DISABILITY AS EPISTEMIC EXPERIENCE: AUTOFICTIONAL REPRESENTATIONS OF DISABILITY IN GERMAN AND AMERICAN LITERATURE

by

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THESIS ABSTRACT

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This thesis seeks to explore how authors with disability create knowledge about the experience of disability that differs from cultural perceptions of disability. This thesis also utilizes autofictional narratives as a distinct phenomenon of disability that straddles the divide between fiction and autobiography. Utilizing critical disability studies as well as traditional literary studies as frameworks, I analyze how the author and the figure in autofiction create a literary identity that resonates back to the experience of the author with emphasis on disability. I examine the German narrative *Psychocalypse oder das Warten auf Fu* and the American narrative *Pain Woman Takes Your Keys and Other Essays from a Nervous System.* Often metaphorized in fiction, disability becomes a source of epistemology in autofiction as the authors represent themselves rather than being represented by others and as others.

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To the community of disabled scholars.

"Words mean more than what is set down on paper. It takes the human voice to infuse them with shades of deeper meaning"

--Maya Angelou, *I Know Why the Caged Bird Sings*

TABLE OF CONTENTS

Chapter Page

CHAPTER I: INTRODUCTION

Disability is a factual experience of life that occurs through biological, social, and cultural constructions of the world. Disability can be conceptualized as biological differences, as social inequities, and as a cultural entity that unites people. The writing around disability has come from doctors, theorists, philosophers, and authors and has evolved as understandings of what constitutes disability fall in and out of vogue, become redefined by biological discoveries, and by the changing cultural norms of society. However, medicine and medical views of disability are also constructed by social and cultural ideas of normalcy and deviation. Current interpretive approaches to literature often theorize disability as a symbolic commentary. This is realized in different texts in a variety of ways. A literary representation of this sort indicates how bodily or mental deviance is utilized in order to differentiate the disabled figure from the norms implemented by culture that are reinstated in fictional narratives. Other narratives and interpretations invert the previous model by characterizing disability through a symbolic register. Autofiction, in contrast to fiction, is a form of literature that contains elements from the life of the author combined with structures similar to fiction. How then is disability autofiction different than autobiography and in what ways does autofiction provide insight into marginalized voices if it has no truth claim? The reason for examining autofiction rather than autobiography is to explore how autofiction simultaneously can contain an embodied experience while at the same time moving away from the complete truth claim present in autobiography. In this thesis, I look at two autofictional novels by two different authors. The first novel is *Pain Woman Takes Your Keys and Other Essays from a Nervous System* by Sonya Huber and the second novel is

Psychocalypse oder das Warten auf Fu by Carsten Klook. The two novels illustrate how narratives written by people with disabilities challenge the literary assumptions of disability as a representation of otherness. Autofictional narratives from the perspective of disabled authors provide insight into how disability functions in literature when it is not metaphorized and demonstrate how autofiction can expand knowledge of the experience of disability even with its fictional elements.

Before the conceptual outline of theory of disability and critical disability studies frameworks are discussed, I will provide a brief summary of the two works of autofiction that this thesis focuses on. Sonya Huber's *Pain Woman Takes Your Keys and Other Essays from a Nervous System* follows Sonya as she goes through the process of being diagnosed with rheumatoid arthritis, coping with the doctors who do not believe her, and managing her life as a professor and as a parent (Huber). Klook's *Psychocalypse oder das Warten auf Fu (Psychocalypse: Or Waiting on Fu)* follows the story of Marco as he deals with multiple sclerosis and is admitted to different psychiatric wards due to panic attacks, which he suspects are being caused by his medication. Marco is waiting for the approval of a new medication in Germany that begins with the letters "Fu" (Klook). These novels are autofictional depictions of living with a disability that demonstrate how disability functions as a knowledge-building experience.

CHAPTER II: DISABILITY STUDIES AND AUTOFICTION

Several different models of disability are recognized in the context of western civilizations. The four main conceptualizations of disability are as follows: moral, medical, social, and cultural. The moral model of disability has been discredited by other models of disability which negate the concept of moral impurity as a cause for disability. However, the tracings of the moral model of disability are also implicated in the contemporary models of disability and are reflected in artifacts created during times when disability was considered a premonition. An artifact that depicts this associated morality with disability is present within the Bible, where blindness was often considered a punishment for past sin (Otieno). Medical models of disability are by far more ubiquitous and longer-lived than either social or cultural approaches as they are predicated on the concept of the body as a pure biological object. Peter Conrad refers to this as the "medicalization of illness" and states, "A more formal definition sees medicalization as the process by which previously nonmedical problems become defined and treated as medical problems, usually as diseases or disorders" (Conrad 195). Biomedical perspectives on disability can be seen in media such as advertisements for products that claim to reduce suffering or increase longevity. Biomedical perceptions of disability also have a moral underpinning. Unlike in the biblical context, disability is not seen as a punishment, but rather something that one has a moral obligation to treat with biomedical advancements. This contrasts in some ways with the social and cultural model of disability though medicalization is not a diametrical opposition to social and cultural models of disability. In the case of the two novels analyzed, *Pain Woman Takes Your Keys and Other Essays from a Nervous System* by Sonya Huber, and *Psychocalypse oder* *das Warten auf Fu* by Carsten Klook, disability is conceived of in medical terms and medical terminology answers seemingly inexplicable problems, but it does not speak to the entirety of the lived experience of disability (Huber, Klook). The language around the body, when medicalized, turns from speculation to irrefutable medical fact through the authority and power of biomedical discourse. In contrast, this thesis revolves on social and cultural constructions of disability as productive. The medical model prevails in everyday life where social and cultural constructions are considered interpretive. Medical models of disability are bolstered by the notion of scientific vocabulary as imperative, categorical truths.

In response to the medical model of disability, activist and scholar Mike Oliver, along with others, coined the concept of the social model of disability (Oliver). This response intended to react to the stigma about disability produced by medical narrative, which always portrayed disability as undesirable and something to be avoided. The social model of disability also sought to emphasize that disability was a part, not a whole, of people with disabilities and fought against reductive notions that disability was the totalization of a person with a disability. The social model of disability has three main components. Tom Shakespeare writes:

> Impairment is distinguished from disability. The former is individual and private, the latter is structural and public...The social model is distinguished from the medical or individual model. Whereas the former defines disability as a social creation – a relationship between people with impairment and a disabling society – the latter defines disability in terms of individual deficit… (Shakespeare 216).

The social model of disability focuses on the disabling environment. Instead of viewing amputation as a disability, the social model of disability considers the structural and architectural constructions that create a world which limits the participation of someone without limbs. Tom Shakespeare criticizes this social model of disability as reactionary and exclusionary (Shakespeare). Nevertheless, the social model continues to gain traction as disabilities are increasingly recognized as a category pertaining to diversity, and not a detriment.

The most recent development of a theory in disability studies is ostensibly the cultural model of disability. Proposed by Anne Waldschmidt in "Disability Goes Cultural: The Cultural Model of Disability as an Analytical Tool", Waldschmidt delineates four requirements for disability to be implicated in cultural studies. As her definition of culture, Waldschmidt writes:

> [culture] denotes the totality of 'things' created and employed by a particular people or a society, be they material or immaterial: objects and instruments, institutions and organisations, ideas and knowledge, symbols and values, meanings and interpretations, narratives and histories, traditions, rituals and customs, social behaviour, attitudes and identities (Waldschmidt 24).

Waldschmidt then lists the four ideas that emerge from a cultural perspective toward disability. Firstly, she asserts that disability and impairment are not produced by pure, scientific fact. Disability is instead relational category produced by the structures within society. Waldschmidt's argument rests on the notion that definitions of deviation are culturally produced by scrutinization of bodies and decisions on what composes the normate. Secondly, Waldschmidt argues that disability is not a natural fact, which is to say that disability is something that sets a person apart from normative constructions. As her third point, Waldschmidt takes note of the symbolic order of disability, stating that disability occurs in prevailing institutional and symbolic orders. The last tenet of Waldschmidt's cultural model of disability should not be centered on disability as a difference to be observed, rather argues for a humanistic approach to disability and people with disabilities that engages in a dialogue (Waldschmidt).

While I focus on the novel as a cultural product, and therefore focus more so on the cultural model of disability as an overarching paradigm in story-telling and the production of narrative, each model of disability has a specific function in the construction of narratives about disability. The medical model of disability is diffuse in western society, which views health and other deviations as pathological differences to be mended. The social model of disability provides some recourse to the medical model of disability. The narratives I analyze in this thesis begin to unravel certain expectations of disability and move toward understanding disability as a partially sociocultural, rather than purely biological, phenomenon. A cultural approach to disability engages in a dialogue that permits a continuous discussion of the formation of disability and normativity as these things are constructed by the worlds we inhabit. In essence, all literature produced about disability is a bio-sociocultural amalgamate and there is no representation that is purely biological, purely social, or purely cultural.

