is still present. Kemmerer shows audiences that surgeries are not the cure-all and in this universe with the alternative of magic, Harper still chose not to be cured. This directly conflicts with extrapolation in science fiction and reveals that narrative prosthetics do not have to

cure disabilities; it is okay to be outside the normal and break the social paradigm.

Another deviation from humanity is the use of cyborgs, especially in SF where being posthuman or transhuman is introduced (Allan & Cheyne, 2020). The line of being human is crossed for the convenience of showing the future and potential of mankind. Science fiction novels without disabilities are difficult to find (Hughes & Wheeler, 2018). Novels that use disability as a prosthetic in a narrative are not beneficial to the field of disability and are immediately distinguishable when reading (Hughes & Wheeler, 2018). In *A Curse so Dark and Lonely*, Harper's cerebral palsy is noticeable because of her limp and not as a narrative prosthetic (Kemmerer, 2020). This maintains her more disabled portrayal of a character because she keeps depicting humanity through her disability. Nobody wants to see a character like them that gets fixed with a cure, people want to see characters working with their disabilities (Hughes, 2017; Goethals et al., 2020). *A Curse so Dark and Lonely* is successful because Kemmerer shows Harper's struggle. It is through struggle that progress is made.

Critique

In *A Curse so Dark and Lonely*, cerebral palsy is not accurately presented because it is a mild case and her symptoms from CP do not prevent Harper from doing most tasks. When she does activities requiring mobility, balance, or coordination - shooting an arrow, sword fighting, throwing knives, jumping from a three-story building, jumping to and from a horse - in the real world, it would be nearly impossible for anybody with CP to achieve. Harper's physical signs of limitations can be defined as a limp. The message of the

book, "you can do anything if you try hard enough" or "your disability can improve" are not the wholesome messages that should be given to young adults. Disability should not prevent someone from missing experiences, but the idea that disabilities are malleable and can be overcome in some way is still a large focus. The book does imply that surgeries and technology can solve disabilities in some capacity. This is something science fiction struggles with and should avoid framing disabilities as such; the novel uses technologies as a plot device to make Harper more able-bodied. There are other people with Harper's degree of CP, but the vast majority are not and so the type of representation readers get is skewed. As a consequence, the awareness of CP is undermined by the lack of an accurate portrayal of CP. The novel is still a good model as it seeks to improve disability studies, disabled characters, and role models for disabled individuals. There is still need for improvement in the disability field.

A Curse so Dark and Lonely is a beneficial addition to the world of disability studies. The novel highlights areas of shortcomings in the lack of representation and research in disability studies. Scholars avoiding topics around disability further this scarcity. The social paradigm is at fault for this systemic inequity in disability representation supported by ableism. Combating ableism and its repercussions can effectively be resisted through the genres of fantasy and science fiction for younger readers. For these genres to be successful in circulating positive disability messages, different theoretical frameworks and tropes should be used to assess the potential progression of disability awareness. Transhuman and disabled stereotypes can also be used to deconstruct

the dichotomy between able and disabled characters. The novel makes a positive impact through the awareness of cerebral palsy, even though the depiction of CP is not entirely accurate. The representation in *A Curse so Dark and Lonely* is substantial

enough to provoke positive responses and can lead to better disabled characters in future texts. The field of disability needs more attention and authentic representation.

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