To engage in an analysis of disability as a literary resource, it is important to consider the fabrication of the body. The normative body has been socially and arbitrarily constructed. Construction of bodies constitutes something outside of the body that codifies and classifies the body socially and culturally. People of color, women, members of the LGBTQ+ community, and people with disabilities have historically fallen outside of the category of "normal". Main characters in literature, movies, and other cultural goods are white, cis-gender, able-bodied and male or if they deviate, they deviate in a way that is acceptable. If the lead character is a woman, she might say some quippy non-sequitur about growing up with brothers when she wins a fight. As representations of marginalized groups become more ubiquitous and marginalized people are allowed space, these instances have become rarer. Yet, representation is still a salient issue. The issue of representation has to do more with power than with majority. The majority of the world is not white or male, yet popular media continually casts white male actors, even white-washing characters of different races. Robert McRuer addresses the idea of normative expectations in his article "Compulsory Able-Bodiedness and Queer/Disabled Existence". He writes, "Like compulsory heterosexuality, then, compulsory able-bodiedness functions by covering over, with the appearance of choice, a system in which there actually is no choice" (McRuer 371). While McRuer identifies correctly that compulsory able-bodiedness occurs in a system with no choice, the literary accounts provided by Sonya Huber and Carsten Klook imply that narratives with disability as a focal point are able to transcend the systematic implication of able-bodiedness.

In "Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature," Rosemarie Garland-Thomson writes, "With the exception notable exception of autobiographical texts...representation tends to objectify disabled characters by denying them any opportunity for subjectivity or agency (Garland-Thomson, "Extraordinary Bodies", 11). Garland-Thomson addresses the general portrayal of people with disabilities as something that defies the realm of literary normativity. The role of stigma has created a sort of dearth around expectations of disability narratives. The narratives discussed in this thesis grapple with the concept of stigma and create insights into worlds that are produced by ideas of normativity and deviance, and stigma and desirability.

Garland-Thomson remarks, “Perhaps most destructive to the potential for continuing relations is the normate’s frequent assumption that a disability cancels out other qualities, reducing the other person to a single attribute” (Garland-Thomson, “Extraordinary Bodies”, 12). The material of this thesis does focus on the role of disability, but it does not intend to be a reductionist view of the author, figure, or reader. Rather, it intends to focus on disability in narrative as a form of empowerment, rather than “enfreakment” (Garland-Thomson, “Extraordinary Bodies”). The body is necessary to the development of this thesis as it is the force on which all normativity and stigmatization acts upon. Disability is not necessarily a cancelling force as Garland-Thomson criticizes, but instead a unifying trait. Not all experiences of disability are universal, yet the texts *Pain Woman Takes Your Keys and Other Essays from a Nervous System* and *Psychocalypse oder das Warten auf Fu* provide a basis on which to separate narratives about disability from narratives that only tangentially concern themselves with the experiences of disabled bodies. Both authors experience disability and write about disability not as metaphor, but as embodied experience.

In this thesis, I identify two constellations formed in autofiction. Firstly, there is the author who has written the story. Then, there is the figural representation of the author within the narrative. This is what I name the author-figure or author-figure, since autofiction represents an inseparable author and figure. This is different from a first-person narration of a fictional novel because autofiction is tied to certain realistic points. Autofiction occurs on a spectrum rather than as a clearly isolated phenomenon, so it shares commonalities with fictional as well as non-fictional narratives. The occupation of this liminal space creates the authorial-figural tension in autofiction that does not occur in fiction. Fiction may not make any claims to the separation of author and figure, but autofiction puts forth the claim that the author and figure are interrelated, and one is inextricable from the other. Relevant to the narrative power in the text is the formation of the text itself. Disability narrative holds a unique and often unrecognized place in literature. In "Illness narratives: Fact or fiction?" Mike Bury outlines the ways in which chronic illness has become its own narrative form. Contingent narratives revolve around social situations, such as times and places where the illness occurs, while moral narratives focus on the norms and perceived virtuous behavior, most often concerned with not meeting a standard or exceeding the limits of patience (Bury). *Pain Woman Takes Your Keys and Other Essays from a Nervous System* and *Psycocalypse oder das Warten auf Fu* are what Bury considers "core narratives" where disability is the focus of the narrative as a central aspect of character identity. Core narratives are important representations of how life with a disability affects either autobiographical or characters with a strong basis in reality (Bury). The components of narrative power I address are selected to demonstrate how disability narratives are qualitative descriptions of disability and the effects of culture on and in disability.

I first focus on the concept of the author. The authors I have chosen to include in primary texts in this thesis are Sonya Huber, author of *Pain Woman Takes Your Keys and Other Essays from a Nervous System* and Carsten Klook, author of *Psycocalypse oder* *das Warten auf Fu*. In “Disability, Narrative, and Life Course” G. Thomas Couser states, “Disability autobiographers typically begin from a position of marginalization, belatedness, and preinscription. Yet one can see why autobiography is a particularly important form of life writing about disability: written from inside the experience in question, it involves self-representation by definition and thus offers the best-case scenario for revaluation of that condition” (Couser 401). In both novels, the author has experience with the disability they are writing about (Huber, *sonyahuber.com*, Klook, *carstenklook.de*)--Huber writes about Hashimoto’s thyroiditis and rheumatoid arthritis (though admittedly, her main focus is rheumatoid arthritis) and Klook has experience with multiple sclerosis, which is the same illness that his character, Marco, has. Huber’s novel is decidedly more autobiographical, while Klook’s is a mixture of factual and fictionalized experiences. By focusing on the author, one can apply Garland-Thomson’s theory of disability as epistemic resource (Garland-Thomson). This perspective is critically relevant when it comes to creating a dialogue about people with disabilities as it provides power to people who are marginalized, rather than rhetoric produced by able-bodied people, which may be accurate and well-researched, but is not a substitute for the experience of the disabled body. The first assertion I make in this section is that Klook and Huber carry out what Couser names “disability life narrative” in an accurate manner (Couser). Secondly, I argue that movements in traditional literary criticism that seek to erase the author seek to maintain narratives of privilege and power. Lastly, in this section, I end with a theoretical link between the figure portrayed and the author.

After the establishment of the author as the creator of the text, the spotlight falls onto the characters present within the text. The central characters in *Pain Woman Takes*

Your Keys and Other Essays from a Nervous System as well as *Psychocalypse oder das Warten auf Fu* are Sonya and Marco respectively. Both of these figures deal with chronic illness as one of the main elements of their narratives. This is a stark contrast to the disabled figure, which traditionally falls on the outskirts of a narrative based on an able-bodied figure. As Ria Cheyne explains in "Disability Studies Reads the Romance: Sexuality, Prejudice, and Happily Ever After in the Works of Mary Balogh," yardstick characters are used as a tool to falsify diversity in literature in order to reflect positively (or negatively, though, more often than not, positively) on the normative main character's arc (Cheyne 208). In "Pain Woman Takes Your Keys and Other Essays from a Nervous System," Sonya Huber uses her first-person identity in the narrative (narrative I). This serves to signify an inseparable bond from author and figure, and it demonstrates and asserts a personal, female experience of disability without censorship or minimization. Even though she uses her own name, the narrative is sprinkled with moments of philosophical insight and poetry not traditionally used in autobiography and contribute to my categorization of the novel as autofictional (Huber). In contrast, Carsten Klook utilizes a character with a different name (Marco) and even a different story in "Psychocalypse oder das Warten auf Fu" (Klook). This usage of a different character with the same disability as the author is a clearer implication of autofictionality and the question: Who better to write about experience than one who has experienced such things? The figure is nevertheless representative of Klook's own experience with disability and serves as a tool to express the hardships and joys found during psychiatric and physical illness, though it is based on the story of a different patient. In this section, I will demonstrate how a central figure with disability provides a different narrative perspective than a yardstick character. By demonstrating this, I also assert that disability narrative written by authors with disability is vitally important to understanding the impacts of disability on people. Lastly, my argument is that disabled figures that are truly representative of disability can only be found in narratives where they are not yardstick characters, and as such, generally only in disability life narrative.

The first thing to address is the analysis of the authors and the identities of the authors as they relate back to the primary texts. To do this, I examine the two novels (*Pain Woman Takes Your Keys and Other Essays from a Nervous System* and *Psychocalypse oder das Warten auf Fu* as whole sums and provide an overview of each novel. Then, I demonstrate similarities between the narrative and the author by examining the social media profiles, websites, and other relevant material about the author. In order to engage in a cultural analysis, I use theoretical texts from disability studies to help examine specific aspects of the authors' lives and their writings.

Secondly, I focus on the figures present in the texts. To analyze the figures, I use a combination of direct quotations from the novel and theoretical texts from disability studies. By analyzing the texts, I outline the ongoing dialogue between the author and the figure and identify how disability and disability representation occur in contemporary German and American literature. Lastly, I bring my conclusions about the author and the figure together into what I call a "literary identity," which serves to acknowledge the role of disability in each aspect of literature and demonstrates how interdependent the roles of author and figure, and as such the conflated author-figure and figure-author role, are in autofictional narratives.

CHAPTER III: THE ROLE OF THE AUTHOR

The first fundamental element of writing that this thesis examines is the author function. The author function plays a vital role in autobiography, autofiction, and fiction, yet there are only a few essays outlining the concept of the author in traditional literary studies. In addition, there are only a small contingency of theoretical literary texts within the French canon (which is often extended to the German canon) that concern themselves with the author. These texts, namely “What is an Author?” by Michel Foucault and “The Death of the Author” by Roland Barthes illustrate approaches to the author that focus on the perceived power of the author. In contrast, when writing about disability life narrative as defined by G. Thomas Couser, or in this case autofictional disability representation, the author is no longer writing from an empowered perspective. G. Thomas Couser writes on the topic of disability autobiographers, “Disability autobiographers typically begin from a position of marginalization, belatedness, and preinscription” (Couser 605). This assertion about autobiography applies to autofiction insofar that autofiction is also an iteration of the experiences of life without the stringent outlines of autobiography. Unlike autobiography, autofiction makes no strict claims of truth. Autofiction operates by articulating things that may or may not have happened that are based on unmentioned things that did happen in the lives of the authors. Authors with disabilities write autobiographies, as emphasized by Couser’s theory of disability life writing. However, autofiction has a sort of ambivalence present in that it teeters between fiction and non-fiction. Therefore, looking at autofiction as a separate phenomenon from fiction illustrates the epistemic realm of disability. Important is the understanding of the author function from a point of deviation from the hegemonic standard is the conceptualization of writing, not as a way to reinscribe power to those already in power, but as a reversal of the power dynamic. This was of course also the goal shared by Foucault and Barthes. However, as Foucault and Barthes have become part of the canon, they have also become part of the system they abhorred. By going against Foucault and Barthes, the canon can be reopened to include the voices of marginalized authors instead of pushing the author to the side. The act of writing from the perspective of experience provides marginalized authors a share of power not previously granted.

The function of the author in Foucault is importantly relational. According to Foucault, authors are first “objects of appropriation; the form of the property they have become is of a particular type, whose legal codification was accomplished some years ago” (Foucault, “What is an Author?”). The author as a subject of legality is in part achieved by the use of the name of the author to indicate power, but Foucault opposes this as he believes the author has little to do with the intrinsic meaning of text. Under a Foucauldian perspective, the function of the author is not singular, but instead rests on the type of authorship. The concept of the author function that Foucault broaches is integral to understanding how the author is conceived in various formats. However, Foucault also writes that the act of writing is “an action that is always testing the limits of its regularity, transgressing and reversing an order that it accepts and manipulates. Writing unfolds like a game that inevitably moves beyond its own rules and finally leaves them behind (Foucault, “What is an Author?”). The disappearing author inevitably privileges identities that have long been seen and have no reason, no discriminatory history, to hide behind the text. Foucault maintains that the author and authorial intentions and experience are fallacious when considered under an interpretive paradigm. However, to articulate disability is to articulate a stigmatized difference and has very real dangers surrounding the articulation, such as discrimination and violence. Therefore, the erasure of the author in Foucault is confounded by empowerment narratives that reclaim the identity of marginalized groups in their own voices.

The essay “The Death of the Author” by Roland Barthes emphasizes that the author “is supposed to feed the book — that is, he pre-exists it, thinks, suffers, lives for it; he maintains with his work the same relation of antecedence a father maintains with his child” (Barthes 4). Barthes’ key argument is that the hegemonic relationship between the proper name of the author and the subsequent interpretation of the text regulated interpretations. If one read Shakespeare, then there was a specific way of interpreting the text because of the name Shakespeare. Barthes’ goal was to open interpretation of texts to discredit such hegemonic readings. However, the denouncing of authorial authority has a different meaning between a white, able-bodied, male author and a disabled, black, female author. Barthes argues that “The birth of the reader must be ransomed by the death of the Author” (Barthes 6). Barthes’ argument intended to break with traditions that codified the identity of the author as the only source of truth in interpretation. In autofiction, it is impossible to disentangle the role of the author from the role of the figure. Likewise, it is equally difficult to separate the figure from the reader, leading to a mixture of the various roles in literature that destabilize traditional thought on the roles of the author, the figure, and the reader.

While Barthes and Foucault first proposed their theories as a challenge to tradition, these approaches have become traditional themselves. The intentions of Foucault and Barthes were similar to the intentions of this thesis, but the circumstances in which Foucault and Barthes wrote and the circumstances in which this thesis came to fruition are very different. Foucault and Barthes were frustrated at the closed circuit of canonical texts and sought to expand the canon. This thesis addresses how the erasure of the author does not function when the author cannot write from a place of privilege, and disabled people are not privileged in contemporary society. Looking to transgender studies informs how an author of disability-centric work such as disability autofiction might be conceptualized. Not all bodies are written from places of power. Only certain bodies are granted permission to fulfill the role of embodiment, in this case in literature. In "(De)Subjguated Knowledges: An Introduction to Transgender Studies" Susan Stryker writes:

> Most broadly conceived, the field of transgender studies is concerned with anything that disrupts, denaturalizes, rearticulates, and makes visible the normative linkages we generally assume to exist between the biological specificity of the sexually differentiated human body, the social roles and statuses that a particular form of body is expected to occupy, the subjectively experienced relationship between a gendered sense of self and social expectations of gender-role performance, and the cultural mechanisms that work to thwart or contain specific configurations of the gendered personhood (Stryker 3).

Focusing on the last part of the quotation, it is noticeable the peripheral and intense effect culture has on how the "gendered personhood" is considered. This is the same for the disabled body, but writing can be an act of subversion for those who are culturally deconstructed. While Foucault and Barthes oppose biographical readings, autofiction is always self-referential. The self-referential nature of autofiction also means that autofiction has a claim to authenticity where there have been fictional depictions otherwise claiming truth. The experience of the disabled author then becomes a source of knowledge that has the authority of experience.

Writing is a tool of power when wielded by those who have been disenfranchised, discriminated against, and disempowered. Donna Haraway writes in “A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late Twentieth Century”, “Cyborg writing is about the power to survive, not on the basis of original innocence, but on the basis of seizing tools to mark the world that marked them as other” (Haraway 175). Haraway’s conceptualization of the cyborg is to erase the dichotomies that are utilized to define human variation and separation from animals and technology. Haraway’s cyborg is a culmination of interspersing identities that indicates how much of human reality is ontologically constructed by false dichotomies. When talking about cyborgs, Haraway focuses on people who have not been in positions of power or privilege. Much in the same way that writing was a way of reinscribing power to women and women of color, the self-representation of disability in literature is a function of empowerment through embodiment of the self in literature. This vital task is undertaken by people with disabilities in an autofictional task that is at once explanatory and communicative, factual and fictional, and individual and collective. The focus of a disability narrative is, according to G. Thomas Couser:

> Like life writing by other marginalized groups—women, African Americans, and gays and lesbian—life writing by disabled people is a cultural manifestation of a human rights movement;

> significantly, the rise in personal narratives of disability has roughly coincided with the disability rights movement, whose major legal manifestation in the United States is the Americans with Disabilities Act, which was passed in 1990 (but which, some would argue has never been fully implemented). The first flowering of disability autobiography is also part of a disability renaissance involving other arts and media. Disability autobiography should be seen, then, not as spontaneous "self-expression" but as a response—indeed a retort—to the traditional misrepresentation of disability in Western culture (Couser 604).

Disability writing is also an expression of the cyborg, which is not born of simple desire, but also of necessity to assert the rights of people with disabilities of expression and embodiment. For Haraway, cyborgs emerge from a system of dichotomous relationships produced by social, cultural, and biological divisions and subvert these dualistic structures. Haraway emphasizes marginalized groups such as black women and disabled people as quintessential cyborgs (Haraway). This is not to dehumanize these groups of people, but rather to emphasize how the function of othering can be utilized dynamically to bolster voices that go unheard. In essence, becoming a cyborg is a form of empowerment that seeks to destabilize the power structures in a society.

For this reason, I propose that there is a specific domain of authorial function called disability autofiction. Firstly, there is the author as an epistemic resource of disability as Rosemarie Garland-Thomson outlines in "Building a World with Disability in It" (Garland-Thomson, "Building a World with Disability in It"). This is supported by the concept of the author as a mediator of experience, which is expressed in Susan Wendell's "Toward a Feminist Theory of Disability," which will be discussed later. The author functions in autofiction, not as a purely authoritarian figure, though the authority of experience is definitely a vital point in viewing disability epistemologically, but instead as a communicative figure, which draws attention back to the author-figure conflation in autofiction and propels the analysis into a figural analysis. The claim that disabled people should represent themselves might also appear authoritarian. The argument I propose is not that disabled people should be the only people to write about disabled people—representation is important and to limit representation to a finite group of people is myopic—but rather that authors with disabilities bring valuable insight to the portrayal of disabled characters. As such, representation of disabled characters by non-disabled authors should be respectful, which means that it should not engage in the devaluation of disabled bodies (Perhaps an exception to this would be to illustrate devaluation in order to critique it). The issue with non-disabled authors writing disabled characters is at its core an issue of power and privilege. Therefore, my assertion is that disabled authors writing about disabled characters provide an epistemological framework that cannot be achieved in the same way by non-disabled authors, and is thus an important contribution to the understanding of disability and the knowledge that disability creates.

It is difficult to analyze the author function with the use of quotations and intertextual thematics. The use of autofiction and the conflation of the author with the figure already implies a certain layered dynamic. These concepts propagate through each other because of the ambivalence and blurriness in autofiction's demarcation of the two roles, making a true separatist approach incorrigible. In the spirit of keeping with the concept of disability writing as a form of life writing, this section examines the function of disability and illness in *Pain Woman Takes Your Keys and Other Essays from a Nervous System* and *Psychocalypse oder das Warten auf Fu* by considering the whole of the text in conjunction with resources about the authors' lives found on websites and in the texts themselves.

The author function is the epistemological realm of understanding disability. In "Building a World with Disability in it" Rosemarie Garland Thomson asserts the idea of disability as a resource for knowledge, writing,

> The current critical generation's critique of objectivity, master narratives, and a universal standpoint has not only discredited 'the so-called view from nowhere' but has also advanced a material turn that furthers a phenomenological approach, bringing together epistemology and ontology in productive accounts of assemblages and material-discursive understandings. This critical exploration has yielded terms that range from oppositional consciousness, standpoint epistemology, outsider/insider perspective, privileged epistemic state, to subjugated knowledge. (Garland-Thomson, "Building a World with Disability It", 56).

Previously in disability narratives, specifically narratives about chronic illnesses such as multiple sclerosis or rheumatoid arthritis, there is the influence of biomedicine as an arbitrator that defines the body by adjudication. That is to say, bodily experience is subjugated for the lens of objectivist science applied to subjective bodies. Kristin K. Barker demonstrates this idea in her book chapter titled "The Fibromyalgia Story:

Medical Authority and Women's Worlds of Pain", writing "Biomedicine seeps into and grows out of our everyday world, giving rise to new types of knowledge, consumer practices, patient movements, and socially constructed identities" (Barker 12). The knowledge constructed by people with disabilities is also entangled with biomedicine, especially when the discourse of biomedicine so prominently overtakes discourse about disabilities. Viewing disability as a source of epistemology involves the myriad ideas and conversations about bodies in medicine and bodies of medicine.

The first novel I look at is *Pain Woman Takes Your Keys and Other Essays from a Nervous System* by Sonya Huber. This is because Huber maintains an online blog that outlines her life and her experiences. When looking at her blog, the bottom of the blog has words that are referred to in her blog often. The larger the word is, the more frequently the idea is tagged. Currently, Huber's blog has the following words tagged: craft, essays, Fairfield MFA, general, nonfiction, health, memoir, public and politics, publishing, random exhuberance (sic), research, rheumatoid disease, solar, teaching, uncategorized, what to read, and writing process (Huber, *sonyahuber.com*). Rheumatoid disease is one of the larger categories, illustrating that it is something that Huber writes about often. Her experience with rheumatoid disease results in the autofictional novel. By writing autofiction, Huber uses disability as an epistemic resource to write about disability from a position that has had power stripped away.

In *Pain Woman Takes Your Keys and Other Essays from a Nervous System*, Huber writes "The question is epistemological, as most questions seem to be: how would this pain feel to another person? Pain is not an abstract essence. It is an experience, a process" (Huber 75). The concept of pain as an epistemological question notes how knowledge is constructed. The knowledge of disability, as evidenced by Barker's chapter, is constructed by biomedicine. Biomedicine itself is influenced by culture. As Rosemarie Garland-Thomson writes in "Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature," "...the freak is represented much like the woman. Both are owned, managed, silenced, and mediated by men; both are socially defined as deviations from the ideal masculine body; both are marginalized in the realm of economic production; both are appropriated for display as spectacles; both are seen as subjugated by the body" (Garland-Thomson, "Extraordinary Bodies" 70-71). The mediation and silence of people with disabilities has long functioned as a reduction of knowledge. Instead of focusing on people, culture has turned toward medicine as a model of objectivity and idealism. This idealism nullifies pain and disability into an abstract essence instead of an experience and process.

Looking at Carsten Klook's *Psychocalypse oder das Warten auf Fu* illustrates also the concept of biomedicine as an intersection of culture and as a re-appropriated way of discussing disability. People with disabilities are organized according to biomedical definitions. Barker emphasizes this when she writes, "A disorder's existence depends on whether it can be translated into biomedical *markers* present among the patients but absent among the controls" (Barker 21). Klook's novel is an interesting subsection of autofictionality because it concerns itself with a character with a different name. Nevertheless, literary criticism hints to Klook's own experience with multiple sclerosis. In a 2019 "Buchtipp der Neurovision" *(Book tip of Neurovision*--a division of the Cranach Apotheke dedicated to studies about multiple sclerosis), Tanja Fuchs writes, “Die meisten Menschen mit Multiple Sklerose könnten sicher eine Menge dazu sagen, ja ganze Bücher darüber schreiben. Carsten Klook hat es getan. Der Autor und Kulturjournalist, hin und wieder auch als Gitarrist unterwegs, lebt in Hamburg und ist selbst an MS erkrankt” (Klook, *carsten-klook.de*). (*The majority of people with multiple sclerosis could say a lot about, indeed write entire books. Carsten Klook did just that. The author and cultural journalist, also occasionally a guitarist, lives in Hamburg and has MS).* Here the knowledge of disability comes to the forefront of the novel. A disability life narrative is created by utilizing disability as an epistemic category. However, the narratives are both autofictional, which may lead to a confusion of the division of the factual and the fictional.

To see the difference between disability as an epistemic resource and disability as a metaphorical resource, one can look at fiction. Franz Kafka’s 1915 novella *Die Verwandlung (The Metamorphosis)* involves a transformation that alienates the main character, Gregor Samsa, from his family and from society. In “Living as the Bug: Kafka’s *The Metamorphosis* as Read Through the Lens of Critical Disability Studies,” Findley argues that this transformation can be understood through the lens of critical disability studies, which is a point that I will extrapolate on later (Findley). In contrast to the autofictional examples, Kafka does not utilize the experience of disability as an epistemic resource. Of course, it would be impossible, or at least very difficult for Kafka to experience turning into a creature as Gregor does. However, the point of this argument is to illustrate that disability as a source of knowledge is often limited to autofiction and autobiography because autofiction resists metaphorizing disability. In *Die Verwandlung* Gregor Samsa’s metamorphosis is seen as a metaphorical commentary on the life of

Gregor Samsa (Kafka). His muteness and inability to move are sudden afflictions that demonstrate some form of dissatisfaction or some sort of innate inability to change his own life. It does not intend to demonstrate disability as a category as something that creates its own knowledge. Rather, it portrays disability as a metaphor for internal struggles as a literary resource.

Another fictional example of the metaphorical presence of disability is perhaps present in the popular *Harry Potter* series. As far as the novels go, there are no explicit references made to disability, but in "Making the Muggle: A Study of Processes of Othering in J.K. Rowling's Harry Potter and how Teachers Can Use the Novels to Work with Issues of Ableism," Robin Aronsson identifies Squibs as the "magically disabled" (Aronsson 29). The role of the "Squib" also functions as a metaphor, this time metaphorizing intellectual disability. Dumbledore is ashamed at first of his sister Ariana, who is a Squib, and then at his treatment of Ariana. A Squib is someone who cannot use magic who is born from a wizard family. This differentiates the Squib from someone born into a "Muggle" or non-magic family because the expectation in wizarding society is that all children born from wizarding families will be able to perform magic (Rowling). In this case, Ariana plays the role of what Ria Cheyne calls a yardstick character (Cheyne). Cheyne describes yardstick characters as characters who are implemented to reflect on a main character's arc, writing, "...the yardstick concept is particularly useful when considering romance novels" (Cheyne 209). This yardstick role is also useful when looking at metaphorical texts about disability, where disability itself plays a yardstick role. It is used as a teaching tool, a punishment, or a moral quandary rather than being a socially, biologically, and culturally constructed method of categorizing bodies.

In this thesis, I analyze two texts from different cultural contexts to demonstrate how the author and the figure in autofiction are interrelated and how autofictional narratives by disabled authors can be perceived as empowerment narratives. This acknowledgement here is to admit that these countries (the United States and Germany) have had individual pasts regarding people with disabilities, though both pasts are sordid. The reason for the selection of these two texts is their contemporary status as well as their relationship with disability. The function of the author as an epistemic resource of disability inverts the perceived docility of disability. On the topic of the docile body, Michel Foucault writes in *Discipline and Punish: The Birth of the Prison*, "A body is docile that may be subjected, used, transformed, and improved" (Foucault 136, *Discipline and Punish*, 136). The reversal of the biomedical naming principles points toward an ability to manipulate biomedicine in the same way it has manipulated the body. Klook and Huber both illustrate this well through their usage of biomedical denominations within texts that largely focus on sociocultural aspect of disability (Klook, Huber). The inversion of biomedical rhetoric as a tool of the disabled author demonstrates how bodies that have been subjected, used, transformed, and improved (in the capitalist sense of improvement associated with productivity) can use the same language that makes them docile bodies to create writings that empower them. Disability as an epistemic resource for authors of autofiction and is therefore part of the author function. Without the power of the author, there is no knowledge, no epistemic construction, and no discourse from within the reality of disability. Tobin Siebers writes in "Disability and the Theory of Complex Embodiment--For Identity Politics in a New Register," "Disability creates theories of embodiment more complex than the ideology of ability allows, and these many embodiments are each crucial to the understanding of humanity and its variations, whether physical, mental, social, or historical" (Siebers 273). Complex embodiment is demonstrated by the reversal model of disability autofiction where biomedical discourse is used in a way that disturbs the ideological mold of biomedicine's striving for authority and for able-bodiedness. Disabled authors have been denied a voice, which makes it imperative for the author to be included when considering disability. The production of knowledge through experience marks the contribution that disabled authors provide that cannot be provided by non-disabled authors.

The author function also serves to communicate this knowledge of disability through the act of writing the text. The mediation of experience is at once a self-expression as well as a sort of extension of the self. In Susan Wendell's "Toward a Feminist Theory of Disability," Wendell argues:

> If disabled people were truly heard, an explosion of knowledge of the human body and psyche would take place. We would have access to realms of experience that our culture has not tapped (even for medical science, which takes relatively little interest in people's *experience* of their bodies). Like women's particular knowledge, which comes from access to experience that most men do not have, disabled people's knowledge is dismissed as trivial, complaining, mundane (or bizarre), *less than* that of the dominant group (Wendell 120).

The knowledge of the human body proposed by authors with disabilities who write about disability indicates an assertion that the dominant group is not the only group with knowledge. Disabled writers still face discrimination and fight with the idea that there is little interest in the knowledge produced by disability. Yet, the knowledge produced by disability, when solidified into text and published also becomes a mediated communicative act. The figure, through its conflation with the author, serves as a tool for this mediation and extends to the reader in a dialogic fashion. One may notice the exclusion of the reader from the majority of this analytical schema that is developed. The reason for this omission is because the focus of the framework is to acknowledge that disabled authors write from an epistemic realm that cannot be paralleled by non-disabled authors. Disabled authors do not write from a position of power, but rather by writing about disabled bodies, they can destabilize the representations of disability that are harmful.

The epistemic resource of disability has been limited by the desire to focus on hegemonic discourses of the body. However, autofiction written by people such as Huber and Klook destabilizes the hegemony of biomedicine's perceived objectivity of the body and indicates that there is a subjective kernel of disability that is predicated by experience. The disabled author functions in a way that does not allow for the erasure of identity. Instead, the complex embodiment of disability is achieved by writing about it as a real, lived experience rather than a metaphorically embodied concept. In *Pain Woman Takes Your Keys and Other Essays from a Nervous System*, Huber expresses her frustration at doctors who refuse to believe a woman in pain (Huber). In *Psychocalypse oder das Warten auf Fu*, Klook describes the markings in Marco's legs created by his injectable medication (Klook). In both cases, disability is not metaphorical—it is real within the text and outside of the text.

CHAPTER IV: THE ROLE OF THE FIGURE

If disability autofiction codifies a complex embodiment of the author as a source of epistemology, the manifestation of the figure is equally complex. The figure remains inextricably linked with the author in autofictional representation. Looking at the disabled figure in representations created by authors with disabilities allows for an insight into narratological representation that has previously been predicated on dominant discourses of disability, which originate from outside the experiential realm of disability as a lived reality. Snyder and Mitchell determine that disability is used as a narrative resource in their chapter "Narrative Prosthesis" writing, "...disability pervades literary narrative, first, as a stock feature of characterization and, second, as an opportunistic metaphorical device. We term this perpetual discursive dependency upon disability *narrative prosthesis*" (Snyder and Mitchell 222). In the process of writing, disability is utilized as a tool to further the narrative. This is especially salient for fictional representations of disability written by authors without disabilities for whom the characterization of disability holds no personal sway nor experience to be relayed into the text.

Snyder and Mitchell continue by outlining the method in which disability is used as a resource in writing. They write, "A simple schematic of narrative structure might run thus: first, a deviance or marked difference is exposed to a reader; second, a narrative consolidates the need for its own existence by calling for an explanation of the deviation's origins and formative consequences; third, the deviance is brought from the periphery of concerns to the center of the story to come; and fourth, the remainder of the story rehabilitates or fixes the deviance in some manner" (Snyder and Mitchell 227). This sort of interpretive paradigm seems to be true when disability representation occurs in fiction. Looking at Kafka's *Die Verwandlung* once again, it becomes clear how the structure operates within the contents of the novel. Firstly, Gregor's transformation is made clear within the first line. Deviance is therefore illustrated early in the novel to communicate to the reader that Gregor has been transformed from a normative body into a non-human body. The novel then moves beyond the deviance to talk about Gregor's life as a traveling salesman. However, the deviance is immediately brought back to the forefront of the novella when Gregor's boss shows up demanding to see Gregor. *Die Verwandlung* has an ending that seems to go against Snyder and Mitchell's last proposition, since Gregor dies as an "Ungeziefer" *(vermin)* (Kafka). However, this death is also a concluding scene which solves Gregor's issues and brings the story to an end. In analyzing fiction, there is an allegorical nature of disability. Lennard J. Davis describes this in the "The Ghettoization of Disability: Paradoxes of Visibility and Invisibility in Cinema," in which he writes, "In an ableist culture disability cannot just be – it has to mean something. It has to signify" (Davis 44). The ableist culture in this instance also ties immediately back to fiction with the metaphorical presence of disability in contrast to the embodied presence of disability. The metaphorical reading of Kafka's *Die Verwandlung* embodies the notion of symbolic prevalence over real world orders. Disability is utilized as a narrative resource. Davis writes:

> In this sense, disability is allegorical – it has to stand for something else – weakness, insecurity, bitterness, frailty, evil, innocence, etc. – and be the occasion for the conveyance of some moral truth – that people are good, can overcome, that we shouldn't discriminate or despair. But, to

> paraphrase Sigmund Freud, sometimes an amputated leg is just an amputated leg (Davis 44).

On the point of representation, Davis emphasizes that the metaphor function of disability is a result of disability being relegated to the category of undesirable. Davis has dubbed this the "ghettoization of disability," which is a terminology steeped in racialized notions. Ghettos are generally areas of a city where people of color or minority background live and are coupled with low socioeconomic status. I will not attempt to unravel the ways in which this term is problematic, which it most certainly is to a large degree. The complexity of identity means that someone who has privilege, such as a white, heteronormative, male, but is disabled does not have the same experience as a black, disabled woman. Therefore, when I use the term "ghettoization," I utilize quotation marks to highlight that the term itself problematic. The concept behind the term is however very useful. Disability is categorized as having a lower status than the norm. Therefore, it stands out and is used as a metaphor or allegory to say something about something else. Disability, in this instance, is not supposed to be anything other than a toy. It is played with by the author in order to make a statement about something other than the reality of disability. The "ghettoization" of disability fails to capture modes in which disability is self-representative and not a metaphorical commentary. Davis' implication here indicates how disability is a negative category when used as a metaphorical resource in narratives. Davis ends the quotation with a paraphrase of Freud on the topic of representation, indicating that sometimes representation is solely self-representation, in essence, sometimes a broken leg or rheumatoid arthritis or multiple sclerosis is just a broken leg, rheumatoid arthritis, or multiple sclerosis (Davis).

However, the issue within literary representations of people with disabilities occurs when representations of disabled people in literature are misrepresentations. Such representations are the core of Davis' theory of the "ghettoization" of disability in which disability becomes a metaphorical rather than an epistemic resource.

To indicate that fiction has no basis in existing world orders and structures is not the intention in this argument. As Gurley and Dekel point out in "Kafka's Golem," the identity of the author in fiction is often neglected when looking at folkloric traditions. Gurley and Dekel write, "The fact that Kafka's golem has gone unnoticed for some time owes not only to its omission from the critical edition, but also to the twentieth-century affinity for reading Kafka as a writer who transcends all ethnic, national, and religious categories" (Gurley and Dekel 532). The inclination to read all fiction as a transcendence of reality blurs out the possibility of the author's presence in narration, which can be influential in how a text is read and received. As Gurley and Dekel point out, the intention to erase Kafka's identity results in the golem texts being secularized. Instead of focusing on how normativity structures society, historical analyses erase Kafka's context. This is perhaps the most salient issue with the comparison of fiction to autofiction. In fiction, the author, as aligned with Barthes' and Foucault's literary critiques, can be erased. However, as Gurley and Dekel point out, this ahistorical reading of Kafka could also detriment the interpretation of the text by precluding important contextual information (Gurley and Dekel). Similarly, when one erases disability as a function in the novel or as a part of the author's (in the case of *Pain Woman Takes Your Keys and Other Essays from a Nervous System* and *Psychocalypse oder das Warten auf Fu*, authors') experience, the narratological structure is altered. Disability representations with no basis in experience rely on conceptual paradigms such as disgust as is demonstrated later with the example of Kafka's *Die Verwandlung.*

An important distinction between metaphorical fictional representations of disability and autofictional representations of disability involves the concept of disgust. Martha Nussbaum writes about two specific kinds of disgust in her work *From Disgust to Humanity: Sexual Orientation and Constitutional Law*. Nussbaum explains, "In virtually all societies, disgust is standardly felt toward a group of *primary objects:* feces, blood, semen, urine, nasal discharges, menstrual discharges, corpses, decaying meat, and animals/insects that are oozy, slimy, or smelly" (Nussbaum 15). Nussbaum's assertion of primarily disgusting objects is tied to ideas in the human psyche of what is disgusting, but this notion is not solely conceptualized as relational to only these objects. Instead, Nussbaum emphasizes the idea of projective disgust, writing, "Disgust is then extended from object to object in ways that could hardly bear rational scrutiny" (Nussbaum 15). The element of disgust is pivotal in the metaphorical quality of fictional disability. A thesis by Katherine Findley titled "Living as the Bug: Kafka's *The Metamorphosis* as Read Through the Lens of Critical Disability Studies" provides insight into how Gregor's transformation can be seen as a metaphorical representation of disability. Findley provides an overview of the ways in which Gregor has become disabled, stating "Gregor's tale can be read as a metaphor for a newly disabled person and how they are treated by not only society, but more specifically family" and notes that "Much of what happens to Gregor is similar to how disabled people in our own world are treated…he loses that ability to make money. He instead is the one who needs to be taken care of" (Findley 4). Most importantly, Findley demonstrates the principle of Nussbaum's projective disgust, writing "People treat him as horrifying or a nuisance" (Findley 4). The interpretation of Kafka's figure of Gregor Samsa as a representation of disability illustrates how disgust has become tied to the concept of disability. Gregor's body is transformed into something toward which humans feel primary disgust. In turn, the interpretation of Gregor's transformation as an experience of disability is incorrect. The linkage of transformative processes and disability implies the understanding of disability not as a real category, but only as a representational category.

The theory of disability as a narrative resource for the construction of metaphors and the concept of projective disgust work well for fictional narratives. However, they fall short when it comes to autofictional depictions of narrative. A simple inversion of the metaphor structure also appears to confound the true structure of an autofictional representation of disability through the figure. The concept of the author remains an important function as a source of epistemology about disability. The concept of primary and projective disgust must also undergo a change within the context of autofiction due to the discursive nature of writing from an epistemic viewpoint. Judith Butler writes in *Bodies That Matter: On the Discursive Limits of Sex* that:

> Indeed the construction of the gender operates through *exclusionary* means, such that the human is not only produced over and against the inhuman, but through a set of foreclosures, radical erasures, that are, strictly speaking, refused the possibility of cultural articulation. Hence, it is not enough to claim that human subjects are constructed, for the construction of human is a differential operation that produces the more and the less "human", the inhuman, the humanly unthinkable (Butler).

To claim that the construction of disability is dichotomous is also fallacious. The construction of disability as a metaphor in fiction fails to engage with the complexity of the construction of subjects. The articulation of norms onto bodies represents the difficulty with which bodies are constructed in reality. In contrast, fictional bodies are easy to create within paradigms that control how real bodies are constructed and viewed. The function of the body in fiction is always tied to the interpretation of that same body in reality, but it differs in that fictional representations are never privy to the pain of stigmatization that real bodies are. While fictional figures may impact the world on a cultural level and may even affect some on a personal level, such as when one identifies their own traits within a fictional character, an instance of fiction that intimates or establishes a disabled figure is fundamentally different from an autofictional appearance of a disabled figure. This is because the body of autofiction is a body that extends past the text and into the lived experience of the author. While both fiction and autofiction can extend into the cultural knowledge of the reader, the importance of autofiction is the extension of the body of the figure to the author and the extension of the body of the author to the figure.

The question is then how disability representation functions in autofiction. The autofictional mode of writing indicates an extension of the real body into a fictional realm. In the autofictional novels utilized in this thesis, the concept of disability is also not “ghettoized,” nor is projective disgust conflated with primary disgust in the representations. The autofictional representation of disability is based in the epistemic resource provided by the disabled author. The role of conceptual paradigms, especially regarding primary and projective disgust, appear to be present in the narratives, yet disability is not given characteristics of projective disgust. Bodily fluids and the other things Nussbaum names under primary disgust happen to be present in medical dialogue which is utilized extensively in the novels. Instead of projective disgust toward groups of marginalized people, the figures in *Pain Woman Takes Your Keys and Other Essays from a Nervous System* and *Psychocalypse oder das Warten auf Fu* project disgust onto the medical establishment and its shortcomings in the humane treatment of people. The construction of bodies in autofiction also demonstrates the limits of discourse about bodies that radically challenge the notion of the idealized body.

Cognitive linguistics allows insight into how representation functions within narratives. In *Women, Fire, and Dangerous Things: What Categories Reveal About the Mind* George Lakoff writes, "Thought is embodied, that is, the structures used to put together our conceptual systems grow out of bodily experience and make sense in terms of it; moreover, the core of our conceptual systems is directly grounded in perception, body movement, and experience of a physical and social character" (Lakoff xiv). Autofiction is a reflection of how categories are implemented within a person and projected onto a person with a disability. The conceptual systems present in autofiction are always results of bodily experience, in this case, the bodily experience of physical illness. The idea of thought as the embodiment of perception illustrates the power of perception. This also indicates something unique about autofiction. Whereas (auto)-biography and fiction place stringent limits on possibilities (fiction through the claim of no pre-existing conceptual systems, yet still utilizing pre-existing systems produced through language and autobiography and biography through the lens of objective statements of apparent truth), autofiction is a mixed modality of truthful experience with elements of fiction, such as non-linear story trajectories and personal non-objective opinions interspersed throughout the novels. The embodiment of knowledge about the experience of disability, its conceptual and perceptive forms and systems, and the effects of these systems are illustrated by autofictional narratives about disability.

Firstly, in each novel there is the concept of disability as deviance, which is adopted from a bio-sociocultural model of disability that determines that disability is a marked difference. The novels then talk about the experience of disability within the medical contexts of each society, one within the confines of the United States and the other in Germany. The novels deal with two different disabilities but the representation is similar across the novels, as each novel describes a medical system in which needs of patients are not met and the effects of capitalism on medicinal structures. In each novel, I identify a metaphor or rhetorical structure that is present. These rhetorical structures illustrate how metaphor is utilized when people with disabilities write the metaphor, which is again to reiterate that disabilities are not metaphorized in order to provide a moral commentary, but instead other objects are metaphorized to demonstrate that metaphor still functions within a conceptual framework that has disability as part of its construction. Snyder and Mitchell's theory of disability as a metaphorical narrative resource asserts that at the end of the narrative, a cure is created in which the deviance returns to normative standards (Snyder and Mitchell). While *Pain Woman Takes Your Keys and Other Essays from a Nervous System* and *Psychocalypse oder das Warten auf Fu* make mention of cures, the narratives do not end with a cure or a search for a cure as the medical model of disability would demand. Rather, the endings illustrate the unfinished underpinnings of the experience of chronic illness and demonstrate that chronicity does not always have a neat conclusion (Huber, Klook). The next section will look at quotations from each novel to illustrate how autofictionality creates its own paradigms for understanding and representing disability.

Huber's *Pain Woman Takes Your Keys and Other Essays from a Nervous System* begins with a preface and a short poem. The beginning of the novel clarifies immediately the role of deviance. The text reads, "I knew self-sabotage, but apparently this wasn't about apologizing too much or dating wily, unreliable men, or trying to be perfect. This was actual physical erosion. I now had two autoimmune diseases. I was devouring myself" (Huber 8). The beginning of the novel introduces the deviation as a part of the figure of Sonya, which is the name of both the author and the figure within the story. This instance in the text demonstrates that the figure deviates from the normative, non-disabled body.

The same concept of disability as a precursor to the following narrative events is present in Klook's *Psychocalypse oder das Warten auf Fu*, where the figure Marco (who bears a different name than Klook, but Klook's own experience with multiple sclerosis is present within the novel. The first mention of multiple sclerosis is in relation to the medication Marco has to inject during a vacation with his girlfriend Ariane (Klook 16). Multiple sclerosis as a part of Marco is mentioned a few pages later. Again, the instantiation of deviation is immediately put forth. However, the intention appears to be different from the deviation that Snyder and Mitchell posit. The purpose of a pre-emptive disclosure of deviation in autofictional narratives about disability serve to outline a condition that affects how the figure perceives their world and how the world perceives the figure. Unlike fiction, deviation is not brought up for the simple purpose of creating a problematic that concludes at the end of the novel. In autofiction, disability extends past the text into the body and vice versa.

The second unifying principle of these autofictional narratives about disability is the use of rhetorical devices. In specific, I identify things that are used rhetorically. The use of rhetorical devices demonstrates that fiction's use of disability as a material for metaphor stems from a different understanding of how disability affects the body. In these two autofictional novels, the authors do not consider disability a metaphor for anything unless ruminating about the notions of disability as a moral failing put forth by cultural notions. In *Pain Woman Takes Your Keys and Other Essays from a Nervous System*, Sonya wonders about her son and his interpretation of her love. The text reads:

> I wonder if my son's rock solid knowledge of mom love will be the smell of animals, the shells of horseshoe crabs we have collected, the skulls and bones to encourage his interest in nature. Maybe it will be my weakness itself, my cane, or the smile I am able to muster that glows with what I know is pure affection no matter how I am feeling. I cannot know what will stand in for cupcakes, what will hold the smell of mother-love, but I know it will not have icing" (Huber 65).

This instance in the text is actually asking what will stand for something else in the symbolic register of a child. Unlike the previous examples from fiction that have been given from Rowling and Kafka, Huber does not utilize disability as metaphor, but metaphor is still present as a linguistic tool. The denunciation of disability as metaphor is not a critique of metaphor as such, rather a critique of the power and privilege granted to metaphorical representations of disability that overshadow the self-representation of people with disabilities.

In *Psychocalypse oder das Warten auf Fu*, there is no instance of this parental curiosity since Marco and Ariane do not have children. Instead, I focus on a moment in the text that takes place after Marco has been re-admitted to a psychiatric clinic that he had previously been in to help him cope with his panic attacks and co-occurring depression. Marco puts on his hood (*Kapuze*) in a therapy session to the chagrin of the therapist. The therapist becomes angry with Marco and demands that he remove the hood in favor of putting a blanket over himself. Marco stands by the decision to use his hood, which provokes the therapist into leaving (Klook 211-212). Later, Marco tells the therapist that the hood is a metaphor for freedom (Klook 217). Yet, the metaphor that stands out is the metaphor that Marco does not tell his therapist. It revolves around the clinic as an entity that seeks to control its patients without meeting their needs as Marco points out throughout the novel. This is a reversal of what could have occurred in the novel if disability had been utilized as a metaphor. If disability itself had metaphorical qualities, then the failure of the clinic would be a result of the moral failing of the person with a disability. This theoretical usage ties also back into Davis' conceptualization of disability as a "ghettoized" characteristic (Davis). However, disability is not negatively connotated in *Psychocalypse oder das Warten auf Fu*. Instead, the medical system becomes a metaphor for moral and ethical breaches of the original intent of medicine, which is to do no harm.

The last function of autofictional narratives about disability is the ending, which is not as conclusive as fictional narratives that use disability as a way to discuss progress of other figures or as a finite resource. The process of disability is often non-linear and this is reflected by the endings of both of the novels. *Pain Woman Takes Your Keys and Other Essays from a Nervous System* ends with the following lines:

> Over and over, doctors have regarded my body to look for the nonverbal, the non-emotional, checking my hands and feet to see minimal deformity. They have called me "lucky" because the body's outward signals, as mute as a nautilus shell's smooth surface, cannot speak about the sharp and segmented poetry within (Huber 177).

Huber's last point in actuality negates the concept of a closed dialogic loop at the end of a narrative and at the end of a body. Here the concept of the body as a physical representation of processes of pain demonstrates how representation goes beyond the surface of the body. Huber often grapples with the question of pain and whether it can be represented accurately to others (Huber). This question is a question of rhetoric as well as of translation, that is to say, how can one rhetorically represent that which is real in one's body through the translated medium of language? An autofictional novel is particularly prone to pose this question because of the infinite dialogic loop.

The end of the dialogic loop represents and extension of the body. Huber will live with rheumatoid arthritis and Hashimoto's thyroiditis past the end of the novel, the novel does not truly conclude except on the level of the word. Similarly, *Psychocalypse oder das Warten auf Fu* ends in a non-conclusory manner, with Marco's continuing life with Ariane and their dog being depicted (Klook 508). The non-conclusory ending seems to be a hallmark of disability autofiction, at the very least between Klook and Huber, and signals that life of real bodies extend past the end of a collection of narrative pages.

One other commonality the novels share is an epilogue that include terminology and sources for certain information. In *Pain Woman Takes Your Keys and Other Essays from a Nervous System*, Huber writes about facts in her chapter "Vital Sign 5". Some examples from this chapter highlight the shortcomings of the biomedical system. Huber writes "Odds of African Americans receiving no pain medication compared to whites for a similar injury: 63 percent greater" (Huber 153). These facts are present in play with personal anecdotes from Huber's life following her diagnosis with rheumatoid arthritis, of which she writes "Specialists I have visited for a condition whose primary condition is chronic pain who did not ask me a single question about I coped with chronic pain: 7" (Huber 153). In *Psychocalypse oder das Warten auf Fu,* Klook opts for a glossary at the back of the novel. In this glossary there are medical facts such as the definition of remyelination ("Remyelisierung bezeichnet die Wiederherstellung der beschaedigten Myelinscheide (Markscheide) eines Nervs" (Klook 524)). *Remyelination describes the replacement of the damaged myelin sheath of the nerve).* The facts in each novel are corroborated by these sources and definitions. However, the reasoning for including factual information in the epilogue is unclear. Is it not enough to read the writings of authors who experience these illnesses on a daily basis? To answer this question, one can look at the fictional short story "Welcome to Your Authentic Indian Experience by Rebecca Roanhorse. In "Welcome To Your Authentic Indian Experience," the story depicts the life of Jesse Turnblatt who is an Indian (Native American) who works on virtual reality tours based on what tourists want to hear about Indian culture. Jesse has one client who is deeply dissatisfied with the “Experience” or “Vision Quest” (virtual reality simulation) and keeps returning to talk to Jesse and this person claims that they are part Cherokee. Jesse names this person “White Wolf” and they strike up a friendship where they meet for drinks at a bar and Jesse tells White Wolf stories. Jesse gets sick and has to miss work for a few days and in these few days he is fired and White Wolf replaces him as the person who gives these virtual tours, convinces Jesse’s wife to leave, and claims to have never met Jesse. At the end of the story White Wolf asks Jesse a question. The story reads, “‘Do you ever think, he says, his voice thoughtful, his head tilted to study you like a strange foreign body, “that maybe this is my experience, and you’re the tourist here?’” (Roanhorse). The stories by disabled people can be co-opted by people without disabilities and twisted to fit other narratives, therefore it becomes imperative to prove one’s own experience. Yet, the experience alone is not enough, so it necessitates the usage of sources to validate the disabled experience.

The use of sources to validate one’s own experience seems almost paradoxical. Yet, there appears to be an emergent pattern in these narratives that indicates. Huber’s sources are organized based on each chapter and come from a variety of sources, including academic works, newspaper articles, and blog posts. The sources define everything from pain scales to concepts like the idea of what it means to exist. This differs from Kafka’s *The Metamorphosis* and other fictional-metaphorical depictions of disability which do not use sources. Fiction can be criticized for its depictions as has been done in much of this thesis. Fiction sometimes propagates internalized and unconscious biases in its depiction. The knowledge in fiction is seen as self-sufficient. As with *The Metamorphosis* and the *Harry Potter* series, commentary can be utilized to address when fiction contributes to the marginalization of minority groups. Fiction is also the other side of the autofictional coin that separates autofiction from autobiography. Despite its fictional elements, autofiction about disability seems to require a certain sort of validation of its knowledge. This again speaks to the idea that the knowledge of people with disabilities has been subjugated and denied. The sources provide a form of validation of experience. Therefore, it seems that one assumption disability autofiction makes is that "facts" (term used loosely here to denote what is popularly taken as objective, despite the social construction of the world meaning that nothing is truly objective) organize experience and therefore organize the discourse around the body.

In *Psychocalypse oder das Warten auf Fu*, Klook takes a slightly different approach to sources. He indexes an assortment of medical terminology in the back of the book also located from a variety of sources (Klook). The emphasis in both Huber and Klook's epilogues is one on medical facts. This ties back to a medicalized model of disability in which knowledge of and about disability is conceptualized through medical terms. Physicians are presented as experts on the biological reality of the body. This is conflated with the social and cultural experience of the body. In some ways, the use of medical sources in literature about disability seems to reify the concept that physicians are omniscient. However, in accordance with G. Thomas Couser, I would argue that this occurs because of the preinscription of disability by society (Couser). Disability, when utilized to categorize bodies, marks those deviating bodies as undesirable and unworthy of the same privileges and rights of able-bodied people. The notion of people with disabilities as people who are "less than" those without disabilities by proxy codifies all knowledge produced by disabled people as "less than". An etymological analysis of the word disabled provided by Douglas Baynton describes the emergence of the word handicapped, which was later replaced with disabled. Baynton states:

> An affliction was what we would call a disability today, though it was also a broader term that could refer to various kinds of misfortunes. God, in His mysterious wisdom, had afflicted people with particular burdens, and they were supposed to bear them with patience and faith, trusting that their afflictions were part of some larger plan. People were afflicted for a reason -- to learn a lesson, to teach other people pity and charity, and so on. So, an affliction was not something to be overcome (Baynton).

As referenced earlier, disability in literature has often had moral undertones that conflate disability with affliction. Baynton's description of the etymological origins of disability explains to an extent how disability became folded into literature as a moral failing. Additionally, Baynton's second point aligns with Cheyne's theory of yardstick characters, which are included in literature to make the other figures in the work seem empathetic. In this essay, Baynton also describes the origins of the word handicap, which was used before disability became widespread terminology. Baynton explains why the majority of stories about disability, particularly in the media, are about a disabled person "overcoming" their disability. He writes, "While an "affliction" was a spiritual burden to be borne with faith and lived with as best as possible, in submission to God's wisdom, a "handicap" was a condition to be conquered, an impediment to worldly success that had to be overcome. Thus twentieth-century success stories about disabled people are most often stories of "overcoming."" (Baynton).

Eventually the word disabled triumphed over the term handicapped as the acceptable designation for disabled people. The words used to talk about disability provide a conceptual foregrounding to disability that is present within the fabric of language itself.

Despite the emphasis on medical knowledge, the narratives themselves illustrate the sociocultural dimension of disability. For the most part, the text within the novel is speaking about experience, and then legitimizing it with sources. This means that the experience of the disabled person is still contained within autofictional narratives; it is just also corroborated by knowledge that is more highly regarded. I argue that this tactic does not subtract from the importance of disability autofiction nor does it really necessarily indicate deferring to the knowledge of people in positions of power over the body (such as physicians). The question of the importance of experience has been addressed repeatedly throughout the body of this thesis. The concept of physician knowledge as additive to the authors' works creates an interrelation of experience-expertise. Both physicians and patients (to use a self-designated term from the novels, which certainly might not apply to all disabled people) have their own experiences with disability. The physician side is generally more scientific and more strictly biological, which creates the concept of expertise. Yet, the patient has experience and expertise also. The inclusion of physicians as references to a ultimate reality is an impulse that illustrates firstly, how the experience-expertise of disabled people is routinely dismissed or minimized, and secondly, illustrates that non-disabled people construct the world of disabled people by what others have to say about them or their condition. What physicians say holds biological validity, but it does not account for the bio-sociocultural effects of disability in whole. Physician expertise in autofiction is a clever rhetorical function, designed to eliminate the possibility of the questioning of one's own experience as a disabled person. Disabled people know their experience will be invalidated if it relies on their own experience-expertise, but by pre-emptively providing absolute "truth," the authors sidestep any arguments against subjectivity, despite disability always having a subjective kernel and the subjectivity that is necessitated in an autofictional depiction of disability.

The representation of figures in autofiction about disability seems to partially fulfill narratological conceptualizations of fiction, yet these narratives also negate certain parts of those given structures. Disability itself is not seen as a metaphor, rather a register on a symbolic scale that allows for an experiential representation. Disability autofiction is inconclusive and the two novels selected both utilized sources to validate the narrative, indicating that autofiction attempts self-validation, but relies on sociocultural norms to embody that self-validation. Representations of disability from experience is the main way in which autofiction distances itself from metaphorical, fictional representations of disability.

CHAPTER V: CONCLUSION

The approach to disability in literature has been historically devoid of the voices of disabled people. Fictional narratives like *The Metamorphosis* by Franz Kafka situate disability in a symbolic-allegorical relationship to the text. Disability in narratives such as these is always preemptively a commentary on something else (Snyder and Mitchell). Perhaps it is equating disability with disgust or with lack of morals (Nussbaum). Disability is never characterized by its own physical-emotional reality. When disability is not metaphorized or symbolically represented, it is utilized as a yardstick to measure the growth of the (non-disabled) protagonist (Cheyne). The argument here is not to indicate that able-bodied authors only utilize disability solely as a yardstick rhetorical tool, but rather to emphasize that disability has historically been used only to measure the value of the other, non-disabled figures in literature.

Autofictional narratives provide a structure that emphasizes how disability creates its own knowledge through experience. Autofiction written by disabled authors achieves the utilization of what Rosemarie Garland-Thomson names disability as an epistemic resource because the experience of the author is vital to the creation of the author-figure and figure-author in autofiction (Garland-Thomson, "Building a World with Disability in It"). The author and the figure cannot be extrapolated from each other and therefore have a unique relationship that lends itself to. At the same time, G. Thomas Couser alerts us to the concept of disability autobiography which is the original literature about disability (Couser). Like disability autobiographers, disabled autofictional authors write from a position of marginalization. However, the flexibility of autofiction and its combination of objective reality and subjective interpretation allow for the figures in autofictional disability narratives to be analyzed using literary-theoretical lenses. The language in disability autofiction is not absent of metaphor or rhetorical devices, but unlike fiction, the metaphors and other rhetoric arise from experience with disability. That is to argue, the experience of disability leads to the creation of rhetorical language, but disability is not a phenomenon used to sensationalize the metaphor. Disability is not a verminous creature as seen in Kafka's *The Metamorphosis* nor is it associated with the perceived moral indecency that might accompany the appearance of such a creature. Klook and Huber's narratives demonstrate how disability leads to the formation of worlds and provide access to these worlds via literature.

One excursus I would like to postulate in this conclusion is that the matter of the thesis focuses on the role of the author-figure and figure-author. These dual roles are integral in the production of autofiction as they are necessary to its creation. As asserted, knowledge produced by the experiences of the authors is reproduced in each novel through the figure. The figure is thus the medium through which the author communicates, but the question to whom the author communicates has not been addressed in this thesis. Naturally, there are a variety of ideas around why texts are created and disseminated. Perhaps the authors wanted to write their experiences out for themselves. Yet, the production of the novel as a cultural good which can be obtained by purchasing with money that is assigned value indicates that there is also a motivation to have others read the text. Barthes' proposition of the death of the author also invokes the role of the reader (Barthes). Therefore, I think that it would be worthwhile to analyze what role the reader plays in autofiction in further thinking about disability narratives and to what degree autofictional narratives about disability engage with a disabled and non-disabled readership.

Another aside revolves around the different experiences of disability in different cultural contexts and for different people. Despite the assertion that there is a universal claim to how disability is represented by people with disabilities, there is no claim to the universality of a disabled experience. Huber's novel and Klook's novel contain similarities, but they are not the same. Each novel provides a unique look into the experience of disability. The use of disability studies as a theoretical area to organize the discourse around disability is also somewhat problematic due to the general overall whiteness of the field. Another critique is that disability studies concerns itself with Western concepts of what constitutes disability and Western attitudes toward disability. This thesis does not adequately alter the current course of disability studies: Huber and Klook are both white and from Western cultures. Therefore, this thesis does not adequately address questions of the relation between race and ethnicity, disability, and writing. Haraway's text emphasizes that people who have been marginalized adopt writing as a tool for empowerment. In this example, she is referring to women of color, whose knowledge had been dismissed as unimportant and irrelevant (Haraway). This applies to writing about disability as well as emphasized in this thesis and by scholars such as Rosemarie Garland-Thomson and G. Thomas Couser (Garland-Thomson, Couser). The lack of non-Western conceptualizations about disability and lack of racial diversity in disability studies is something that must be addressed, however the scope of this thesis did not provide an opportunity to provide significant contributions to those areas of the field.

It is also incorrect to make broad claims that only authors with disability can accurately represent disabled characters. There is no viable, credible reason that figures with disabilities should not be portrayed in all sorts of literary and artistic works. However, the historical representation of people with disabilities has had a negative impact. When we see authors like Wendell talk about feminist theories of disability and Garland-Thomson's assertion that disabled people also have knowledge, it is apparent that there are long-standing representations of people with disabilities in literature that do not consider people with disabilities as complex and multi-faceted figures (Garland-Thomson, Wendell). People with disabilities are either horrific and disgusting as emphasized by Nussbaum's theory of disgust (Nussbaum). They are yardstick characters used to inform readers about other more important characters (Cheyne). Alternatively, they have some heroic timeline of overcoming their disability and becoming "normal" which negates the rich cultural knowledge and epistemological insight disabled perspectives bring to literature (Wendell). By utilizing disabled authors' epistemic experience, the notions of disability as disgusting or simplistic can be overturned.

As a last stipulation to the conclusion of this thesis, I want to address the conceptually murky difference between fiction, autofiction, and (auto)-biography. Biographic depictions are supposed to contain objective factual accounts of people's lives. Yet, even things that are seemingly objective are interpreted and moderated through a human lens. What is factual information in one moment may be false in the next. More often than not, I would argue that there is not a simple dichotomy between fact and fiction. Fiction can draw on experiences just as autofiction can. Likewise, autofiction can incorporate fantastic elements into a narrative. The assertions in this thesis, at some points, may seem like an attack on fiction as something that does not originate from experiential knowledge, which is not the case. Another work that I reference which straddles the unclear divide between autofiction and fiction is Rebecca Roanhorse's short story "Welcome to Your Authentic Indian Experience." Roanhorse depicts a story that is not about her own life, but Roanhorse certainly has experience with an existence that has been racialized (Roanhorse, *Locus Online*). Likewise, Klook indicates that he is writing about another multiple sclerosis patient from Germany (Klook). The emphasis I want to make here is that the divide between what is autofictional and fictional is impossible to divide into a clear, dichotomous ontology.

Looking at autofiction across American and German cultures illustrates how disability is conceptualized in both cultures, both individually and in aggregate. The experiences of people with disabilities, when written about from disabled perspectives, build a new form of literary genre. Traditional theoretical approaches erased the affect and intentionality of the author and focused on the complete erasure of the author, indicating that the author was not important to the interpretation of the text. This sort of erasure was predicated by a desire for hermeneutic neutrality. The argument for the separation of the author from power resulted in literature becoming a domain to be subjectively interpreted by readers and critics. The goal of erasing the author is understandable to avoid interpretations based solely off of the intended meaning of the author as reading and writing are communicative processes and not absolute truths.

In conclusion, this thesis illustrates the importance of the experiential realm of disability in the literary genre of autofictional narrative. Informed by the experience of the author, the stories are formulated around disability as a real experience rather than a metaphorical toy to play with within a story. Disability is not a symbol for anything else, but instead stands for itself as a category of human diversity. In these narratives, disability is afforded its full complexity. It is not a singularly negative nor positive attribute; instead, disability is a descriptive attribute that organizes a discourse around the lived experiences of the authors. The figures in disability autofiction are not developed for the sole purpose of injecting a character to act as a sort of moral compass for other characters. Therefore, disability autofiction is a unique literary representation that is grounded in the knowledge produced by disabled experiences by disabled people that embodies the knowledge produced by the experience of living with a disability.

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